NURSING ETHICS IN END-OF-LIFE CARE IN JAPAN

By

Shigeko Izumi

A Dissertation

Presented to

Oregon Health & Science University

School of Nursing

In partial fulfillment

Of the requirements for the degree of

Doctor of Philosophy

August , 2003

APPROVED:

[redacted]

Christine A. Tanner, RN, PhD, FAAN.
Professor, Oregon Health & Science University School of Nursing.
Research Advisor

[redacted]

Virginia P. Tilden, DNSc, RN, FAAN.
Associate Dean for Research, Oregon Health & Science University School of Nursing.
Committee Member

[redacted]

Michael J. Garland, D.Sc.Rel.
Professor Emeritus, Oregon Health & Science University School of Medicine.
Committee Member

[redacted]

Yoko Nakayama, RN, PhD.
Professor and Dean, Fukushima Medical College School of Nursing.
Committee Member

[redacted]

Kathleen Potempa, DNSc, RN, FAAN
Dean, Oregon Health & Science University School of Nursing

Acknowledgement

This study was partially supported by Yamaji Fumiko Nursing Education and Research Foundation from 2001 to 2003.

Acknowledgements

This research project reflects contributions from many people and could not have been completed without their support. First I would like to thank the Japanese nurses who took time from their busy work to share their experiences through rich and precious narratives. They encouraged, inspired, and supported my belief that there are morals and ethics inherent in nursing. I also want to thank the nurse administrators who welcomed, accommodated, and guided me through the recruitment process in their facility. Their belief in the importance of this project gave me support to accomplish this inquiry.

I would also like to acknowledge my friends, classmates, and senior/junior students whom I met through the PhD program. Susan Shapiro, whom I worked with throughout the program, shared the joys and struggles of being a novice researcher and became my best friend and twin sister separated by birth (despite our ethnic differences). We learned the practical side of nursing research together and she taught me to appreciate life in America. She shared her home and her friends and kept me laughing and smiling and gave me energy to keep going. Dawn Doutrich and Peggy Wros inspired me to pursue the subject of nursing ethics and cultural values in Japan. They invited me to join their inquiry about the cross-cultural exploration of nursing ethics in early phase of my doctoral study. Since then,

they have been models and mentors for me throughout this study. They applied their experience in phenomenological research to help me analyze and validate my data. Dawn and her husband, Michael, have a wonderful home which has been a warm and welcome place for me where I could relax. All my other friends deserve special thanks: Maggie Emery, Karen Tetz, Napaporn Wanitkun, Jesika Gavilanes, Tammy Schuman, Supinda Ruangjiratain, Lissi Hansen, Yoshiko Colclough, and Caroline White; their support was, and continues to be, invaluable. I am also thankful for Ms. Sarah Wight, my editor, who corrected the English in my dissertation.

My research advisor and committee members deserve much praise. Dr. Christine Tanner, my research advisor, mentored me and my project by sharing her knowledge about interpretive phenomenological study and her passion for nursing. She pushed me forward in the development of my research by asking questions that were always a half-step ahead. Had her questions been a full-step ahead, I would probably have gotten lost in the muddy field of the hermeneutic circle. Dr. Virginia Tilden, my academic advisor, accepted me into the program, showed me the breadth and depth of nursing research, and helped me to narrow the focus of my interests to a manageable size. Dr. Michael Garland, professor emeritus and a great ethicist, helped me understand what ethics are and encouraged me to articulate the vivid but often tacit ethics existing in Japanese nursing practice. His enthusiasm for this project inspired me when I doubted the value of this study. And finally, Dr. Yoko Nakayama, my Japanese mentor and committee member, made time in her busy schedule and twice flew to Portland from Japan for my defense. She is extremely knowledgeable in both the interpretive phenomenological approach and Japanese nursing culture. Her insightful comments and advice kept me close to true Japanese nursing practice; her careful and thoughtful readings of my data gave most valuable culturally sensitive validity and added trustworthiness to my findings.

Finally, I would like to thank my family for their support, patience, and faith in me. My parents, Akira and Miyoko Izumi, allowed me to study abroad from the very beginning, and have faithfully been there for me all the time. My big sister, Hisako, her husband, Masao Nagamura, their new son Kazuki, and their daughter-dog, Uruma, gave me a comfortable place to stay while I was in Japan. My husband, Michael, whom I met during the journey for this project, and with whom I will spend the rest of my life's journey, fed me, comforted me, patiently listened to my "touchy-feely" ideas, and helped me stay healthy. Without him, my life in the final stages of this dissertation would have been less enjoyable. Thank you.

ABSTRACT

TITLE: Nursing Ethics in End-of-Life Care in Japan

AUTHOR: Shigeko Izumi, RN, MSN

APPROVED: Christine A Tanner

Christine A. Tanner, RN, PhD

The purpose of this interpretive phenomenological study was to understand and describe nursing ethics in end-of-life care in Japan. Specific aims were (a) to explicate moral concerns inherent in nursing practice for the care of dying patients in Japan and (b) to describe the ethical nursing practice that reveals nurses' moral concerns. Thirty-two nurses in Japan who worked in hospitals where they provided care for dying patients were interviewed about their end-of-life care experiences. Interpretative phenomenology was the methodology chosen, and thematic analysis, exemplars and paradigm cases were methodological strategies used during the interpretive process of the interview data.

Seven moral concerns were identified in the interviews. They were (a) not hurting the patients, (b) honesty, (c) isolation/loneliness, (d) regard for the patient's personhood, (e) respect for the patient's wishes, (f) comfort/relief from suffering, and (g) meaningful/ pleasant time for the patients. These moral concerns have particular meanings for the nurses their narrative accounts. Having moral concerns is not sufficient to make the nurses' practices ethical; to carry moral concerns into ethical practice, nurses need to have the skills of involvement, attuning, and responsiveness. The most meaningful concern for a particular patient in a particular situation can be grasped only by skilled involvement and attunement. Skill of responsiveness transforms identified concerns into tuned actions. Moreover, the responsiveness as ethical sensitivity is the driving force that moves nurses to ethical nursing practice.

Limitations of the study include insufficient representation of nurses working for dying patients, and a retrospective interview design that limits access to taken-for-granted everyday practices. The findings suggest similarities of nursing ethics in end-of-life care in Japan and caring ethics developed in the U.S. Yet it was also clear that cultural and social background meanings have an enormous impact on nursing practice and shape the practice and their view of the world. Further studies are indispensable to fill the gaps in nursing ethics in Japan. Development of ethics which reflect the notion of good that is inherent in nursing practice will empower not only Japanese nurses, but all nurses throughout the world.

TABLE OF CONTENTS

Approval ii
Acknowledgement iii
Abstract vii
Table of Contents ix

Chapter I: Introduction 1
  Aims of the Study 6
  Significance of the Study 8

Chapter II: Literature Review 14
  Ethics in Nursing 14
    Different Approaches to Ethics 14
      Principle-based ethics 16
      Virtue ethics 19
      Ethics of care 22
    Nursing and Ethics 25
  Discrepancies in Studies on Nursing Ethics in End-of-Life Care in Japan 29
    Difficulties in End-of-Life Care and Moral Concerns 29
    Ethical Comportment as Embedded Practice 37
    Japanese Nursing and the Influence of Western Science 38
  Need for Studies in Japan 46

Chapter III: Methodology 52
  Philosophical Assumptions of Interpretive Phenomenology 53
    View of Humans 54
    Knowing and Knowledge 57
  Research Design 59
    Sample 60
    Data Analysis 65
    Rigor in Interpretive Methods 69
  Human Subjects Protection 72

- Chapter IV: Results and Discussion: Nurses' Moral Concerns in End-of-Life Care in Japan 74
  - Moral Concerns in Nursing Practice 74
  - Solicitation of Moral Concerns from Nurses 77
  - Nurses' Moral Concerns in End-of-Life Care 80
    - Not Hurting the Patients 80
    - Honesty 89
    - Isolation/Loneliness 94
    - Regard for the Patient's Personhood 100
    - Respect for the Patient's Wishes 106
    - Comfort/Relief from Suffering 119
    - Meaningful/Pleasant Time for the Patients 122
  - Summary 126

- Chapter V: Results and Discussion: Background Meanings of Nurses' Moral Concerns and Ethical Practice in End-of-Life Care in Japan 128
  - Cultures in Nursing 130
    - Nursing Culture in a Unit 131
      - Different culture in each unit 131
      - Unit culture sets nurses' perceptions and practices 135
      - Rules in a unit frame what is good/not good 138
    - Influence of Senior Nurses 139
    - Team Consensus 141
    - Deference to the Primary Nurse 143
    - Western Influence in Japanese Nursing 144
  - Terminally Ill Patients and Their Families in a Japanese Hospital 150
    - Patients with Cancer 150
    - Patients in the End-of-Life Stage 153
    - Patients in Japanese Culture 155
      - Insider and outsider 155
      - *Omakase:* Leaving decisions to others 157
      - *Omoiyari:* Japanese-style empathy 162
    - Patients' relationships to Health Care Providers 165
      - Patients' relationship to physicians 165

Patients' relationship to nurses 167
Families of Terminally Ill Patients in Japan 174
Nurse-Physician Relationship 180
How and Why Nurses and Physicians Collide 182
Why Nurses Follow Physicians' Orders 189
Nurses' Strategies to Deal with Physicians 198
Summary 205

Chapter VI: Results and Discussion: Nurses' Ethical Practice in End-of-Life Care in Japan 207
Ethical Practice in End-of-Life Nursing Care 208
Paradigm Case: Taking Her to a Hot Spring 210
Paradigm Case: He Died as He Wished 217
Practical Skills in Ethical Practice 225
Involvement 226
Being in Tune 230
Responsiveness 231
Development of Practical Skills 233
Ethical Sensitivity 236
Ethical Practice: Moral Concerns, Practical Skills, and Ethical Sensitivity 239
Searching for Nursing Ethics in End-of-Life Care in Japan 243
Summary 250

Chapter VII: Summary, Implications, and Conclusions 252
Summary of the Study 252
Purpose of the Study 252
Procedures and Analysis 252
Findings: Nurses' Moral Concerns 253
Findings: Ethical Nursing Practice 257
Limitations 258
Implications 262
Implications for the Philosophy of Nursing Ethics 263
Implications for Nursing Practice 267

    Implications for Nursing Education 271
    Implications for Nursing Research 273
  Conclusions 276

References 278
Appendix A: Letter of Invitation to Participate in the Study 303
Appendix B: Informed Consent 306
Appendix C: Interview Guide 313

Chapter I: Introduction

Nurses caring for dying patients and their families often experience various difficulties in providing the quality care they envision. Japanese nurses are no exception. Relevant literature supports the presence of nurses' perceptions of difficulties in caring for dying patients in Japan, as well as other countries such as the United States. (Ferrell, Virani, Grant, Coyne & Uman, 2000; Holmes, Pope & Lamond, 1997; Iba & Kawagoe, 2000; Konishi & Davis, 1999; McGrath, Yates, Clinton & Hart, 1999; Storch & Dossetor, 1998; Tamura, 2000; Tilden, 2000). In Japan, there are studies reporting nurses' stress and dilemmas in caring for dying patients (Nakajima & Kakuta, 2000; Sawada et al., 2000; Tahata & Nakamura, 2000). Many case studies and anecdotal narratives also explicate the difficulties nurses experience in end-of-life care (Kiba et al., 1998; Tamura, 1997).

Findings from several studies in the United States suggest that knowing the patient is a critical component in providing nursing care (Benner, 1994b; Jenny & Logan, 1992; Radwin, 1995, 1996; Tanner, Benner, Chesla & Gordon, 1993). Nurses use their knowledge of a particular patient, gained from their involved relationship and their experience, to advocate for the patient in a fundamental, existential way (Gadow, 1980; Liaschenko, 1995a). Benner (1994b) concluded that knowing a patient and following the body's lead prevented nurses from misusing technology and doing harm while intending to do good, even in cases of nonverbal adult or infant patients. Knowing a patient through an involved relationship and concern usually leads the nurse to a good understanding of what is "good" and "right" for each unique patient. It is common in end-of-life care that the patient's personal interests yield to the best treatment from a medical standpoint, in part because patients' wishes are not known or understood by the health care team. Thus nurses' knowledge about the patient as a person becomes more important in determining what is good for the patient. Nurses are expected to take an advocate role for the patient's best interest (Liaschenko, 1995a, 1995b; Millette, 1993).

Yet there are abundant studies and anecdotes in which nurses could not stand as an advocate for their patients despite their knowledge of what is good and right for the patients (Astrom, Jansson, Norberg & Hallberg, 1993; Doutrich, Wros & Izumi, 2001; Holly, 1993; Jameton, 1984, 1993; Redman & Fry, 2000; Taylor, 1997; Wilkinson, 1989, 1999; Yarling & McElmurry, 1986). These are moral dilemmas nurses often confront in their everyday practice (Millette, 1993). Health care is always provided by a team, never provided or planned by a single person. The care a nurse provides is influenced by physicians' treatment policy and orders, hospital administration, and the preferences of the patient and his or her family. Therefore, a nurse's judgment of what is good for the patient may contradict others' idea of good care. Moreover, although a nurse may have an ethical concern about not providing good care to a patient based on her personal knowledge about the patient, she can rarely explain why it is unethical and convince other team members to change their approach. Nurses who are not able to fulfill their ethical obligations feel bad and struggle in their role as professional nurses. That is the difficulty many nurses in end-of-life care often express, and the reason why many nurses think end-of-life care is challenging.

Furthermore, nurses' inability to practice the best care based on their ethical judgment means that patients and their families are not receiving the full benefit from their nurses. The care patients and their family receive is somewhat degraded when nurses are not allowed to fulfill their roles. The difficulty perceived by Japanese nurses in end-of-life care is not only a burden for nurses, but also a disadvantage for care recipients.

Nurses sense and judge moral problems through intuition and emotion (Astrom et al., 1993; Cooper, 1991; Gramelspacher, Howell & Young, 1986; Holly, 1993). Because their responses to the issues are often intuitive and emotional rather than rational, the nurses' concerns are discounted in academic discussion of ethics in health care (Bishop & Scudder, 1990, 1991; Omery, 1995; Taylor, 1997). Nurses' ethical concerns in everyday practice are often dismissed from major health care ethics accounts because the values and language commonly used for ethical principles (i.e., right, justice, and autonomy) are not adequate to capture and explain the nurses' ethical concerns in everyday practice (Cooper, 1991; Doutrich et al., 2001; Parker, 1990a, 1990b; Taylor, 1997). Difficulties in applying principle-based ethics to nurses' everyday ethical concerns have been recognized and discussed extensively as a tension between principle-based ethics and ethics of care in nursing (Carse, 1996; Condon, 1992; Cooper, 1991; Fry, 1989; Grundstein-Amado, 1992; Millette, 1994; Olsen, 1992; Omery, 1995; Parker, 1990a, 1990b; Twomey, 1989).

From the mid-1980s, the traditional justice-based ethics that had been dominant in the biomedical arena began to be questioned for its utility in actual clinical situations and criticized for its unilateral, off-context view (Dreyfus, Dreyfus & Benner, 1996). Carol Gilligan's work (1982) shed light on another ethical approach. In her study, she clarified that women who do not detach themselves from a situation and do not justify their actions using universal principles are not necessarily ethically immature; rather, their responses to the situation are highly ethical but in different way. Instead of detaching themselves and rationalizing, they stay involved in the situation and respond intuitively and emotionally. Her findings invited a challenge to the traditional view of ethics in which being ethical means standing outside the situation and judging actions based on universal moral principles (Dreyfus, 1991; Dreyfus et al., 1996).

The approach to ethics suggested by Gilligan provided an opportunity for nurses to reexamine their everyday concerns. Some nursing scholars addressed the idea that principle-based justice ethics is incompatible with the nursing paradigm (Cooper, 1989). Another study suggested that principle-based ethics is limited in capturing the socially embedded practical knowledge of everyday skilled ethical nursing practice, which needs to be considered in terms of its context, the particular relationship, and the involved perceptual recognition (Benner, 1994a). There is a need to explore the ethics and morals inherent in nursing in a way that reflects the actual experience of nurses (Jameton & Fowler, 1989; Smith, 1996; Yeo, 1989). Within the last decade, a number of nurses have started inquiries into the theory of ethics and morality in different areas in nursing (Astrom et al., 1993; Benner, 1994a; Grundstein-Amado, 1992, 1993; Holly, 1993; Liaschenko, 1993, 1995b, 1999; Millette, 1993; Tarzian, 2001). Because of the comparatively mature development of nursing scholarship and because the challenge to traditional ethics first took place in the United States, most of the inquiries into moral theory in nursing have also been conducted there.

Japanese nurses share common concerns with their U.S. counterparts regarding the need to establish a theory of ethics grounded in nursing practice. Although interest is increasing, few studies have been conducted to explore nursing in Japan. Instead of exploring and developing their own nursing ethics, Japanese nurses have imported and tried to apply traditional Western ethics to their own practice. However, ethics are strongly value laden, and values are constructed by their social, cultural, and historical context. This application of an ethical theory that was developed in a different background, without examining its underlying values, is risky. In addition to the potential and expected cultural value differences, because traditional, principle-based Western ethics devalues the involved ethical judgment often seen in nursing practice, the imported ethics is even less relevant to nursing practice in Japan. To explore the ethics that reflects the real experience of Japanese nurses, it is necessary to look into nursing practice within Japanese culture and society.

Aims of the Study

Although Japanese nursing scholars are increasingly interested in ethics, empirical studies of nursing ethics in Japan are scarce. Most of the current literature of nursing ethics seen in Japan is abstract and ideal discussion applying Western ethical principles to the Japanese nursing role (Shimizu, 2000; Shirahama, 2001). With the exception of the study done by the Ethics Committee of the Japanese Academy of Nursing Science (Yokoo et al., 1993), which explored ethical issues Japanese nurses face in their practice, few researchers have focused their inquiries on the ethics and moral issues inherent in Japanese nursing practice.

The aim of this study is to uncover and understand the moral concerns existing in Japanese nursing care for dying patients, and to explicate how these moral concerns are implemented in actual ethical practice. This research aim is based on the assumption that there are ethics inherent in Japanese nursing and that they appear as the nurses' moral concerns in their everyday practice.

The terms *ethics* and *morals* are often used interchangeably (Davis, Aroskar, Liaschenko & Drought, 1997). Nurse ethicists Davis et al. defined ethics and morals as "conduct, character, and motives involved in moral acts and [they] include the notion of approval or disapproval of a given conduct, character, or motive that we describe by such words as good, desirable, right, and worthy, or conversely by such words as bad, undesirable, wrong, evil, and unworthy" (p. 1). In this study, nursing ethics refers to the notion of good/bad or right/wrong in nurses' conduct, character, and motives. Being "ethical" means the acts and character of nurses are in accordance with goodness. Although the terms *ethics* and *morals* have very similar meanings, *ethics* comes with the connotation of scholarly conceptual argument, whereas *morals* implies more socially embedded values.

Therefore, although these two words are used almost interchangeably in this study, the term *moral* was intentionally chosen to delineate the nurses' subtle, almost reflexive concerns. The nurses' concerns discussed in this study are not the products of logical argument, but are formed through their personal experience living in the society and culture and what matters to them. Thus the phrase, *moral concerns,* seems to be more appropriate. On the other hand, the term "*ethical practice*" will be used, because the practices focused in this study are acts by nurses based on their notion of good or bad, and they are the subjects of scientific inquiry in this study.

The specific research questions are:

1. What are the moral concerns inherent in nursing practice for the care of dying patients in Japan?

2. What are the ethical practices, skills, and behaviors that reveal these moral concerns and thus the ethics of Japanese nurses in end-of-life care?

Significance of the Study

This inquiry into the moral concerns and ethical practice inherent in Japanese end-of-life nursing care is expected to have three important implications for nursing: (a) the findings will contribute to framing a code of ethics that reflects nursing practice in Japan and helps to characterize nursing as a profession; (b) the findings will provide a language to communicate nurses' moral concerns among nurses, and to other members of health care teams and society; and (c) nurses with ethical voices will be able to advocate for dying patients and their families more effectively and to provide patients the best care they can devise. Detailed explanations of these three implications follow.

Ethics form the foundation of the nursing profession (Beauchamp & Childress, 2001; Fowler, 1997; Fry, 2001). In order to adequately characterize the profession of nursing, an accurate description of its ethical foundation is indispensable. To date, ethics and morality in Japanese nursing have been discussed in terms of either the virtues of the nurse's personality, derived from the history of conventional nursing practice (Hashimoto, 1964; Shibata, 1970), or the principles used in bioethics. Now, both conventional personal virtue ethics and principle-based ethics are being questioned for their adequacy to frame actual everyday ethical nursing practice. The former approach, which is heavily reliant on the nurse's personal virtues such as being obedient to physicians and being polite to patients and their families, is not based on professional values and is inappropriate as a professional code of ethics. And as discussed in some of the nursing literature following Gilligan's study, traditional principle-based ethics does not necessarily reflect actual nursing practice (Benner, 1994a; Benner, Tanner & Chesla, 1996; Cooper, 1989, 1991; Dreyfus & Dreyfus, 1991; Dreyfus et al., 1996). Thus we need to explore and clarify the moral concerns and skills that reflect actual nursing practice in Japan. The identification of these concerns and skills will contribute insights toward the foundation of a professional code of ethics to guide the practice of Japanese nurses.

Second, uncovering the ethical values inherent in nursing practice in Japan will help empower nurses to practice as health care professionals (Erlen & Frost, 1991). Since nurses grasp and respond to ethical issues so intuitively, nurses who are in practice take them for granted and have not developed a language to explicate and communicate their concerns to other nurses, to those in other health care disciplines, or to society. The moral concerns and skills uncovered in this study will add vocabulary to help nurses explain their ethical judgment and practice, and to convey their concerns to others.

The difficulties nurses experience in end-of-life care are often due to the different values and goals of the people involved in the situation. Nurses face situations where they see care they believe is not good for the patient, yet are unable to stop or change it because other people believe it is good for the patient. In order to implement ethical practice, nurses need to negotiate and convince others who have a different opinion about what is good for the patient. Unfortunately, according to the literature, Japanese nurses are not very successful in making their concerns explicit and persuading others to agree with their ethical judgment (Kiba et al., 1998; Yokoo et al., 1993). Part of the reason they cannot convince others is their lack of language for rationalizing and conveying their concerns. According to the traditional view of ethics, emotional and intuitive responses by nurses to ethical issues are viewed as immature; therefore, nurses' voices about the ethical issues in everyday practice are devalued as non-philosophical argument and ignored. If nurses obtain the language to argue their concerns logically and persuasively, their voices as patient advocates will be heard by others involved in the situations. Having a language and being heard will thus help nurses to accomplish one of their expected professional roles, which is advocating for the patient's best interest and providing the best care for a particular individual based on their professional judgment.

In addition, explicit moral concerns will provide educational and practical guidelines for ethical nursing practice, contributing to improve nursing care. Nurses will be able to make judgments about what is and what is not ethical nursing practice based on verbalized concerns. Novice nurses and nursing students can also use the uncovered concerns and skills as norms of ethical nursing practice and will be better able to understand the ethics existing in nursing. Third, patients and families who are the recipients of nursing care will also benefit from inquiry into ethical values in nursing. By vocalizing their moral concerns and recognizing their ethical practice, nurses will become more efficient communicators in advocating for their patients. Because nurses are often in the best position to know the patient as a person (Liaschenko, 1995a, 1995b, 1997; Tanner et al., 1993), nurses' ethical judgment concerning what is good for the patient has to be expressed so as to require attention from all members of the team. If a nurse can successfully convince others to agree with his or her ethical judgment in regard to the patient's best interest as a person, the patient will benefit most from the nursing practice.

In end-of-life care in Japan, because of the cultural value of protecting patients from bad news, patients are often left out of decision-making about their lives. In such situations, ethical judgment by a nurse who knows the patient should be counted as a surrogate voice for the patient. If nurses gain recognition as ethical agents to advocate for the patient within the team, nurses will be able to represent patients' voices in the decision-making without breaking the culturally customary nondisclosure practice.

Description and understanding of nurses' ethical practice and moral concerns can serve as an opportunity to probe the substantial meaning of nursing. Findings will give language to nurses to explain and justify their moral concerns and behaviors in end-of-life care, and contribute to developing educational and practical norms of ethical nursing practice. Nurses who gain an ethical foundation that fits their actual end-of-life care practice will be able to overcome their ethical dilemmas and difficulties in care for dying patients in Japan. In consequence, patients and their families will benefit from efficient and appropriate ethical nursing practice.

Chapter II: Literature Review

Little has been studied about nursing ethics in end-of-life care in Japan. Several issues contribute to the lack of inquiry in this area. First, Japanese nurses tend not to recognize ethical conflict and dilemmas in their everyday practice as ethical issues. Second, the ethical reasoning and judgments nurses make are deeply embedded in their practice and often taken for granted. Third, Japanese nurses tend to look for solutions from nursing in Western countries rather than looking for the ethics inherent in Japanese nursing practice. End-of-life care was chosen as an area where nurses' ethical conflicts and dilemmas appear frequently and in their most significant form. An overview of ethics in nursing will be followed by an outline of the study of nursing ethics in Japan to date in relation to these three challenges.

Ethics in Nursing

Different Approaches to Ethics

According to bioethicists Beauchamp and Childress (2001), "ethics is a generic term for various ways of understanding and examining moral life" (p. 1), while morality refers to norms about conduct, character, and motives, i.e., whether something is right or wrong, good or bad, approved or disapproved according to social consensus. Morality is a social enterprise and not mere guidance invented by an individual (Davis et al., 1997). Morals predate us. All individuals in a society learn its basic moral standards and responsibilities as they grow up, and ethical norms are thus readily understood and embedded in the members' value systems.

Ethics is commonly discussed in terms of norms, that is, how people should behave. Moral norms commonly seen in modern health care include to respect, not to harm, to do good, and to be fair, responsible, truthful, compassionate, and conscientious (Beauchamp & Childress, 2001; Benner, Tanner & Chesla, 1996). In normative ethics, these norms are organized to prescribe how people should behave and judge what ethical behavior is. Another approach to discussing ethics is descriptive ethics. Descriptive ethics gives an account of how people *actually* behave, not how they *should* behave. When the underlying norms or ethical theories are unknown, descriptive ethics is used to understand and characterize the ethical values and norms in the society.

Several approaches to normative ethics are particularly related to nursing: principle-based ethics, virtue ethics, and caring ethics (Davis et al., 1997). Sometimes, the proponents of each approach compete so hard that it gives an impression that no more than one ethical approach can be applied to a situation. However, different approaches can shed light on the different dimensions of a situation; there are also situations where one approach is more adequate and meaningful than the others.

Principle-based ethics. This approach raises questions of what ought to be done in a situation where an ethical problem or dilemma exists. Ethical problems are interpreted and resolved by applying rules and principles to factual circumstances (Carse, 1996; Cooper, 1991). Within this framework, moral discourse needs to be objective, impartial, and consistent in the application of ethical principles. The principle most prominent in determining right or wrong conduct varies depending on the underlying moral theory, such as utilitarian, deontological, or natural law theory. For example, in biomedical ethics, the four principles used most broadly as moral norms are respect for autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2001; Davis et al., 1997).

The principle-based approach is widely used in both biomedical and nursing ethics and represents the dominant conception of ethics in health care (Cooper, 1991; Fry, 1989). As Pellegrino (1993) notes, principle-based ethics became dominant when European societies became more religiously heterogeneous and committed to reason rather than faith to justify social norms. Thus, the value foundations of principle-based ethics are derived from the modern rationalist concept of an individual who is autonomous, independent, and has the right and power to make self-determining decisions (Fry, 1989). Based on this rationalist value foundation, the major lines of moral reasoning appeal to autonomy for individuals and not harming others, doing good to others, and seeking fairness in social distributions of benefits and burdens.

Although principle-based ethics is the most frequently used approach in the bioethics arena, there have been a number of criticisms. The critiques address a lack of coherence, inappropriate attempts to universalize values, and "top-down" reasoning that is isolated and does not reflect the particularities and relationships in everyday human existence (Beauchamp & Childress, 2001; Carse, 1996; Parker, 1990a; Tong, 1996).

In nursing, it is difficult to apply principle-based approach to determine what a nurse ought to do. In part this is because the nurse is obligated to multiple parties who may hold conflicting ethical values. Nurses act for patients as well as for physicians and institutions (Aroskar, 1986; Bishop & Scudder, 1990, 1991; Engelhardt, 1985; Jameton, 1984, 1993; Liaschenko, 1995b; Wilkinson, 1988, 1989; Yarling & McElmurry, 1986). Nurses serve two powerful individuals in their practice: the patient, who has power as the person who gives authority for health care endeavors, and the physician, who has legal authority to prescribe medical intervention in order to save the patient's life or alleviate pain and suffering (Engelhardt, 1985). There is some literature discussing the institutional constraints that impede nurses from acting morally in practice (Jameton, 1984, 1993; Liaschenko, 1995a; Wilkinson, 1988, 1989; Yarling & McElmurry, 1986). Because nurses are serving three different parties, they are not in the position to make autonomous ethical decisions and act based on the decisions.

If all participants in the situation—likely physicians, patients and families, the institution, and nurses—shared the same values and the same goals, it would be easy to agree on what ought to be done for the care of the patient by applying ethical principles. However, physicians tend to aim for a cure and the prolongation of life, while patients have the right to autonomy and respect for their personal values, which may not support prolongation of their life by life-support technology. Meanwhile institutions need to sustain their business in order to serve the community and provide fair health services. Thus, when nurses serve and act for others, they internalize the value conflicts that result from the different values and goals of different team members (Liaschenko, 1995a). In addition, nurses may not have the authority to make a judgment but must often act based on another person's decision. Nurses make ethical judgments in terms of what kind of care they ought to provide to a particular patient, but even this judgment about care is determined in relationship to the values the patient has, or sometimes the values of the family members, the physician, or the institution. Such ethical judgment based on the relationship with patients, family, and other health care providers cannot be pursued from the objective, detached, impartial stance required by principle-based ethics (Carse, 1996; Cooper, 1991). The situations nurses face in the real clinical setting are often too complicated to reduce to an argument that focuses on one simple principle used by one decision-maker to make a unilateral judgment.

Another criticism is that principle-based ethics presumes that principles are universal and thus absolutely right within any context (Davis et al., 1997; Tong, 1996). The four prima facie principles addressed in Beauchamp and Childress 2001 are based on the notion of the independence and equal rights of autonomous individuals, and they reflect mainly white, male, European values. Therefore, in a culture like Japan's, where individualism and independence are recently imported foreign concepts, these principles may not be the most appropriate set of norms on which to base judgments. Yet, because principle-based ethics is currently the most dominant and commonly used ethical approach in health care, Japanese nurses sometimes have to use this approach to communicate and justify their conduct within multidisciplinary teams.

Virtue ethics. Virtue ethics focuses on morally valued character traits within people. The question raised is what sort of person one ought to be (Davis et al., 1997). Sometimes, moral life is associated with reliability, conscientiousness, and emotional responsiveness rather than with principles and rules (Beauchamp & Childress, 2001). The presumption is that good character will produce right action, and virtue will accomplish duty. Without a proper motive, even if the act is in accordance with a moral obligation and thus right, it cannot be understood as virtuous. This distinction between right action and proper motive was made by Aristotle, who analyzed it in terms of internal state and external performance (Beauchamp & Childress, 2001; Carse, 1996; MacIntyre, 1984). An external performance can be virtuous only if performed from the right internal state of mind. For Aristotle, the right state of mind includes right motivation (not egoistic reasons), and right emotion and desire (Beauchamp & Childress, 2001). A virtuous person will experience appropriate feelings, such as sympathy, compassion, and regret that impel action. A virtuous person feels the right emotions at the right times, to the right objectives, towards the right people, with the right motives, and in the right way (Aristotle, trans. 1941). For Aristotelians, feelings and emotions are the key to discerning moral issues and to directing right motivation (Beauchamp & Childress, 2001; MacIntyre, 1984).

Professional roles generally incorporate the virtues and obligations expected of the profession in the society. In the traditional model of nursing, in which nurses were handmaidens of the physician, a virtuous nurse was obedient, submissive, and obligated to her master, the physician (Beauchamp & Childress, 2001; Fowler, 1997; Hashimoto, 1964; Shibata, 1970). As nursing became a more autonomous and independent profession, the roles of nurses changed, along with their expected virtues and obligations. In the contemporary model, virtues expected of nurses include compassion, respect for patients, conscientiousness, fairness, and truthfulness (Beauchamp & Childress, 2001). Those virtues are believed to produce the right motivations and appropriate feelings that will lead the nurse to take morally right actions.

Historically, ethics in nursing focused more on the virtues of the nurse than on the ethical values of her conduct (Fowler, 1997). In contrast to medicine, which was built on a guide of ethical conduct, the Hippocratic oath, nursing did not have its own ethical guidelines for professional conduct until the middle of the 20th century (Fowler, 1997). Instead, the sources of moral nursing were seen to be the manners and personal character traits of the nurse, which influenced relationships to patients, patients' families, other nurses, and other health care professionals (Fowler, 1997). The assumption was that moral behavior was derived from the moral character of the person. Professional behavior was not separable from personal character. Therefore, early statements of nursing ethics included comments about nurses' etiquette and behavior in their personal lives.

Although virtue ethics had been the standard approach to ethics in nursing, nurses had started to look for a more legitimate, "professional" code of ethics in order to establish nursing as a profession in early 1900's (Fowler, 1997). Professional roles are seen to be consisted of motivations originating from the virtue of the professional as well as of the contracted professional obligations to the society. However, because virtues are emotion-bound, and virtue ethics in nursing had been based on ideals of nurses' personality, they cannot be reduced to elementary principles of good conduct in order to put it in the statutory form. The focus therefore shifted from virtue ethics to principle-based ethics (Fowler, 1997). The American Nurses Association's (2001) current Code of Ethics for Nurses does not include virtues of nurses as a part of its codified moral standard.

Ethics of care. The ethics of care takes into consideration one's relationship with others and views the moral/ethical responsibilities of care as being derived from attachments and involvement in these relationships: "Caring in this account refers to care for, emotional commitment to, and willingness to act on behalf of persons with whom one has a significant relationship" (Beauchamp & Childress, 2001, p. 369; see also Carse, 1996; Davis et al., 1997). Caring ethics was derived from a feminist perspective that focuses on the nature of human relationships. According to the philosopher Noddings (1984), caring ethics values love, compassion, and sympathy. Moral good is acted upon within the context of an involved, intimate relationship. In the ethics of care, patients are viewed as unique individuals who are enmeshed in a web of relationships rather than as isolated bodies. Persons are respected as members of an interrelated community rather than as independent autonomous beings.

Feminist philosopher Sherwin (1992) points out that principle-based ethics is primarily derived from Western philosophy by male Europeans and favors abstraction and generality, which are not representative of women's reasoning. This male biased view of ethics was also evident in Kohlberg's work (1981) on the cognitive model of moral development, which is based on his study of 75 American adolescent boys. According to Kohlberg, moral consciousness begins with involved ethical comportment, and the highest stage of moral consciousness is guided by universal ethical principles. The rational explanation of the ethics of justice is viewed as the most developed form of moral comportment. Most early discussions of ethical reasoning in nursing used Kohlberg's theory as the basis for evaluating nursing conduct (Cooper, 1991; Parker, 1990a; Smith, 1996).

Psychologist Carol Gilligan identified a different approach to ethical comportment in her 1982 study. She observed that many women were unable to explain the rationale for their moral response by detaching themselves from the relationship and articulating their principles. Instead, women tended to stay involved in the situation and respond in a more intuitive manner, which would be viewed as cognitively immature from Kohlberg's standpoint. Gilligan does not say one approach to ethical/moral decision-making is better than another. Caring ethics is oriented toward persons who emphasize relational aspects, and justice ethics is aligned with those who rely on principles (Millette, 1994). Although Gilligan was clear that ethics of care is not bound to gender, her work shed light on a subtle moral sense that had been overlooked for a long time in male-dominant, rationally oriented society. The dominance of principle-based ethics had devalued alternative perspectives, but the caring ethics approach Gilligan outlined attracted attention as a fitting paradigm for nursing (Cooper, 1991). Caring ethics clarifies and uncovers some of the moral issues women, and particularly nurses, have experienced.

There is a connection between caring ethics and virtue ethics. The fundamental requirement of caring ethics is an account of skills and character traits, i.e., the virtue of being a caring person (Carse, 1996). In ethics of care, concern for others' good and the relationship with others are important. This emotional attunement and attachment to and personal interest in the other, based on the mutual relationship, are crucial to moral discernment and deeper understanding of the moral contours of the other's situation (Carse, 1996). Through the well-cultivated emotions of the moral personality, a person apprehends the other's predicament, and virtue then motivates the person to take action to care for the other. Thus, the ethics of care includes virtue ethics, since virtue is a basic element constituting the caring person.

The ethics of care has been criticized for its partiality, lack of completeness, and lack of explanatory and justificatory power (Beauchamp & Childress, 2001; Crigger, 1997; Omery, 1995). Because the ethics of care emphasizes engaged, contextual, and passionate moral thinking, the view is always biased. In the ethics of care, moral reasoning may be guided by universal rules and principles, but it is not always derived from fixed principles. In addition, caring ethics is still a new school of thought. The development of the language and logic of justification is still immature. Yet this new perspective on moral issues may fit well with the nursing philosophy.

Nursing and Ethics

Principle-based, virtue, and caring ethics are commonly used to frame ethics in nursing. But the application of these theories, particularly principle-based ethics, implies that the theories preexist and establish ethical nursing practice. In contrast, I would argue that ethics in nursing preexist, although this ethics has not yet been adequately articulated. Benner and her colleagues (Benner, 1994a; Benner et al., 1996) identified ethical comportment as a critical part of skilled knowledge in nursing practice, which nurses learn experientially. Although they do not articulate it, it is manifest in their practice. Because the ethical values and moral sense held by nurses are the core elements that compose nursing as a caring profession, it is necessary to explore and describe this inherent nursing ethics rather than seeking to apply external theories.

Nursing is a moral profession (Bishop & Scudder, 1990, 1991, 2001). That is, nursing is both a moral endeavor and a profession. Pellegrino (1985), a humanist and a physician, contends that the term *profession* refers to "a special promise to help humanity and to place it above one's own interest" (p. 28), and that this notion is the source of an ethical obligation indwelling in health care professionals. In his opinion, the essence of a health care profession is responding to the call to care by using knowledge and skill for the good of the patient. Although his contention is based on the physician-patient relationship rather than the nurse-patient relationship, his approach successfully integrates professional care and moral care. In accordance with Pellegrino's opinion, nursing is a moral endeavor because it is a health profession that has a moral obligation for the patient's good.

Another approach to establishing nursing as a moral endeavor comes from a group of scholars who take caring as a foundation for nursing. Gadow (1985) argues that the willingness to protect and enhance the human dignity of patients in the health care system emerges from caring and makes a nurse a moral agent. Watson (1985) views caring as a human value that involves "a will and a commitment to care, knowledge, caring actions and consequences" (p. 29). Caring requires the nurse to protect human dignity and preserve humanity. For Watson, caring becomes a professional ideal when the notion of caring transcends specific acts of caring in the practice to influence the collective acts of the nursing profession (Fry, 1989). Nursing, as a caring profession, is thus a moral endeavor.

Noddings (1984) also describes caring in personal relationships as evidence of moral sense in caring. In her view, caring is not an outcome of ethical behavior, but caring itself constitutes ethics (Fry, 1989). Caring is the attitude of being moral. According to Noddings, there are two kind of caring: natural caring and ethical caring. Natural caring comes out of love and natural inclination for the other. In ethical caring, the person may not be motivated to care by natural caring, but the person is called to be a caring person. Here, calling is an inner urge that could, though not necessarily, have religious connotations. When Noddings's concept of two types of caring is applied to nursing, there is no higher or better caring than the other to motivate nurses. Ethical caring articulates the moral obligation of nurses as professionals. In other words, nurses have a moral obligation to care for anybody, even those for whom they do not naturally care. Nurses care for patients because the nurses recognize caring as the way they ought to be.

The moral imperatives inherent in nursing become clearer when Noddings's notion of ethical caring is combined with the philosophical interpretation of the ethics of authenticity by Taylor (1991). Taylor contends that authenticity is morally significant, because it commits a person to a better or higher mode of life that is not what she/he desires, but what she/he ought to desire. By being authentic and listening to the internal voice that tells us what we ought to desire, nurses are able to focus on inherent moral purpose: fostering the well-being of the other and maintaining the relationship through which the caring purpose is fulfilled (Bishop & Scudder, 2001). As an authentically caring profession, nursing entails care for the authentic well-being of the other. If the orientation of authenticity residing in nursing is a moral attitude, as Noddings describes, nursing practice implies a strong moral sense and is inseparable from its inherent moral imperatives. It is important, therefore, to look into nursing practice to uncover and describe its inherent motivations and the moral sense that makes nursing an ethical profession, rather than prescribing what nurses should do in terms of external norms.

Discrepancies in Studies on Nursing Ethics in End-of-life Care in Japan

Difficulties in End-of-Life Care and Moral Concerns

Nurses are involved in situations that require ethical decision-making on a daily basis. Especially in care for dying patients and their families, issues such as information disclosure, patients' rights and values about how to live or to die, patients' autonomy in decisions about treatment, who is the decision-maker, and how much is good enough, pose critically important ethical questions to nurses. However, few studies in Japan discuss these issues from an ethical perspective. Among Japanese nurses, such situations are often labeled and discussed simply as difficult cases.

Japanese nurses experience various difficulties in providing quality care for dying patients and their families (Iba & Kawagoe, 2000; Konishi & Davis, 1999; Tamura, 2000). There are studies reporting nurses' stress and dilemmas in caring for dying patients (Nakajima & Kakuta, 2000; Sawada et al., 2000; Tahata & Nakamura, 2000). Many case studies and anecdotal narratives also explicate difficulties nurses experience in caring for dying patients in Japan (Kiba et al., 1998; Tamura, 1997). According to Kiba et al., of the articles published in the *Journal of the Japanese Society of Cancer Nursing* from 1988 to

1997, 51.4% were case studies or descriptive studies related to care for terminal-stage cancer patients. Until 1993, case studies were the most common method used to present such inquiries. However, as more nurse researchers become oriented to empirical science and seek generalizability and objectivity in their scientific efforts, case studies have gone out of favor as a scientific approach. As a result, the number of case studies accepted for publication in the scientific journals, including the *Journal of the Japanese Society of Cancer Nursing,* has decreased. Although there are some descriptive studies of nurses' difficulties, the case study is still commonly seen as a style of presentation where clinical nurses express their concerns and reflections about end-of-life care in their everyday practice (Kitamura, 1998).

At the Annual Conference for Clinical Research on Death and Dying, several case studies are included in the proceedings as standing sessions, and nurses are the most frequent presenters at the conference (Iwasaki, 2001; Matsubara, Katou & Takehisa, 2001; Nakajima, Kikuchi, Takase & Maeshima, 1999; Oosawa et al., 2000; Takamiya & Minagawa, 1999; Yasui, Miura & Iwakiri, 2001). The case studies presented at the conference vary in their practical topics; however, their shared primary issue, which nurses discuss and reflect on at the conference, is the struggle and distress nurses perceive in providing care for dying patients across the board. The majority of situations in which nurses have difficulties involve perceiving that patients are not receiving the “right” care, and feeling “bad,” “worried,” or “regretful.”

In one case study, a group of staff nurses in an oncology unit sought advice from nursing school faculty with expertise in consultation and end-of-life care. The case was brought up because the nurses felt difficulties in caring for the terminal-stage cancer patient in their unit.

> A 65-year-old man with advanced lung cancer was in a cancer center in Japan to receive chemotherapy. He was told at the time of hospitalization that his diagnosis was lung cancer by his physician. Two sessions of chemotherapy did not make much improvement in his disease, and his condition started to deteriorate because of the damage from the chemotherapy. The physician left the decision to him whether to go for the third chemotherapy session or go back to his home with only palliative measures. The physician was concerned that the patient would not survive more chemotherapy and his prognosis was very grave. However, the physician did not tell the patient about the prognosis, because the patient’s family asked the physician not to tell him that he was dying. The patient became irritated that nobody gave him clear information or support.

> The patient asked a nurse, “I wonder how long I can live, how I am going to be. What do you think?” The nurses wanted to tell him his prognosis and give him information about possible courses of action. But the nurses thought they should not tell him anything the physician had not, especially when the family strongly resisted telling the truth and had asked the physician not to tell. The nurses tried to persuade the physician to share all the information he had with the patient, but the physician said he could not, because of the family’s request. The nurses wanted to provide care and support to the patient so he could make this very important decision, but they did not know what to do within the restricted situation. They felt difficulties taking care of this patient. (Minegaki et al., 1997, my translation)

In this case study, the nurses could identify the difficulties in the concrete context of this particular situation, but could neither articulate their concerns using the language of ethics nor identify the issues using abstract ethical norms isolated from the context.

Several descriptive studies intend to capture nurses’ experiences of difficulties in end-of-life care and their reasons. Nakajima and Kakuta (2000) interviewed five nurses who were providing palliative care to dying patients in a mixed unit. Six categories of sources of stress were identified in the study. The most frequently seen source of stress was self-criticism about such issues as lack of knowledge about palliative care, inability to provide appropriate symptom management, emotional control, working with a multidisciplinary team, and heavy responsibility as a primary care provider. Other stressful factors were institutional restraints, such as heavy workloads, difficulties in meeting the needs of physicians in different specialties and in working with multiple team members, and relationships with physicians, patients, and their families. Nurses felt caught between patients, families, and physicians. The nurses also named as stressful their uncertainty about the quality of care they provided and their inability to provide the care they thought the patients should receive.

Sawada et al. (2000) conducted a survey of nurses working in university hospitals in Japan. Out of 1,626 respondents, more than half reported being distressed or having difficulties in caring for dying patients. The reasons for their distress and difficulties included physicians' lack of pain control skills, insufficient seeking of informed consent by physicians, physicians not listening to patients, inadequacy of the nurses' own knowledge about palliative care, not having enough time, inability to provide spiritual care, and difficulties in communication due to nondisclosure of diagnosis and prognosis.

Nurses are also troubled in carrying out ethically questionable treatment decisions made by physicians, such as pain management and sedation for terminally ill patients. According to Tahata and Nakamura (2000), 87% of nurses giving sedation medicine feel conflict or question the physician's prescription. The major reasons for the nurses' problems carrying out sedation orders were misconception of the purpose of sedation, and disagreement on treatment decisions among nurses, physicians, and patients and their families due to inefficient communication. In Izumi's qualitative study (1997), the nurse participants expressed the difficulties of pain management for terminally ill cancer patients, and their distress that they could not provide the appropriate care to alleviate patients' pain and suffering. Pain management is complicated for nurses in this situation by nurses' lack of knowledge of symptom management, inadequate communication between nurses and physicians due to their hierarchical relationship, and difficulty understanding the patient because of the barrier generated by the false information provided to the patient in terms of diagnosis and prognosis.

Those issues nurses identify as difficulties in end-of-life care are often moral/ethical problems. However, nurses, not only in Japan but also in other countries such as the United States, usually do not connect the problems in their daily practice with ethics, because they think ethics is something abstract and distant from their everyday concerns (Doutrich et al., 2001; Taylor, 1997; Wros, 1994). Because treatment decisions are not a part of the nurses' role, the nature of the nurses' ethical concerns is different from the ethical conflicts related to treatment decisions, which are frequently the issues discussed in bioethics. In the bioethics field, non-physician health care providers' concerns about everyday practice not involving treatment decisions are not deemed worthy of discussion (Taylor, 1997). In addition, nurses' ethical concerns in their daily clinical practice are often dismissed from major health care ethics accounts, because their ethical concerns are embedded in the reality of complex situations and cannot be captured adequately by the commonly used prescriptive ethical principles. Nurses also often lack the rational language to articulate their issues and concerns (Cooper, 1991; Doutrich, Wros & Izumi, 2001; Parker, 1990a, 1990b; Taylor, 1997). Wros (1993) found in her study of critical care nurses in the United States that "nurses often feel that their role in ethical decision making is not legitimate or important because they are not skilled in the language or process of formal (principle-based) ethics" (Doutrich et al., 2001. p.448). Bioethics has broadly accepted principle-based ethics as a formal approach, and unfortunately, nurses' concerns in everyday practice often cannot be described clearly with those principles (Cooper, 1991; Krishnasamy, 1999; Parker, 1990b). Therefore, nurses think that the difficulties they confront are trivial or unrelated to bioethics, and they do not frame their concerns as ethical/moral issues. Many bedside nurses in Japan share this viewpoint (Doutrich et al., 2001). For them, ethical discussions are understood to center on controversial treatment decisions caused by new and advanced technology, such as abortion, withdrawal of life support, organ transplant, genetic operations, and so forth.

Although nurses in Japan may not frame their concerns as ethical issues, their emotional responses and feelings about difficulties in practice reflect their moral/ethical sense and verify that there are ethical/moral issues in nursing practice. They feel uncomfortable, uneasy, that something is wrong or not right. When nurses feel upset and powerless in a situation, they find it difficult. The basic moral norms the nurses have, regarding what is good or bad and what is right or wrong, trigger those feelings when they are involved in a situation where they see immorality or cannot act morally (Parker, 1990b).

Benner et al. (1996) argue in their study about expert nursing practice that, for practicing clinicians, ethical and clinical knowledge are inseparable. Ethical principles and notions of good provide an essential guideline for clinical decisions, and ethical principles are embodied in actions through ethical comportment in everyday practice. Based on the same study, Benner (1994a) points out that ethical responsiveness is often expressed in emotional terms by nurses in clinical settings. “Feeling like good/bad nurse” and “feeling like I was doing something (to)", "feeling like I wasn't doing anything" are examples of emotional response that guide an ethical sense of the situation. Some schools of thought suggest emotional response is a critical part of ethical comportment (Beauchamp & Childress, 2001; Oakley, 1992; Taylor, 1985). Therefore, the Japanese nurses' feelings of difficulties and emotional responses in giving end-of-life care merit examination as moral concerns.

Ethical Comportment as Embedded Practice

The social and cultural embeddedness of nurses' ethical comportment is another reason why it has been overlooked. Ethical comportment refers to the embodied, skilled know-how of relating to others in ways that are respectful, responsive, and supportive of their concerns (Benner et al., 1996). Comportment is more than intents, beliefs, or values; it contains stance, orientation, thoughts, and feelings embodied in behaviors and actions (Benner et al., 1996; Benner & Wrubel, 1989). Nurses learn ethical comportment through experience. The concrete experience of seeing better and poorer outcomes, distinct patient/family concerns, and contrasts and similarities among various clinical situations helps nurses to gain an ethical sense of a situation and how to respond and act (Benner, 1994a). Ethics of care must be learned experientially because it is situated in specific communities, practices, and relationships, and it is dependent on recognition of salient ethical comportment in specific situations (Benner et al., 1996). Because gaining insight into ethical comportment is experiential learning, just like any other culturally and socially embedded practical knowledge, ethical comportment in nursing is taken for granted in nurses' conscious reflective thinking (Benner, 1984; Benner & Wrubel, 1989; Dreyfus, 1991; Dreyfus & Dreyfus, 1991; Heidegger, 1962). Although nurses make ethical judgments with ethical reasoning, they perceive them as emotionally imbued personal concerns instead of recognizing them as important ethical predicaments that need to be shared with others. This is another reason nurses' ethical comportment has not been discussed explicitly or studied much in Japan.

Japanese Nursing and the Influence of Western Science

A third reason Japanese nursing has not developed its own nursing ethics in end-of-life care is the strong influence of Western science on Japanese nursing. Although Japan is now one of the most developed and industrialized countries in the world, for about 250 years prior to 1868, while modern industrialization took place in Europe, Japan had a closed-door policy to foreign countries. When the United States and Russia asked the country to open in 1853, Japan was far behind Western countries in terms of industry and technology. Under the threat of being conquered, the Japanese government had to catch up quickly.

Therefore, Japanese intellectuals at that time set the highest priority on adopting Western industry and technology. Japan has since tried to import and cultivate the most advanced scientific knowledge. As a result, Japan had developed its national strength to compete globally by early in the 20th century, and despite the damage from its World War II defeat, it returned to being one of the world's most developed countries by the late 20th century.

Lock (1995) points out the complex and ambivalent attitudes Japanese have towards Western values and traditional Japanese values: "Contemporary Japanese attitudes towards science and its associated technology are difficult to pin down because they are intimately linked to a widespread ambivalence about the process of Japanese modernization. Moreover, Japanese attitudes towards modernization cannot be understood in isolation from ever changing interpretations, given both inside and outside the country, about the relationship of Japan to the West" (p. 15). In the late 19th century, Japanese were more aware of the grounds of their cultural values and separated them from science, which they viewed as mere technical knowledge (Najita, 1989). This attitude was expressed in phrases such as "*wakon yosai*" (Japanese spirit and Western technology) and "*toyo doutoku, seiyou gijutsu*" (Eastern morality, Western technology). However, the extraordinary belief in Japanese spiritual superiority, along with confidence in its advanced technology, led Japan to go to war. Thus, after World War II, many Japanese suppressed or denied the traditional, unique philosophy of Japanese spirituality for fear of being an extreme nationalist. Instead, rational Western science has been received blindly and institutionalized into various social systems, such as education and health care. Western science and technology have since been perceived in Japan as reliable, ideologically neutral, and laudable (Lebra, 1974).

Concepts, knowledge, and skills in nursing from the West are also very welcome in Japan as an advanced model of nursing as a science. Nursing became a scientific endeavor after World War II. Under the guidance of American nurses with the U.S. occupation forces, the level of nursing education was upgraded, and the role of nurses was expanded from acting as a conventional physician's assistant to providing unique nursing care to patients as well (Japanese Nursing Association, 1993; Minami, 1985). These changes were based on Western ideas of nursing. Nursing schools in Japan invite nurse educators from the United States in order to build a foundation for professional nursing education, and many Japanese nurses have visited other countries, often the United States, to acquire advanced nursing knowledge, techniques, and new ideas (Doutrich, 1993; Minami, 1985). This knowledge brought back from the United States and other countries is received enthusiastically by Japanese nurses. New nursing knowledge and models have been accepted in nursing education and superimposed on clinical practice in Japan without examining their underlying values.

Nursing ethics in Japan has followed the same pattern. With almost blind trust in Western empirical scientific thinking, Japanese nurses import and try to apply, without examination, ethical approaches based on the Western concept of personhood to their practice in Japan. Discussion about ethics in nursing in Japan is increasing. As nurses struggle to gain autonomy as a profession, they desire to establish the foundation of nursing practice, and to articulate and clarify their ethical standpoint to justify their practice to patients, other health care disciplines, and society. Nursing in Japan, like other professions, is guided by an ethical standard that states the goals of practice: the Japanese Nursing Association Code of Ethics in Nursing. However, the Japanese Nursing Association used the International Council of Nursing's Code for Nurses as a prototype for its code without thoroughly examining the cultural compatibility of the underlying values. Moreover, how these values manifest in practice in Japanese society was not deliberated.

Studies of nursing ethics in Japan have been scarce until recently. From 1991 through 1992, the Nursing Ethics Committee of the Japan Academy of Nursing Science (JANS) conducted a study to delineate ethical issues Japanese nurses confront in everyday practice (Yokoo et al., 1993). The nurse members of JANS were asked to describe their experiences with ethical problems in their clinical practice in free text in their questionnaire. Using 72 cases submitted, a group of researchers inductively extracted five themes: inappropriate provision of information; limited patient participation in health care decision-making; lack of patient input in decision-making about death; inadequate therapeutic environment; and unreasonable invasive treatment. In their discussion, Yokoo et al. point out that the issue underlying the ethical problems identified by the participants is the lack of congruence between the recognized ethical value of respect for the individual and uncertain understanding of the concept of the individual. The concept of the individual was only recently imported to Japanese society from the West. Previously, a person had always been viewed as a part of a circle of family and society. One person's opinion was embedded in the family, and family consensus overruled one person's opinion. Therefore, nurses are not certain how to support and act on the ethical value of respect for the individual and rights of the person within Japanese society. Yokoo et al. conclude that nursing ethics in everyday practice needs to be examined in its cultural and social context.

A group of nurse researchers in Nagano have been rigorously studying nursing ethics in Japanese society (Davis, 1998; Davis, Konishi & Mito, 2000; Konishi, 1998, 2000a, 2000b, 2000c, 2000d; Mito, Konishi & Davis, 1999; Soyano, Konishi, Davis, Suzuki & Ota, 1999). Their studies describe and examine the ethical issues surrounding end-of-life care in Japan, such as informed consent, disclosure of diagnosis, and possible use of advance directives. Under the strong influence of Davis, an American nurse ethicist, they have been successful in describing ethical dilemmas Japanese nurses often face using principle-based ethics as a framework. Their works contribute to raising awareness of ethics in the Japanese nursing community.

However, the simple application of principle-based ethics to Japanese nursing ethics is questionable. Studies such as Yokoo et al. (1993) and the case studies similar to Minegaki et al. (1997) raise the same kind of questions about the principle-based ethics approach as have been seen in the current U.S. nursing ethics movement. The principle-based ethics approach attempts to apply universal principles to justify nurses' conduct. Its “top-down” reasoning focusing on judgment may not be particularly useful for nurses, who are often not in a position to make a judgment about treatment choice and who are caught between two or more decision-makers. The detachment and objectivity required in the principle-based approach also do not fit with nursing practice, where care is provided based on the mutual relationship between the patient and the nurse. Isolation or detachment could harm the caring relationship.

Another reasonable question regards the universality of the commonly applied four principles (autonomy, nonmaleficence, beneficence, and justice). The assumption in the principle-based approach is that these principles can be applied to any situation. However, these principles have been developed in Euro-American culture, and reflect European male values. These may not be the same values Japanese nurses hold. In Japan, nurses are predominantly female, and the culture they reside in has its own traditional values that are significantly different from those of Western culture. Although in the last 100 years Japan has been exposed to enormous influence from the United States and European countries, the concepts of the individual and autonomy are still new and not rooted. How to balance these imported concepts with somewhat conflicting traditional values, such as harmony and interdependence, has not been deliberated and determined.

What are the Japanese traditional ethical values? Commonly, Japanese are considered to employ situational ethics (DeVos, 1960; Doi, 1974). In situational ethics, decision-making regarding ethical issues is based on the particular situation and often concerns whether one's action will result in betraying the group to which one belongs (Doi, 1974). But a recent study done by Davis et al. (2000) shows that 27% (the largest number) of participants (nurses, physicians, others; *N* = 53, 21, 24) indicated there are no ethical guidelines in current Japanese health care, whereas only 2% of the participant indicated situational ethics as the ethical guideline. In the same study, 40% of participants identified "patient autonomy" as the future Japanese ethical guideline, followed by "integrate Western and Japanese traditional ethics" (25%) and "develop Japanese ethics" (10%). It is very interesting that many participants thought of patient autonomy as a future ethical guideline, considering that the value of individual autonomy is at odds with the cultural value of harmonious relationships. This may be due to the influence of ethical theory developed in Western countries. How does a nurse who values the autonomy of the patient provide care to a patient who may want to act based on the value of maintaining harmony with his or her group, i.e., family and society? Minami (1985) points out the problem that Japanese nurses are not aware of the differences between their professional orientation, which is strongly influenced by Euro-American ethical values, and the cultural orientation where they are practicing.

If the principle-based approach does not work well to frame Japanese nursing ethics, should the ethics of care approach or virtue ethics be used instead? Because these two approaches originate from the actual caring relationship and character traits that compose moral practice in nursing, they might be useful to articulate the ethics inherent in Japanese *nursing. However, I would hesitate to assume the values of either approach, which derive from other cultural and social backgrounds, as moral values for Japanese nursing. The distinct strength of caring ethics is its rootedness in real practice. If we impose the values found in U.S. caring ethics onto Japanese nursing, we will make the same mistake of applying imported concepts without examining their cultural and social values. Instead of borrowing values from other cultures, Japanese nurses need to look into their practice and uncover their own moral values, which are inherent in and constitute their practice.*

Need for Studies in Japan

Further studies on nursing ethics in Japan are needed for two purposes: (a) to shed light on and understand the ethical comportment inherent in nursing that has been overlooked for a long time; and (b) to identify nursing ethics that reflect nursing practice in Japan and fit Japanese culture and society. Despite the strong presence of a moral sense in nursing, it has been rarely discussed until recently (Cooper, 1991; Jameton, 1984, 1993; Krishnasamy, 1999; Millette, 1994). Nurses confront many dilemmas and conflicts in their practice that pose challenges to their morality and ethics. So why has the moral and ethical sense in nursing been so neglected? One reason, as mentioned previously, may be the lack of adequate descriptive language. Nurses may simply not use the terms *ethics* or *morality* to define the issues they confront, because they believe that *ethics* strictly indicates principle-based ethics, and it is awkward to describe the issues they usually confront in its language.

Nurses frequently describe their nursing experiences in the technical and professional language of nursing rather than moral/ethical or philosophical language (Bishop & Scudder, 2001; Cooper, 1991). Nurse scholars and educators have tried to define nursing as a morally neutral technological activity. In order to establish nursing as a scientific profession, nurses needed to present themselves as a profession in the sociological sense rather than the moral sense. Therefore, a nurse's immoral practice has been described as "unprofessional," and the term *professional* is substituted for the moral imperative (Bishop & Scudder, 2001).

In a sociological sense, a profession should have a body of knowledge, criteria for competent practice, educational standards, and a code of ethics (Jameton, 1984). There are codes of ethics in nursing, such as the Code of Ethics for Nurses by the American Nurses Association and the Code of Ethics in Nursing by the Japanese Nursing Association. However, Bishop and Scudder (2001) claim that, because the motivation to develop and own a code of ethics in nursing was to establish nursing as a profession instead of to articulate the ethical values in nursing, the code failed to give significant ethical direction to nursing practice. Bishop and Scudder point out that "the profession does not establish the moral sense. The moral sense constitutes the profession" (p. 79).

Many nurses respond to situations according to their non-deliberative moral sense of right or wrong, good or evil. Dreyfus and Dreyfus (1991) outline this preexisting, spontaneous moral action using skill acquisition theory as a framework. They contend that most everyday ethical comportment consists of unreflective, egoless responses to the interpersonal situation. In their article, a phenomenological description shows that the greater the experience, the rarer the need for deliberation. Given that the moral sense of nursing is deeply embedded in its professional culture and fundamental to the notion of caring, it is understandable that nurses have taken it for granted and have not recognized the need to deliberate. Only when their spontaneous intuitive responses do not function will expert practitioners question the appropriateness of their intuition (Dreyfus & Dreyfus, 1991). The Japanese nurses feeling difficulties in caring for dying patients are an example. They are in situations that challenge their spontaneous moral actions, in which they cannot act unreflectively because something prevents them from acting as they ought to. Meanwhile, because the motivation for the disrupted action has become so natural to them, they cannot detach themselves to articulate the rationale for their action and their motivation.

Moral sense, or concerns, are a guideline for the conduct of nursing practice as well as a driving force. According to their moral sense, nurses judge a situation and determine the action to take. Without moral sense as a motivation, the care the nurse provides becomes just a skill to carry out a task. Benner, Tanner, and Chesla (1996) contend that the nurse's moral sense of what is good and right is the background of her practice and sets up what she notices and how she responds. So what is the moral sense that constitutes and guides nursing practice? Benner, Tanner, and Chesla argue that it is not principle based, in the sense of rules that are generalizable across situations; rather it is a good that becomes apparent in the actions of the nurses in the particular situation. This account resonates with the caring ethics approach, which focuses on the situated relationship. They continue, "It is also not totally particularistic, subjective, and private. There are common goods that show up across exemplars in nursing; for example, the intention to humanize and personalize care, the ethic for disclosure to patients and families, and the importance of comfort in the face of extreme suffering or impending death, all of which set up what will be noticed in the particular clinical situation and which shape the nurse's particular responses" (p. 16). For example, one nurse responded to the disruption of her moral sense about comfort measures: "This nurse was outraged by the young residents' inability to see the patient, to understand the likelihood that this procedure was going to be painful. . . . The sense of frustration and anguish at not being able to prevent needless suffering is a common theme in these nurses' narratives" (p. 17). The exemplars in their study were collected from nurses in the United States; however, they share much in common with the frustrations and emotional responses Japanese nurses experience in end-of-life care.

Given these commonalities, should the findings from these studies be applied to Japanese nursing practice? Ethics is strongly value-laden, and values stem from the social, cultural, and historical context. Application of ethics that have been developed in a different background without examination is risky. In particular, considering that the ethical comportment and concerns are extracted from nurses' actual practice, which reflects their social and cultural background, the application of ethical findings from other societies to Japanese nursing is irrational. In order to explore the ethics inherent in Japanese nursing, it is necessary to examine its own practice within its culture and society.

Minami (1985) expresses concern that applying models based on a Western value orientation to Japanese nursing without examining their potential conflict with traditional values causes confusion and, as a result, nurses and others suffer from the discrepancy between those values. She makes the insightful suggestion that the ethical dilemmas perceived by Japanese nurses in practice must be explored in order to identify the principles behind nurses' ethical decisions. Yet recent approaches to ethics, such as caring ethics, give us another dimension to explore in the context of nursing ethics. Some other Japanese nurse leaders also suggest that Japanese nurses need to look to their own practice and its underlying values in order to clarify and establish a nursing practice reflecting Japanese cultural and social values (Kojima, 1987). Since nursing is a moral endeavor, and since nurses' ethical comportment is inherent in everyday nursing practice, which reflects background cultural and social meaning, we need to examine actual everyday practice to try to uncover the existing nursing ethics in Japan.

Chapter III: Methodology

This study focuses on phenomena associated with everyday ethical practices and nurses' concerns in end-of-life care in Japan. An interpretive phenomenological approach was selected as the appropriate methodology for this study for two reasons: the ontological characteristics of the focused phenomena; and the particular epistemological orientation underlying interpretive phenomenology. Since everyday ethical practice consists of embodied skills grown out of involved caring practice (Benner, Tanner & Chesla, 1996), it cannot be fully explained by universal, abstract theories and rules detached from particular cultural and historical contexts (Benner, 1994a; Dreyfus, 1994). Interpretive phenomenological research attempts to capture and describe unarticulated, taken-for-granted skills and practices from narratives about everyday life and from observation of actions in meaningful context (Benner, Tanner & Chesla, 1996). The epistemological orientation of interpretive phenomenology is to understand practical skills and knowledge within their context and to reveal human concerns. Interpretive phenomenology aims to capture the philosophical underpinnings of unarticulated practical skills. Since the underlying ethical values and norms in end-of-life nursing care in Japan are both unknown and covered by imported theories, this study is designed to produce a descriptive ethics using the interpretative phenomenological approach. Therefore, this approach is appropriate for this descriptive study of ethical practice and concerns of Japanese nurses in end-of-life care.

The following sections present the philosophical assumptions of the research paradigm in interpretive phenomenology, followed by the research design for this study, which is based on these philosophical assumptions. The specific strategies used in the research as well as the approaches to interpretation of the data reflect the philosophical underpinnings of this methodology.

Philosophical Assumptions of Interpretive Phenomenology

Interpretive phenomenology blends the hermeneutical (interpretive) element and the phenomenological element, i.e., interpretation of human meaning and explication of concrete aspects of everyday life as it is encountered in the real world (Van Manen, 1990). Interpretive phenomenology refers to a research approach derived from Martin Heidegger's ontological account of what it means to be human. As an existential philosopher, Heidegger departed from the European traditional philosophy of Cartesian dualism (the mind-body split), and took an approach to understanding humans as integrated beings who are part of their world. In his view, questions of ontology (what it is to be) need to precede questions of epistemology (what it is to know), and the answer to the question of knowing is revealed from the answers to the question of being (Benner & Wrubel, 1989). In other words, without understanding what it is to be a person, we cannot understand how we, as humans, know the world clearly. This shift of the starting point of inquiry from the problems of epistemology to ontology radically altered the nature of human science and its methods of inquiry (Benner & Wrubel, 1989; Dreyfus, 1994; Van Manen, 1990). It is critical in human science, such as nursing, to consider and clarify what it is to be a person before we start asking research questions, for what to ask and how to ask it depend on how we define being a person. The answer to this ontological question will determine what we look for, how we ask research questions, and how we answer the questions we raise (Leonard, 1994).

View of Humans

In *Being and Time,* as a first step in his project, Heidegger (1962) raised the fundamental question of what it is to be human. Heidegger claimed the traditional Western view of human nature represented by Descartes misrepresented human beings (Dreyfus, 1991). Human beings are neither some combination of body and mind independent and isolated from outside objects, nor are they assemblies of traits and attributes (Dreyfus, 1994; Leonard, 1994). Rather, a person is a self-interpreting being formed through reciprocal interactions with the world. According to Heidegger, a person has a world that is not merely an environment or the physical objects surrounding the person. World is constituted by and constitutive of the person (Leonard, 1994). World is a priori and it is a meaningful set of relationships, practices, and language that a person has by virtue of being situated in a culture: "The world is constitutive in that the self is raised up in the world and shaped by it in a process that is not the causal interaction of self and world as objects, but rather the nonreflective taking up of the meanings, linguistic skills, cultural practices, and family traditions by which we become persons and can have things show up for us" (Leonard, 1994, p. 47).

Within the background world, things have significance and value for the person. Because of their significance and value, things matter to the person (Benner & Wrubel, 1989). Things appear as threatening, attractive, or ethical to the person, and thus they solicit the person's attention and call for his or her care. Heidegger (1962) calls this "concerns," and he argues that we become involved and engaged in the world because of these concerns (Benner & Wrubel, 1989; Leonard, 1994). Concerns are solicitudes that call for our attention, but they are neither tangible objects "out there" nor the subjective intention to look outward. Concerns reveal themselves in response to specific situations, reflecting the background the person brings to the situation. For Heidegger, concerns account for *why*: why people do things, and why they make the choices they do in a situation (Dreyfus, 1991). Thus, concerns move the person. The person is involved with the other through concerns. The world is understood in the light of concerns, and the person is defined by his or her concerns (Benner & Wrubel, 1989).

While concerns explain why, *what* people do is bounded by their world. Their freedom of action is "situated" (Taylor, 1991). That is a very different view of humanity from Cartesianism, in which the self is radically free. In the interpretive phenomenological view, a person is thrown into a particular cultural, historical, and familial world, and that particular world constrains the person's possible ways of being. For example, because a nurse's possibilities are limited by the world into which she was thrown, she cannot make free choices apart from and outside of her world. The choices a nurse makes, what she can know, what she does, and how she feels are all formed by the world she lives in; she is free only within her world (Leonard, 1994). Although there are abstract and universal concepts that transcend a person's world, what these abstractions mean and how they appear to the person depend on her background and are limited within the range of meanings she has given the language and culture of her world (Leonard, 1994). Although people are capable of thinking conceptually and deliberatively, a person does not know what to do with such abstract, conceptual thinking unless it is situated in a meaningful context for the person (Benner & Wrubel, 1989).

Knowing and Knowledge

In the Heideggerian view, there are two kinds of knowledge: one is conceptual, reflective, deliberative thinking, and the other is a nonreflective, nonconscious, immediate grasp of meaning. According to Heidegger (1926/1962), the second kind of knowledge composes most of everyday life. The immediate grasp of a situation and one's nonreflective response to it are made possible by the characteristics of humanness described above. People are brought up in the world and are always situated in a meaningful context; therefore, people can grasp a situation nonreflectively, and the body knows how to respond and move through the situation without deliberation (Benner & Wrubel, 1989). In other words, this sort of knowledge bypasses the conscious cognitive process and is embodied directly in responsive actions. A good example of this kind of action is a craftsman's skilled activities: craftsmen are often not able to explain what they do, but just "know" what it is and how to do it.

This kind of knowledge and skilled activity has been disregarded for a long time, partially because in the Western history of philosophy such embodied knowledge has been regarded as "lower" than intellectual, reflective knowledge and was not explored in intellectual philosophical discussions (Benner & Wrubel, 1989). In Japan, culturally there has been more respect for the craftsman's embodied knowledge (Nakamura, 1992). However, this knowledge has been accepted as intangible, implicit skills and therefore also not explored. Another reason why embodied knowledge has been dismissed is its taken-for-granted nature, due to its smooth operation. When this nonreflective thinking is working well, it is rapid and nonconscious, and everything proceeds smoothly; therefore, these acts do not rise into consciousness.

Embodied nonreflective knowledge and acts are involved in a wide range of activities, and the highly complex everyday ethical comportment of nurses is one example (Benner, 1994a). Because most everyday practices are enacted in this nonreflective mode, it is difficult to access and explicate them. Whenever a person puts herself in a reflective position to explicate, she has to step outside of the situation; thus, what was significant in the situation becomes vague and is lost in the detached context. Benner (1994a) wrote, "The socially embedded practical knowledge of everyday skilled ethical comportment exceeds what can be captured by ethical theories because the particular relationship, context, historical understanding, skilled know-how, and perceptual and recognition skills as well as skilled responsive readings of the situation encompass more than prescriptive or descriptive theories can accommodate" (pp. 401-402).

Heidegger's intention was to illuminate and understand nonconscious ways of grasping the significance of a situation and the consequent rapid, nonreflective responses. Based on Heidegger's notion of human and embodied knowledge, human scientists such as Van Manen (1990), Packer and Addison (1989), and Benner et al. (Benner, 1984, 1994a; Benner & Wrubel, 1989, Benner, Tanner & Chesla, 1996) have developed an interpretive phenomenological approach to study lived experiences of humans as a way of understanding practical knowing. In order to understand Japanese nurses' practical knowledge of ethical comportment and their moral concerns in end-of-life care, the following research design reflects the interpretive phenomenological approaches developed by these researchers.

Research Design

Knowledge and skills in practice are not easy to access because a nurse often lives through and is unable to explicate them (Wros, 1993). Asking nurses to discuss their ethical concerns also does not give a complete picture, because analytic discussions bypass practical knowledge and tend to frame knowledge into preexisting, abstract, detached concepts. Studying engaged practical activity becomes possible by interpreting background meaning and concerns from thoughtful observation and discussion with nurses about their activity, or from dense description in full narratives about care of particular patients that include the context and history of the episode (Benner & Wrube, 1989; Benner, Tanner & Chesla, 1996). An interpretive phenomenological approach was taken to derive meanings from the observations and narratives generated (Taylor, 1985). The application of interpretive phenomenology as research methodology in this study is discussed below.

Sample

A purposeful sampling method was used to recruit participants into the study. The goal of purposeful sampling is to select information-rich cases from which one can learn a great deal about issues of central importance to the purpose of the research (Patton, 1990). Stratified purposeful sampling is particularly useful to capture and contrast variations as well as commonalities of particular subgroups of interest (Patton, 1990). In this study, the researcher did not know in advance all the kinds of subgroups that needed to be sampled, and it turned out not to be feasible to have participants from all potential subgroups. Yet an attempt was made to identify and include appropriate comparative variations as the themes of interest emerged.

Nurse participants were recruited from three large hospitals, randomly selected, in the Kanto area in Japan. Directors of nursing in the three hospitals were contacted and asked to participate in this study. Once they agreed to participate, they identified the units where nurses often provide care for dying patients (excluding pediatric units), and the researcher asked to disseminate the letter of invitation to the study (Appendix A) to the nurses working in these identified units through their nurse managers. The nurses interested in participating in the study sent a contact sheet (enclosed in the letter of invitation) back to the researcher directly, and then an interview was scheduled.

Primarily, the units identified for recruiting participants were general adult units, not hospice or palliative care units. Hospice care and palliative care for dying patients is gaining popularity in Japan, but most death still happens in non-hospice, non-palliative care units in hospitals (Ministry of Health, Labour, and Welfare, 1996). Among Japanese, there is always great interest in dying at home; however, the actual number of deaths at home is still small (Ministry of Health, Labour, and Welfare, 1996). As revealed by the significant impact of each unit's culture on the nurses' practice, background differences were expected in hospice care and home care settings from the general hospital environment. Thus the third hospital, which has a palliative care unit and a home visiting section, was added to the study.

The key informants of this study were nurses with more than one year of experience caring for dying adult patients in the Japanese health care system. At the beginning of the study, the inclusion criterion was set at more than two years of nursing experience. However, through the course of the interviews, it became apparent that the nurses' focus on their concerns and the way they practice change as they gain experience. This suggested that including less experienced nurses would add more contrast to the developmental aspect of their acquisition of practice skills. Thus, the inclusion criterion for the study was changed to more than one year of experience during the recruitment process, with permission from the Oregon Health & Science University Institutional Review Board (OHSU IRB).

The letters of invitation to the study were distributed to the nurses in 22 units at three hospitals. A total of 39 nurses responded and agreed to participate in the study. However, 7 nurses out of 39 could not schedule the interviews for various reasons. Thirty-two nurses actually participated in the study and completed an individual interview.

All participants were female, ranging in age from 24 to 50 (mean age = 31, SD = ±5.8). Their years of experience in nursing ranged from 1 to 29 years with a mean of 8.7 years. Years of experience in end-of-life care varied between 1 and 15 years. All of the nurses worked in general units for adult patients, except 4 nurses who worked in a palliative care unit. Although the letter was sent out to the nurses in the home visiting department in one hospital, no response was received from them. Five nurses were chief nurses in a section of their units, with some staff teaching, administrative, or leadership roles in addition to their patient care role.

The individual interviews took place at a location of each participant's preference. Most of them were done in conference rooms in their hospital, except two interviews done in a coffee shop for the participants' convenience. Before the interview, the brief description of the purpose and method of the study were presented followed by the informed consent procedure using the OHSU IRB-approved form (Appendix B). In-depth conversational interviews were conducted in Japanese using the interview guide (Appendix C). The interview guide was used as an aid in staying close to the purpose of the research, but I tried not to let the guide obscure or interrupt storytelling by the participants. All the interviews were tape-recorded. The mean recording time was one hour and 8 minutes, and times ranged from 46 minutes to one hour and 31 minutes.

This study was structured to elicit interpretive narratives of ethical practice and moral concerns from nurses in end-of-life care. To study nurses' everyday ethical practice, the researcher must access the smooth flow of engaged activity rather than cut off the structure of that involvement. One approach to accessing involved activity is "to ask nurses for full narratives about care of particular patients, which includes the context and history of the episode, the ways in which the situation presented itself and how it evolved over time, and the nurse's concerns and actions throughout the episode" (Benner et al., 1996, p. 353). Adopting a narrative approach, rather than a logico-scientific mode of inquiry about opinions, ideology, or general accounts of their typical practice, gives a closer access to practice and particular experience (Benner, 1994b). The Heideggerian view that a person acts according to what matters to her adds another reason to use narrative inquiry to understand and have access to actual experiences. Since concerns show up most forcefully in the actions taken by a person in a particular situation, and the person remembers the episode according to her concerns and understanding of the situation (Benner, 1994a; Benner et al., 1996), narrative accounts can point out what is worth noticing and what the concerns are in the particular situation.

The goal of the interviews was to let participants tell stories frankly and freely in their own language and from their clinical experience. Individual interviews seem more appropriate than group interviews for Japanese nurses. Although a group interview has the advantage of easing the tension of interviews and inspiring nurses with each other's stories (Benner et al., 1996), the hierarchical nature of the Japanese culture (Lebra, 1976) and the value placed on harmony and homogenous agreement in a group (Aida, 1972; Doi, 1973;

Ohnuki-Tierney, 1984) mean that group interviews would limit and restrain each participant's description of her personal experiences of practice. Private, individual interviews were therefore chosen to encourage open and free storytelling.

As an interviewer, I asked the nurse participants to tell stories of their experiences of taking care of dying patients that were memorable for them. Additionally, I asked them to tell stories in which they felt "good/bad" or "right/wrong" in care for dying patients, or about experiences in which it was difficult to implement the care they wanted to give. I encouraged the nurse participants to use everyday language, and I engaged in active listening. Occasionally, I asked for clarification and naturally responded to the participant's episodes and stories. A set of probes and questions for following up on and filling in narratives (see Appendix C) was used as a general guide to elicit rich descriptions only when the interview flow required it.

Data Analysis

The tape-recorded interviews were transcribed verbatim by the researcher. When the tape was reviewed for the first time, after the interview but before transcribing, all the identifiable information was erased or replaced with random initial codes on the tape recordings. Field notes taken at the interview sites on the setting, as well as my analytic memo developed through the transcribing process, supplement the recorded narratives. Some participants provided written journals or memorabilia related to their experience of care for dying patients, and those were added to the analysis.

I read and interpreted interviews in Japanese, attending carefully to the narratives of practice contained within each interview and noting inconsistency and coherence, questions, recognized patterns, and meanings in the situations. Because interpretation and open coding occurred simultaneously with ongoing data collection, open coding from early stage interviews formed a list of preliminary themes that were further explored and verified in subsequent interviews.

All interview transcripts, verbatim in Japanese, were submitted to the Japanese dissertation committee member (YN). I met with the Japanese committee member, who has experience of working as a nurse in Japan and is skilled in interpretive processes, to discuss interpretations of the texts. The Japanese committee member guided me in processing the interviews and their interpretations and acted as an expert to validate the interpretations within the cultural and linguistic context. Questions, identified meanings, and patterns that emerged through reflective thinking and subsequent reading of the data were shared and explored in the original language in this level of interpretation. These sessions were held simultaneously with ongoing data collection, and the potential patterns and questions that emerged from the discussion were added to the line of inquiry in forthcoming interviews. After several interviews, I started to generate a list of emerging thematic labels and statements, which was shared with the Japanese committee member to use for more in-depth interpretation. The meetings during this phase were also in part a debriefing so I could identify and explore emerging themes and methodological issues, as well as deal with my own personal biases, and to stimulate aspects of inquiry which I might have overlooked.

Initially, I planned to translate into English the list of codes, identified potential themes, and all clinical episodes from interviews. After comparing my interpretation with that of an American member of my advisory committee (CT) on four English versions, it became apparent that the interpretation of translated transcripts could be misleading because the nuances and context in the original Japanese were lost in translation or the placement of different nuances in English. I realized that English translation needed to include the clarification of background meanings. Therefore the data analysis procedure was modified as following. All interpretations were conducted based on the Japanese transcripts with consultations from the Japanese committee member (YN), and then the interpreted findings were presented with related episodes and transcripts translated into English with careful consideration of background meanings and contexts of the interpretation.

Three strategies were employed to understand and delineate socially embedded practical knowledge: paradigm cases, exemplars, and thematic analysis (Benner, 1994b). The paradigm cases are strong instances of concerns or particular patterns of meanings that stand out from other examples (Benner, 1985, 1994a; Benner et al., 1996). Paradigm cases usually stand out as being new or puzzling for the researcher (Benner et al., 1996), and in this study, the paradigm cases illustrate aspects of nurses' ethical practice that are recognized as important but largely unarticulated. They also delineated how the ethical practice was constructed. An exemplar is an instance that captures the meaning of the situation for the interpreter. Exemplars are substitutes for "operational definitions," which demonstrate nuances and qualitative distinctions of intents and concerns within contexts (Benner, 1994b). Through the examination of exemplars, the story will be filled in and deepened, and the interpreter will become more grounded in the range of possibilities for involvement in the practice (Benner et al., 1996).

Thematic analysis facilitates emergence of the meanings from the text and attempts to articulate the content of notions about that experience (Van Manen, 1990). A thematic analysis was conducted across the narrative accounts to clarify distinctions and similarities in meaningful patterns, stances, and concerns in the exemplars (Benner, 1994b). In thematic analysis, the interpretive researcher engages in cycles of understanding, interpretation, and critique by moving back and forth between the parts and the whole of the text, and shifting in and out of the participants' world (Benner, 1994b). Such changes in perspective may reveal inconsistent and incoherent aspects of the text. These inconsistencies and incoherence allow the interpreter to confront new questions, which leads to deeper understanding of everyday practice (Benner, 1994b; Gardner, 1985; Merleau-Ponty, 1962). Benner (1994b) points out that a text may not be completely coherent and rational, and that the practice may not be perfectly matched with the idea of the practitioner. The task of interpretation is to bring to light the most coherent and complete story possible, but not to make the practical world more rational and coherent than it really is. As Benner suggests (Benner, 1994b; Benner, Tanner & Chesla, 1996), unanswered puzzles were acknowledged and marked to be addressed in future study.

Rigor in Interpretive Methods

Given that interpretive phenomenology differs from empiricism in its philosophical assumptions and view of humans and knowledge, the criteria for rigor in interpretive phenomenological research are different from those for empirical studies. Packer et al.

(Packer & Addison, 1989; Packer & Richardson, 1991) outline four approaches to evaluating the rigor of interpretive accounts: coherence, participants' interpretation, consensus, and pragmatic usefulness. These four approaches are built into this study to increase the trustworthiness of the findings.

A good interpretation should be coherent and plausible. As Packer and Addison (1989) point out, interpreters tend to look for evidence that supports their interpretation while ignoring evidence that goes against it. Therefore, there is a critique that coherence does not function as a validation procedure. Material that fits with an interpretation is spotted easily in the data, but counterevidence can appear in the rich data. Therefore, disconfirming evidence should be looked for across interviews, between a part and the whole, and across situations. These challenges and critiques enhance the coherence of the interpretations. In this study, my dissertation committee and two American colleagues added other lenses to look for counterevidence that I might overlook. These two colleague researchers have experience in phenomenological study of both end-of-life care and Japanese nursing. Although they did not have the chance to review all interview transcripts, their expertise and experience in their subject areas added critical examinations to explore disconfirming evidence in the selected narratives.

Participants' interpretation is another way to check the rigor of interpretations. This is similar to what Lincoln and Guba (1985) called "member checks." This approach does not check whether their interpretation is "reality" but rather asks participants' views on the appropriateness and accuracy of interpretations (Packer & Addison, 1989). In this study, early interpretations of narrative accounts were brought to later interviews and the participants were asked whether or not the interpretation made sense in addition to their general comments regarding the interpretive accounts. Originally, second interviews with selected participants were planned. However, time restrictions and other practical constraints did not permit any follow-up interviews.

The third approach to evaluating the interpretive accounts is seeking consensus among researchers. A convincing interpretation should be communicable to others, make sense to them, and be useful to interpret new material (Packer & Addison, 1989). This was done by discussions and reading the interpretive accounts with the dissertation committee and the two American phenomenology researchers.

The fourth approach is examining the pragmatic usefulness of the interpretive account. Using an interpretive account for predictive generalization is inappropriate (MacIntyre, 1984). Interpretive accounts in human science are not intended to predict a *useful explanation (Packer & Addison, 1989). Rather, interpretive accounts should be useful for understanding related phenomena and for improving, challenging, changing, or extending practices (Fischer, 1987; Lather, 1986). Evaluating the account in terms of its usefulness in everyday practice may be done through publication or presentation. Applying the findings from this study to related phenomena will add credibility to this interpretation, but that will have to wait for the next step of this study.*

Human Subject Protection

This study was reviewed and approved by the Institutional Review Board at Oregon Health & Science University. In addition, review and approval of the procedure were obtained from the hospitals where the nurse participants were recruited.

Informed consent was obtained from all participants. The letter of invitation for the study included a description of the study with expected risks and benefits of participating in the study. Nurses who received the letter responded to me if they were interested in participating. The nurses who thus showed willingness to participate were contacted to schedule individual interviews. When I met the participant before the interview, I obtained written informed consent (see Appendix B). The written informed consent form included the goals and methods of the study, the potential risks and benefits of participation, and the participants' right to withdraw from the study or decline to answer specific questions at any time.

There are minimal risks anticipated in participating in the study. The participants might experience psychological discomfort during interviews concerning specific episodes. Some nurses cried during the interview session recalling certain experiences, but none of the participants wanted to stop or withdraw from the interview. I promised not to report to the presidents of the hospitals, nursing directors, or nurse managers which nurses had agreed to participate in this study. To protect privacy and confidentiality, the participants' names were substituted with consistent speaker identifiers, and all identifiable information was replaced with a random initial code, making it impossible to identify specific individuals or hospitals from the narrative texts in this study. For the protection of participants' privacy, the coding scheme of individual information and any contact information about the hospitals and nurses were kept in locked cabinets.

Chapter IV: Results and Discussion: Nurses' Moral Concerns in End-of-Life Care in Japan

Many of the narratives from the interviews with Japanese nurses elicited their moral concerns and the ethical practices embedded in the culture of nursing specifically related to caring for dying patients in Japanese hospitals. What follows is an interpretive analysis of data from individual interviews of 32 Japanese nurses working in hospital units where terminally ill patients are often admitted. The analysis is written in three chapters: moral concerns in this chapter, background meanings, and practice. In Chapter V, the background meanings that constitute and are constituted by the nurses' experiences will be described to understand why these moral concerns matter to the nurses and how they are manifested in ethical practice. In Chapter VI, ethical nursing practice in Japanese end-of-life care will be explicated and described in relationship to the moral concerns discussed below, to delineate nursing ethics.

Moral Concerns in Nursing Practice

In the phenomenological perspective, concern is the reason why people act. The world is apprehended directly in terms of its meaning for the self. Things, including other people, matter to a person because of their meanings, and the person becomes involved in the world through concerns (Benner & Wrubel, 1989). Nurses act because patients matter to them, and nurses provide their caring practice because they have concerns regarding the patients.

Not all of the concerns nurses have count as moral concerns. Concern becomes a moral account within a meaning-filled context and only with attention to what is good or bad for others, or for the self, and to what is right or wrong in human action (Budan, 1994). Moral concerns, as discussed in this chapter, are what the nurses believe to be good (or bad) or right (or wrong) in a particular context. The nurses' moral concerns appeared in their narratives about what they valued in their practice as well as about situations where their smooth practice was disrupted.

Most of the nurses had stories where they felt good about the patients, and these stories reflect what they considered important in good nursing care. Few nurse participants used the terms *right* and *wrong* to articulate their concerns. This may be due to the strongly judgmental connotations these words have in Japanese. Japan is a society where harmony in the circle is highly valued, and confrontation is avoided as much as possible (Aida, 1970; Lebra, 1976; Nakayama, 1998). Japanese nurses may not want to confront themselves or other colleagues by judging what happened as right or wrong. Also, moral judgment based on a sense of right or wrong, which seems to be inherent in Western ethics, is not a substantial part of Eastern ethics such as Confucianism, which has a historically strong influence in Japan. Japanese nurses interviewed in this study expressed their concerns with the term *good,* or more fluently with the emotional terms related to *good*, rather than in terms of right or wrong.

Nurses' moral concerns also appeared in narratives about situations that the nurse found bad, difficult, uncomfortable, or hard. These are the situations where the nurses' smooth ethical practice was disrupted. They knew the things happening were not good, but they didn't know what to do or how to change the situation. Sometimes nurses knew exactly which of their concerns was neglected; sometimes they just felt uncomfortable. They wondered whether "this was all right," or they felt difficulty without understanding why they felt that way. Even later, when they looked back on the situation during the interview, they were not always able to articulate their concerns, but just remembered the situation as difficult or painful.

Some ethical norms in nursing are theoretically derived and prescribe how nurses should behave. These are articulated in literature such as nursing textbooks. However, many Japanese nursing textbooks are translations of literature developed in Western countries, or their theoretical bases are not clearly specified (Fry, 1998; Kojima, 1997; Minami, 1985). Other moral meanings and concerns in nursing are articulated from the standpoint of caring ethics (Bishop & Scudder, 2001; Gadow, 1985; Gordon, Benner & Noddings, 1996). Again, the moral concerns in caring literature are also derived from another culture and society. Their background meanings may be different from those Japanese nurses have. In order to explicate the moral concerns inherent in actual Japanese nursing practice rather than superimposing already developed ethical norms, I have tried to be true to the real-life experiences of Japanese nurses recounted in the interviews.

The following moral concerns are extracted from the interviews. I acknowledge, however, that as a person – a being-in-the-world – it is inherently difficult to bracket my own knowledge and the worldview constructed through my life experience and particularly the broad background readings done for this study. By being aware of the existence of my own background and by intentionally avoiding the application of already developed ethical concerns and norms, I have attempted to be as faithful as possible to the narratives of lived experiences of Japanese nurses and the language they used.

Solicitation of Moral Concerns from Nurses

One way to understand nurses' moral concerns is through the interpretations of their language in the narratives and their stories about everyday practice (Benner, 1994a, 1996; Bishop & Scudder, 2001). Because humans live in the world in engaged, practical activity, the everyday practice of nursing care often becomes unreflective, involved action that is taken for granted and therefore difficult to describe (Benner et al., 1996; Dreyfus, 1991; Heidegger, 1926/1962). One approach to accessing engaged activity is to ask nurses for full narratives about care of particular patients, including the context and history of the episode, how the situation was presented to the nurse, and the nurse's concerns and actions throughout the episode (Benner et al., 1996).

In an attempt to stay close to the actual experiences of nurse participants and to avoid abstract discussions using predetermined ethical terms, the participants were not directly asked to describe their "moral concerns" or "ethical practice" during the interviews. Instead, participants were asked to tell stories about their most memorable patients and the care they provided to the patients (see interview guide in Appendix C). Initially, the interview guide was developed to elicit nurses' experiences of good or bad care and situations where they felt right or wrong. However, after several completed interviews, it was apparent that the questions including terms such as *good/bad* or *right/wrong* required the nurses to make judgments about the ethical components in their experiences. That induced normative responses rather than descriptions of their actual feelings and perceptions in the situations. In addition, it was difficult for some nurses to recall "good" or "bad" care because often they could not determine whether it was good or bad. Thus, asking for stories about the most memorable patient care emerged as the most effective way to explore nurses' real moral concerns without constraining their stories in ethical terms determined a priori. Although the question did not include moral terms, their stories about memorable patient care involved morally relevant issues of care. These episodes are understandably memorable because of the significant meanings that constituted or evoked the moral concerns of the nurse participants.

Nurses' concerns were manifested most significantly in the actions taken by nurses in particular situations. Concerns were also explicated by nurses as reasons for responding to a situation in certain ways. Although these retrospective reflective interpretations by the nurses about what was salient at that moment are helpful, their interpretations are sometimes based more on their abstract ideas of good nursing care rather than on their actual situations. Therefore, the nurses' retrospective statements were interpreted vis-à-vis their concrete actions within the situation and did not stand alone. Depending on the explicated stories, further questions were asked to clarify participants' concerns. Sometimes, moral concerns are too ordinary for the nurses to articulate. To probe further their taken-for-granted concerns, for example, the nurses were asked what was most important in their care or what they would want to do if they were in the same situation again.

In the following discussion of the moral concerns elicited from the narratives in the interviews, I have attempted to stay close to the everyday language of the nurses rather than adopt the language of moral philosophy. Narrative texts are presented to preserve and demonstrate the contextual richness of their moral concerns, and show the complex backgrounds that constitute the meanings of the phenomena for the nurses and situate them so that their concerns can be implemented in practice.

Nurses' Moral Concerns in End-of-Life Care

Seven concerns were expressed or revealed in the interviews with Japanese nurses who care for dying patients. These were (a) not hurting the patients, (b) honesty, (c) isolation/loneliness, (d) regard for the patients' personhood, (e) respect for the patients' wishes, (f) comfort/relief from suffering, and (g) meaningful/pleasant time for the patients. These concerns are often interrelated, overlapped, and sometimes in conflict with each other.

Not Hurting the Patients

Some of the nurses' memorable episodes explicated their moral concern of not hurting the patients in the context of telling the truth to the terminally ill. These are the episodes they remembered because they felt “bad,” “uncomfortable,” or “difficult.” Facing death evokes existential anguish and the person becomes very vulnerable. These nurses were concerned about hurting the patients’ feelings, when they were so vulnerable, by telling them they would die.

Nurse V, who had three years of experience working in a general unit, described her difficulty talking about death and dying with one terminally ill patient. The patient was about fifty years old and had been diagnosed with advanced lung cancer upon admission to hospital. He tried to be hopeful about the treatment and was popular among the nurses in the unit because he was friendly and nice. However, as his disease progressed and his legs were paralyzed by bone metastasis, he began to question the nurses about his death.

> V: Because the nurses on our team liked him, we could not tell him anything. We could not tell him he would recover, either. When he asked, “Am I going to die?” the nurses thought maybe he wanted to hear, “You’re going to be all right,” but it also seemed that he wanted to know the truth. He had probably studied the condition himself and knew the reality of how people in the same condition die. But we weren’t sure if he really wanted to be told how he was going to die. So we just listened to him and stayed with him. It was hard. I didn’t know what to do. There was nothing we

could do. . . .

IN: Did he know the truth?

V: They told him [about his diagnosis of lung cancer and bone metastasis], but they did not tell him how long he had left, or how he would die. They [physicians] told his wife and brother, but his wife asked us not to tell him. . . .

IN: You said before, he had asked the nurses if he was going to die.

V: Yes. I was his primary nurse, and he was getting so frustrated. Then I talked with him and at that time [he asked me], that's right.

IN: When he asked you those things, you said that it seemed he wanted you to deny it, but that he also wanted to know the truth and so it was difficult for you. So how did you reply?

V: At that time I thought he really wanted to know the truth. That was before the paralysis occurred. But he had been in a wheelchair a long time and was frustrated because he couldn't walk. This was also about when he started to take Iressa [an oral anticancer drug], so he had some hope in that and wasn't too uptight. He asked, "In some books, it is said that [patients like me have a very low survival rate and will die], but am I really going to die?" I said, "I don't know if you're going to die. Nobody knows that."

IN: So what did the patient say?

V: He said, "Yes, I guess that's right. Nobody knows." Then he asked me, "How do patients like me die?" I asked, "What do you think about how you will die?" He said something like, "I don't have any respiratory symptoms at all now, like pneumonia or fever. So I have no idea how I am going to die from here." But I couldn't say, "You may die of pneumonia," or so on. When he said that he might die of pneumonia or deteriorated breathing function, all I could say was, "Well, I guess you may." [Sad laugh] . . .

IN: You said you couldn't tell him he would die of pneumonia. Why could you not say that?

V: I wonder why. I don't know. I felt maybe I shouldn't say that much. I worried if I should go that far.

IN: Do you mean that it might hurt the patient and cause the patient to lose hope by saying something so severe?

V: Well, I guess.

IN: Or maybe is it possible you thought that as a nurse, not a doctor, you shouldn't talk to the patient about his prognosis?

V: Well, that might be a part of it, too. He often wanted to talk personally, one to one. It seemed he wanted to hear my personal opinion. I guess I wondered if it were really OK to tell him even though he was not officially told. I could not decide. [Pause] My first concern was that he might be shocked if I told him that much. [Pause] I never told patients. I'd never been asked that by a patient before.

IN: So his question was basically, "How does a person like me, a person with lung cancer, die?"

V: Yes, that's about it.

IN: So it seems [pause] so for your answer, what did you think you should not tell him . . . that he would die from pneumonia, or that he would die at all?

V: Something made him associate [to death], [pause]. I didn't know should I answer or not. I thought it best not to answer if I ended up doing it badly. Inside, I didn't know how to answer.

Throughout the interview, Nurse V repeatedly expressed the discomfort and burdened feeling she had when the patient raised the question of his prognosis and imminent death. When the patient asked her, she "could not tell him" that he was dying and she felt "maybe

I shouldn't say that much."

Several background issues relate to the nurse's inability to answer her patient's questions. In Japan, it is the physician's role to tell patients and their families about the patient's condition, treatment options, and prognosis. Due to a still somewhat hierarchical relationship between nurses and physicians within the Japanese health care system, there is a tacit rule in most hospitals that nurses should not preempt the physicians in giving the patient medical information. In a terminal case like this, the physician may not tell the patient everything either at the family members' request or because of the physician's judgment that disclosure would not benefit the patient. Also, how much physicians expect nurses to tell patients varies depending on each individual physician's preference. Commonly, in Japanese health care practice, what nurses can and cannot tell the patient is restricted, and how much they can tell is unclear. Nurse V did not know "should I answer or not," and she "wondered if it were really OK to tell him even though he was not officially told."

One of Nurse V's concerns was whether a nurse could give her patient bad news without an official and previous explanation by the physician. Yet a more important and compelling concern for her was that she would shock the patient by confirming his fear that he was dying. In Japan, empathy *(omoiyari)* is a highly valued virtue in general, and nurses particularly are expected to have empathy and not say anything that could cause displeasure for the patients. It is also commonly believed among health care providers that saying something to imply a poor prognosis is excessively shocking and cruel to the patients. For a moment, Nurse V thought maybe this patient really wanted to know what was going to happen. But then she assumed that what the patient at heart wanted to hear was reassurance from the nurse that he was not going to die and would be fine, rather than his true but grave prospects. Thus she thought telling him her honest expectation would cause him pain.

Nurses' moral concern of not hurting the patients appeared in other interviews as well, especially in the stories related to truth-telling and communication. Several nurses said they were strained when talking to terminally ill patients because they have to be careful not to hurt the patients when responding to their questions without preparation. Some nurses said it is tiring to be very careful to read patients' cues correctly and to be vigilant in how they answer the patients' questions without hurting them or causing shock.

This concern seems to be similar to the ethical principle of "do no harm." Yet the Japanese terms *harm (gai wo ataeru)* and *hurt (kizu tsukeru)* have slightly different connotations. "Do no harm" in the ethical principle of nonmaleficence usually focuses on physical harms or setbacks to other interests (Beauchamp & Childress, 2001), while the Japanese nurse participants' concern about not hurting the patient usually did not involve any physical damage. Rather *hurting* was used by the nurses, particularly in contexts like this, to describe acts that result in psychological pain. The participants' concerns about physical discomfort and harm were expressed in other dimensions such as lack of comfort or suffering, and were discussed in a different manner.

Even in English, the principle of "do no harm" can embrace not only physical harm but also almost any condition that could restrict autonomous action in its broader sense (Beauchamp & Childress, 2001, p. 117). The principle of nonmaleficence is based on the belief of the autonomy of each individual, and functions to protect and respect the autonomy of the patients. Any condition that would restrict the autonomy of the patient could be harm. If their prime concern were autonomy, the Japanese nurses would think not telling the true prognosis was harmful. But their concern is about how patients would feel if told that they are terminally ill and dying. For these Japanese nurses, protecting the patients from cruel news is empathetic, whereas causing psychological pain and grief by telling the patients their prognosis hurts the patients and is "bad."

Interestingly, the nurses appeared to differ from Japanese physicians in their reasoning for not telling patients about their dismal prognosis. Although Japanese physicians sometimes mention that, out of empathy, they don't give patients a dismal prognosis because it is cruel, physicians' "official" ethical justification for nondisclosure is nonmaleficence out of concern for the potential harmful effects of disclosure such as suicide, lost hope, and depression (Asai, 1995, 1996; Hattori, 1991; Kai, 1993; Konishi, 2000a; Long and Long, 1982; McDonald-Scott, 1992). In contrast, nurses' concerns appeared to stem from their emotions, such as compassion for the patients. The nurse participants could not logically describe why they did not want to hurt patients any further. They said such things as "I did not want to hurt him," "I was afraid what I said might shock him," or "I felt pity for her and thought it would be very hard for her. I was very sad for her," usually followed by silence. The nurses anticipated the pain and anguish the patients would feel when faced with their imminent death, or anticipated loss of their own existence among loved ones. Therefore, unlike the physicians who justify their decisions in logical terms, it is hard for the nurses to justify their acts of nondisclosure other than through the emotionally loaded moral concern of not hurting the patients.

Because of this moral concern, V decided not to answer the patient's questions about his death. Yet this dialogue with the patient stayed in V's mind as a difficult situation.

What made this situation difficult for her? Despite her ethical belief in not hurting the patients as a justification for not telling the truth, she was still vacillating between "should tell" and "should not tell." For a moment, she thought this patient really wanted to know what was going to happen. However, instead of responding to or confirming her perception that he wanted to know the truth, she negated his verbal questions by assuming it was a double-bind message and that, in fact, he wanted her to deny his approaching death. Even at the moment of the interview, she was still not sure whether she should have told him or not.

Honesty

Some participants of the study expressed their discomfort when they felt unable to express their honest thoughts or were forced to dodge questions in similar situations to V's story. Several nurses expressed concern about being dishonest to patients. When patients appeared not to recognize or accept their serious condition, they asked nurses to reassure them that they would recover. This caused difficulties for the nurse participants.

> T: The patient probably understood that his illness was not good and he had metastasis, but whenever we talked, he told us about his hope for treatment and asked us [the nurses] to agree with him. "I will get better with this anticancer drug, don't you think?" "I will be able to walk again, won't I?" and so on. We did not

> know what to tell him. Finally we decided, in the [nursing] team, not to deny him, because he probably knew in the bottom of his heart but just wanted us to agree with his hope. So we just tried to go along with him without confronting him. But then, I had to say something different from what I thought, and it probably appeared in my face. . . . After we determined as a team not to confront him and to go along with his hope, I did not feel so bad. But it took a while to achieve that decision and until then I felt troubled. I felt like I was lying to him.

Another nurse with three years of experience in nursing described her dialogue with a patient regarding how to live out her remaining life.

> W: She was a patient who was admitted recently. She was terminally ill and she had so many unfinished things she had to leave. She was very frustrated worrying what to do with the unfinished business. A while ago, I would have said something like "Well, you will be fine," mindlessly. Even though I knew it would not be fine, I would say, "You will be fine," because it is scary to say anything else. But with this woman, I just implied to her, "It [this time, your course of recovery] might be different, I wish it is really so [goes well] though." [Pause] There was a patient who was not able to accept her condition at all. She said things like, "By doing this [IV

drip for treatment], I hope it becomes better right away," and "I want to be cured and go home soon." At that time, I said, "It would be very nice, it would be wonderful, if it becomes better right away. But sometimes it doesn't happen. In that case, what would you like to do?" I was able to say it like this and ask. . . .

IN: When you said that, how did the patient reply?

W: Ah, I said "It would be nice if it is all right," then she said, "Ah, you say it like that. It is not all right."

IN: She responded like that.

W: She said, "Ah, it is not all right. You say it like that." She said, "It is not all right, you say it like that."

IN: Was she surprised?

W: She said so. [Pause] What I thought at that moment was, Ah, she wanted to be told it is all right. Although I realized she wanted to be told it is all right, I thought it wouldn't be good for her to say, "It will be all right" then, and [pause] I also did not want to tell a lie. So I said it to her like that to hint.

Nurse W did not agree with the patient's wishful talk because W did not want to tell a lie. In

Japan, there is a common saying, "Circumstances may justify a lie," that allows Japanese health care professionals to justify not telling patients their actual diagnosis and prognosis in order to protect them. For Japanese, telling a lie can be explained by relational or situational ethics and is not necessarily always bad (Lebra, 1976). However, the Japanese nurses in the study expressed uncomfortable feelings and conflict between lying to a patient and their desire to be honest. Their negative feeling about dishonesty does not seem to be derived merely from social virtue. Being dishonest in order to support a patient's inadequate hope distances nurses from the patients.

Nurse T described her attitude toward a face-to-face confrontation with the patient as "getting ready to run away" from the patient and "like touching a time bomb." She expressed her response to a patient's unrealistic hope for his treatment:

> T: I told him something like, "I really hope it [the treatment] will work this time," and "Let's look forward to the next evaluation by CT scan."
>
> IN: What did it feel like for you when you talked to him like that?
>
> T: Well, I was ready to run away. [Weak laugh] He liked to talk, once he started to talk it was hard to stop him. At the beginning, for a while, I could keep up with him and stay cheerful. But as it got longer . . . I could not keep up with him, it got harder

> to keep my mind going along with him. So before it appeared on my face, I needed to get away from him quickly.

Nurse T explained she was nervous about talking with the patient because she was afraid of saying something incongruent with his expectations. Because what she said was not her honest opinion, she was afraid to stay with the patient long enough for her honest feeling to show on her face.

Some nurses appeared to be able to stay with the patients in similar situations, although they saw the incongruence between what the patients was wishing for and what the nurses were foreseeing. In a similar situation to Nurse T's, Nurse AA stayed with a patient without being dishonest. The patient with bone metastasis unrealistically believed that she would be able to walk again.

> AA: We never tell the patient what is going to happen, because the prognosis has not yet happened. So we just focus on the present symptoms. Talking about topics such as the patient wanting to walk again, we don't let her have great expectations but also help her keep hope. So we don't say, "You will walk again." Instead we say, "We hope you will be able to walk." . . . When the patient says she wants to walk, we now often say, "Yes, that would be good."

In response to this patient's unrealistic hope, the nurse replied with an "I hope" statement. The nurse knew this patient would not be able to walk again, but in the meantime, she expressed her honest hope for the patient. Thus she did not feel as if she were lying, and she did not need to run away from the patient to hide her real thinking. Telling the patient something that does not match the nurse's professional assessment does not necessarily mean dishonesty. It was the distance generated by dishonest responses to the patient that makes telling a lie seem immoral for nurses. This concern for honesty is related to the next moral concern about isolation.

Isolation/Loneliness

Several nurses identified a moral concern about isolating terminally ill patients. Many nurses think it is a good death if the family is present. The nurses think no one should suffer and die in isolation. The following three excerpts illustrate this concern.

> E: Every time he awoke, he got panicked, and his mind was not calm or peaceful. He had shortness of breath for sure, but more than that, he got panicked every time he awoke. If he had someone whom he needed or his family beside him when he opened his eyes, I thought he might have a little bit of peace of mind and ease his panic. I got a report from the evening shift nurses that the family said, "We cannot

stay with him. We will hire someone to sit with him from now on," before they left [the hospital]. I was very irritated with that. I was upset thinking, "That is not the point!" They thought he needed someone to baby-sit him. I was irritated that they did not understand that he needed his family to be with him, not just a baby-sitter. Maybe partially because of the report, I strongly felt I wanted his family to stay here and that it would be better for him if his family were here when he opened his eyes.

V: Oh yes. Things that were not so good . . . there are many. One time when I was very busy on night shift, there was a young dermatology patient, and his disease had progressed very fast. Even the doctors were not ready for his rapid progression. So they had not explained it to the patient or the patient's family, and he died maybe the next day. He was all alone, in a semi-private room. I think he had a young son. The patient seemed to be suffering so much. But I just couldn't do anything. It was in about my second year. I wished I had had more experience then, to see his condition and take care of him that evening and night. I wished I could have called the family, let the doctor talk more with the patient.

H: He [the patient] must have been very happy having his last moment surrounded by so many people.

In Japan, family ties are much closer than in Western countries and interdependent relationships within the family are common. Therefore, many nurses expect the immediate family members to be with patients when their death approaches. Culturally, seeing the patient before he or she takes a last breath and being there at the moment of death has special meaning. Not only the immediate caregiving family members but also distant relatives who have never visited the hospital before may want to be at the bedside at the moment of death. As the patient's death approaches, nurses usually ask a key family member if there is anyone the patient wants to see or if there is anyone who needs to be there at the moment of death, and advise them of the time to call these family members. This effort is based on their belief that no patient should die alone, and that everyone deserves to die surrounded by loved ones.

The nurses are concerned not only with physical isolation from family at the moment of death but also with patients' psychological isolation from others. Following is an example of a patient isolated psychologically rather than physically. The patient was an elderly lady from a large rural family. Her sons moved to a big city for their business and brought their mother to the city to receive advanced medical treatment. However, the patient's cancer was so advanced that pain management was the only treatment. Her sons did not tell the patient her diagnosis, and they thought they would lose face if they brought their mother back home without advanced treatment. Although the patient was not told her diagnosis, she seemed to realize she did not have much life left. She wanted to go home one more time and see the view from her window.

> CC: Yes, there was a patient who had GI cancer. She was a wife in a large old family in another area. In her case, saving the sons and daughters-in-law's face became the first priority in the family. Her children thought they had to do all possible treatments for the sake of saving face [not for the patient's sake]. The patient wanted to go home. Although she was not told her diagnosis, she kind of knew that she was dying. She really wanted to go home at least one time, but she could not do that. She was not told, but she knew, she felt a hard mass in her abdomen. Meantime she was ambivalent about her disease and she kept saying, "If you take this out, I may get better," and "Why don't they [the doctors] do anything for me?" Through this time, she was alone—she was left in the hospital all alone. Then she died in the hospital. It was too much to bear watching her [dying isolated from everyone].

This patient had many family members, but none of them stayed with her closely for long periods. The decision-maker in this family was the eldest son. This nurse saw him a couple of times in the patient's room, but he was doing his work in the room, and the nurse was not able to talk to him. Because the family decided not to tell the patient her diagnosis, nobody could answer her questions and stay with her honestly. As described in the classical study by Glaser and Strauss (1965) and discussed above, hiding information and deceiving patients about their prospects often distances the health care providers and family from the patient. Although the nurse was concerned about this patient's physical and psychological isolation in the hospital, she was not able to solve this problem. Her ability to be open with the patient was limited by the family's decision.

Another situation where psychological isolation became a nurse's concern involved care for a patient with neck cancer who could not communicate because of the tumor. The cancer caused swelling of the patient's tongue and face, making it very difficult for the patient to speak or even communicate through facial expression. The nurse tried to get to know the patient by talking with his family, asking what kind of person he was and what kind of life he had. From talking with his family, the nurse thought, "He was most lonely, he was sad because he could not make himself understood. He might feel the loneliness and sense of alienation most painfully." Although his wife stayed with him most of the time, this nurse believed the patient was isolated because nobody could understand him. Thus, she thought the most important care for him was trying to be with him.

Most nurse participants in this study demonstrated their concern for patients' loneliness by working to prevent their physical or psychological isolation. They often described their efforts to help patients spend time with loved ones. Nurses also tried to stay close to patients when they expressed loneliness. One nurse said that, in the terminal phase of illness, many patients become anxious and they want someone to be with them. Some patients call nurses frequently without specific reasons. Therefore, this nurse tries to stay with the terminally ill patients as much as possible "to ease the time the patient is exposed to loneliness."

Interestingly, two nurses mentioned that being with patients to ease their loneliness was the reason they chose to work with terminally ill patients. During the interview, one nurse recounted why she chose nursing. She had read an essay by a dying Japanese novelist. She said he wrote, "When a nurse holds a patient's hand, the pain is reduced by half. There are two components in pain. One is actual physical pain and the other is the pain of loneliness that you have to bear with the pain all alone. When a nurse holds a patient's hand, the person feels that the nurse takes on half of the pain of loneliness and his pain is cut in half." When she read this essay, she decided to be a nurse to take on the pain of loneliness. The loneliness and isolation of patients seem to be predominant concerns of nurses in end-of-life care.

Regard for the Patient's Personhood

Regard for the patients' personhood is a concern that many nurse participants mentioned. Since the concept of respect for the individual is popular within nursing literature, when nurses are asked what they think is important in care for terminally ill patients, respect for the individual is one of the typical answers. Often the ideal answers from this kind of conceptual thinking do not have implications for actual practice. However, following is an exemplar of what it means to respect the patient's personhood in real practice for one nurse.

The patient had advanced liver cancer and was admitted to the hospital for symptom management. One day, *Methicillin-Resistant Staphylococcus aureus* (MRSA) was found in her stool. Patients infected with MRSA are usually isolated in a private room without a bathroom. The practice in such a situation is to leave a portable commode at the bedside that nurses empty and clean after each use. The patient has to stay in the room until the MRSA is cleared. With this particular patient, the nurse designated a bathroom for her and instructed her how to wipe and sanitize the facility after use. The nurse said she did it differently for this patient out of respect for her.

> Q: I worried about the psychological effect on her. Not only me, but other staff also thought that it would be risky to put her in a private room. She would be depressed severely if she was isolated in a room. So what should we do? It was just her stool [that they found MRSA in]. Primarily she should use the potty in the room. But she was a very neat and tidy lady who was very careful about her appearance. Although she became yellow because of the jaundice, even in the hospital she always wore makeup and lipstick. She was the kind of person who cannot accept messy hair, even when she becomes unable to move. [Laugh] She could not stand having a BM in the middle of the room. We really understood her feelings about it, we were able to get permission from the doctors [not to isolate her in a private room and to let her use the designated bathroom], and the whole unit was able to accommodate her. . . . I believe it [what was important] was letting her be as she was. She was really neat and tidy. For a person who can walk around, it is very embarrassing to have a BM using a potty in the room. She was the kind of person who would hesitate or even refuse for someone to clean it [her stool] up for her. So I wanted to respect her wish to take care of it by herself, using the bathroom.

This nurse perceived that it was important to respect this patient by maintaining her dignity instead of embarrassing her by forcing her to use a commode in the room.

The disease process or medical treatment can create dehumanizing and undignified situations for the patient. The nurses' concern to maintain the patient's integrity in those undignified situations is for the sake of patients as well as for their families. One nurse (BB) was greatly distressed to see a patient and his family shocked when the patient had delirium due to the illness. The patient was frightened and shamed about losing control of himself and knew he did "something wrong" when he returned to the normal conscious level. The patient's family was also shocked to see their husband and father act like a totally different person. In addition, when patients have delirium, sometimes nurses have to restrain the patients for their own safety. This is another disrespectful measure for the personhood of the patients. Nurse BB said she finds it difficult to see patients with delirium because it hurts the integrity of the patients' self-image and the family's image of the loved one.

Another nurse (M) told a story about taking care of a patient dying from hepatitis. She described how she tried to save the "good image" of the patient for his family. A couple of days after admission, the patient developed hepatic encephalopathy and became confused, talking incoherently and screaming.

M: When I did personal care such as cleaning excretions, I asked them [his family] to be out of the room, because I wanted the family to keep a beautiful image of him. I wanted them to keep many memories of him before he became like this. . . . I wanted to maintain the image from when he was healthy. He liked to be neat and clean, so we shaved him every day. Even when he was restless and moving, we got another nurse to keep him still and shaved him nicely. We also let him wear his own pajamas, whatever he used to wear every day, not a Yukata [the robe] . It is harder for him and for us to change pajamas than the Yukata, but we encouraged him and we also worked hard to keep him in his own clothes.

IN: Why did you care about maintaining his image from when he was healthy?

M: Well, I guess the family will keep living after his death thinking about him, remembering him. When they think about him later, I thought, he [the patient] wants them to remember him as he used to be, not him suffering, not him in a Yukata with a lot of tubes. I had an impression this patient cared a lot for his family. So I thought that was what he would want. I don't have much evidence though.

These nurses' concern regarding respect for personhood resonates with what Gadow (1985) described as the ultimate goal of caring. Very similar concern about maintaining dignity also emerged in Wros's study (1993) on the caring practice of nurses caring for dying patients in U.S. intensive care units. As Wros explicated, dignity is embedded in the meaning of the experience for the individual patient. The Japanese nurses have to understand the meaning of the experience for the patient, even when the patient is comatose or in confusion, in order to respect and protect his or her dignity. Nurse Q *felt* the patient could "*not* [italics added] stand having a BM in the middle of the room." Nurse M "thought he [the patient] wants them to remember him as he used to be, not him suffering, not him in a Yukata with a lot of tubes."

Sometimes, respecting the patient's values conflicts with what the nurse believes is good for the person. Nurse M's story about a dying patient with alcoholic cirrhosis shows how she tried to understand the meaning of drinking alcohol for this patient.

> M: It is a secret story. [Laugh] He was also a terminal patient with liver [disease]. He had alcoholic cirrhosis, but kept saying he wanted to drink. He had a girlfriend and mother, he had a lot of precious people to think about. But he could not stop drinking. He was 32, 33 years old then and he had been like that all the time. Society often treats alcoholic people very harshly. But I think, without alcohol, he would have killed himself a long time ago. Because of the alcohol, he could live up till then. He

was able to meet his girlfriend and have happy times with her. I tried to see his relationship with alcohol from a different perspective. I thought it was important to acknowledge and appreciate his life like that. About the last three months before he died, I stopped talking about quitting drinking or his drinking problem. Instead, I started asking what he wanted to do when he was discharged from the hospital. He said, "I think I would probably start drinking again." I responded to him, "It could be one way," trying to accept who he was. He was readmitted again due to hematemesis. At the end, when he said he wanted to drink, he was at risk for choking and [pause]. But then I realized it was my, or a health care provider's, value for good life. If that is his happiness, it might be all right, I thought. . . . Our idea of a happy life is to stop drinking. Well, but there was nothing much he could do for his already damaged liver. He might live life with his family while taking care of the liver. But it would be associated with the stress of being in the rehab facility and all the time he would be suffocated by the pressure to stop drinking. I thought there might be a gap between my kind of happiness and the happiness he would want. If that was his choice knowing the risks, I thought it might be all right to support his choice. . . . His parents deplored his drinking problem for such a long time, hissed and yelled at him in the

> past. But when we decided to let him drink for the last time, his family talked with all their might about which liquor he liked and where they could get it. Umm, I thought it was good for the family, too. His family also might be able to accept him as he was dying from drinking. Of course, they could not accept it 100%; they must still be very regretful. But they might accept it a little bit.

In this story, the nurse tried to find meaning in the patient's life and accept who he was despite the social stigma associated with his drinking problem.

Nurses' concern for respecting the patients' personhood covered a wide range of issues, from seemingly trivial preferences in personal care to accepting the patients as they were while maintaining their integrity. Regardless of the magnitude of the practical implications, the basis for this moral concern was genuine respect for humans and advocacy for the person as a precious being with a unique history.

Respect for the Patients' Wishes

Respect for the patients' wishes overlapped to a large extent with regard for the patient's personhood. In a sense, the former is one part of the latter. Although patients' wishes are a reflection of who they are and respecting their wishes means respecting the patients' personhood, the nurse participants seemed to differentiate between listening to and advocating for the patients' end-of-life decision-making and respecting the patients' small personal preferences in everyday life. The nurses seemed to have a separate concern regarding end-of-life decision-making that involved medical interventions, such as choices about treatment and place of death.

Almost all the participants had stories related to patients' wishes regarding their deaths, which suggests this is a fundamental nursing concern in end-of-life care. Helping patients to have a good death is a nursing role, and nurses believe a death is good when the patient can live and die as he or she wishes. Nurses are often in a position to hear patients' real wishes through daily personal care and contact, and most of the time nurses witness how those wishes are carried out. If the nurses do not know a patient's desires, they try to find out. Unfortunately there are constraints and situations where the patient's wish cannot be granted. Following are exemplars in which nurses' concern was focused on knowing the patient's wishes and whether or not these wishes were respected.

One patient left a strong impression on a nurse by living his life as he wished, and the nurse felt honored to witness the end of his life. The patient, a man in his 70s, had progressive interstitial pneumonia. He had known about his diagnosis for a while, and he had talked with his wife regarding his use of medication when his death approached and his breathing became too difficult. When he experienced increasing shortness of breath and the medical treatment no longer alleviated the symptom, the physician told the patient's wife his death was close. The wife then asked the physician to tell the patient. After he did, the patient asked Nurse O to stay.

> O: So he said, "Give me a little time. And Nurse O, would you stay here a moment?" Then he asked me, "I am going to tell my wife what I was told now. Is it really the time [that I am dying, and time to start morphine], do you think so, too?" I told him, "The PULSE [treatment] is not working. I believe it is a very severe condition." Before, we had discussed what he wanted to do when this time came, for about a month prior to this moment. So I told him that this was the time. Then he told me, "I am going to call my wife. When I say OK, would you start the medication?" He was very calm, although he was having a very hard time breathing. He talked to his son, who had come back from the United States a couple of days earlier, and talked with his wife for one half to one hour. Then he called me and said, "Well, Nurse O, please start dripping it." Within one hour from when I started dripping the morphine, he died.

Nurse O was very impressed with this patient, because it is very rare to have a patient with such a clear idea about how he wished to die[1] and who died exactly as he wished. The nurse acknowledged that he died as he wished not because of any particular nursing intervention but rather because of the patient and his family's effort to clearly communicate and understand what he wanted. Although this patient might not have required any direct nursing intervention to realize his wish about care, the nurse stayed attentive through the process and assisted him in accomplishing his wish.

More often, nurses told stories about patients whose wishes could not be realized. Sometimes the way the patient died left some questions in the nurses' mind about whether that was how the patients had wished to die. Nurse U remembered a middle-aged woman who wanted to go home and did not want her appearance changed by edema or other causes.

> U: She was not my [primary] patient. She said she wanted to go home even after she decided to have a bone marrow transplant. It was a very high-risk transplant, and in the end, she was on the ventilator and received heart massage. I seriously wondered, "Do we need to go that far?" In the hematology unit, it is hard to determine from what

---

[1] In this story, this patient died after he had started to receive morphine drip as he wished. The purpose of the morphine dosage was not shortening his life but alleviating his shortness of breath. The patient did not wish to die in suffering from shortness of breath, and he chose to use morphine to alleviate this symptom while understanding its possible consequence of respiratory depression and lowering conscious level. This is not a case of assisted suicide.

> point it becomes terminal phase. . . . We tend to do everything if the patient chooses to do a transplant, and the line where it becomes end-of-life care is very blurry. Even when we know the treatment does not cure, we keep doing the treatment thinking it will ease the symptom, such as tumor fever, a little bit. . . . So for this patient, although I was not involved in her direct care much, I really wondered if putting her on the ventilator was what she really wished for. When I talked to her before the transplant, she said things like "I want to go home" and "I want to stay as beautiful as I am now, I don't want my face to change or be swollen." But in the end, she was swollen so badly, and her body was covered with hematomas. When I saw that, I really thought, "Is this what she wished for?"

In this case, although the patient chose the transplant treatment, her wish about the extent of treatment she really wanted was not clarified. The patient was not given all possible consequences of the treatment she chose, limiting her ability to make a decision that would correspond with the wishes she had mentioned earlier.

In another story a different nurse showed similar moral concern about the neglected patient's wish.

> CC: It was also a male patient with lung cancer. Only his wife was told his diagnosis

> and his wife agreed to chemotherapy. He did not know his diagnosis, so he did not want to stay in the hospital. He told nurses about that in tears. But his wife had already consented to the treatment. Then he deteriorated gradually. When his condition was stable, we [nurses] thought it would be a good time, and maybe the only time, that he could go home once more. So we told his primary physician that he wanted to go home. But he [the physician] did not pay any attention to our words. Eventually he died in the hospital without being able to go home even once. When I saw that. . . I hope they [patients] can decide, choose their own end.

From a Western ethical perspective, this story may look more controversial. The patient did not receive informed consent and the treatment was the patient's wife's decision. The patient's autonomy was ignored completely. Unfortunately, this is still common practice in some units or institutes in Japan, although the concept of informed consent is becoming more widespread. In this situation, the nurse was concerned about ignoring the patient's wish, which resulted in the violation of his autonomy. The nurse worked in a unit where the common practice is to disclose the patient's diagnosis to the family, and the family then decides the treatment. The disclosure of the diagnosis to the family without permission from the patient and the family decision-making without patient's consent were not the nurse's primary concern. For this nurse, listening to the patient's voice and allowing him do what he wished was the more imminent issue.

Even with informed patients, nurses' concern regarding respecting patient's wishes is raised in situations where the condition of the patient unexpectedly changes. In the following case, what the patient would have wanted to do was unknown. Additionally, there were gaps between what the nurses thought the patient desired and what the family wanted for the patient.

> Q: There was a patient who had advanced lung cancer. Although he was checked out in the outpatient unit for back pain, they could not find that the pain was bone metastasis from lung cancer. So he was admitted to the unit for evaluation of the cause of the back pain. The attending doctor said he talked to the family and they decided not to do anything [DNR order]. But it was right after I was rotated to the unit, so I was not familiar with what the order meant exactly in that unit. I was just thinking, OK, not doing anything, like in my old unit. But when his saturation monitor dropped suddenly below 90, they started giving oxygen, and he revived. His conscious level did not come back, but for quite a long term, his life was prolonged. Umm, I don't know if it was good or not. Before then, he always said, "Please don't do anything to

cause me suffer." He did not even like an IV drip. It had been about one week since he was transferred from another unit to mine. He had exams every day to find out the diagnosis. He kept saying he was tired because of the continuous examinations, but he was a very sweet man. He always said, "I am sorry to trouble you every day." He also said, "Oh, you are my nurse today again? Thank you, I am glad." Anyway, he asked me, "Please don't do anything [painful]" from the beginning. But because I had not told his words to the physician before and it was a sudden unexpected respiratory drop, once they started giving him oxygen, he had to suffer for a long time. Towards the end, he had phlegm, so we inserted an airway tube, too. As time went on—he had two sons—the sons had different wishes about what they wanted to do for their father. One said, "It's OK now. He doesn't need to suffer anymore, let's make him comfortable." Then the other said, "No, even without responses, it is so important he is still alive. Please do everything you can to keep him alive." So, in between that, I was concerned about what he [the patient] really wanted to do. Eventually, he died the day before he was scheduled to be transferred to the hospital near his house.

IN: You had said that depending on the physician, the meaning of "not doing anything" varies. For you, what was your thinking in terms of "DNR" for this patient?

Q: Well, except for the sudden status change, that is whatever the patient wishes. In his case, he did not want to have IV drips. He said he just wanted us to take care of his pain. So I was planning to confirm and thrash out his exact wishes within the next couple of days. Because I was not sure whether he had made the decision with enough information or just gave up without knowing other options, I thought I needed to clarify and confirm his wishes with him sometime soon. However, his condition changed rather suddenly before I did that. . . . I asked the physician, "Didn't you say not to do anything?" Then he said, "This [giving oxygen] is the minimum requirement." Since I was new in the unit and to respiratory care then, I could not insist. I don't think I am always right, and I just thought it was the way in this unit, so I did not say any more. I told him what the patient had said before, but that was it, I could not say anything more. . . . Yeah, I felt very sorry. I apologized to him [the patient]: "I am sorry, I just did not have enough power."

IN: Why didn't you persuade the physician at that time?

Q: I just did not have confidence, I think. The respiratory unit was a new area for me then, and there was no one who supported my idea.

In this situation, even though the nurse had heard the patient's views before, the moment that required the decision to be made occurred unexpectedly soon, before she could confirm and legitimize his real wishes. This nurse had 14 years of experience at the time of the interview and shared several stories about when she had been able to grant patients' wishes. Yet, in this situation, in a new environment and unfamiliar with the culture of the unit, she had difficulty advocating for the patient's voice as she wanted. While she had some idea of the patient's wishes through some words he had said before the change, she felt she did not have enough power to assist the patient in getting the treatment he wanted. Although her concern was focused on the patient's wishes, she could not implement them, and she "felt very sorry."

Nurses not only wait for patients to tell them their wishes but also ask patients what they want explicitly or implicitly. Some nurses ask patients questions to explore their concerns related to end-of-life decision-making, such as "Do you have any concerns, questions, or matters you are troubled with?" Depending on the situation and the patient, other nurses explore the patients' wishes more indirectly, often through knowing the patient's history and personal coping pattern.

> HH: At the beginning, when I gave him [personal] care, we just chatted. "What did you do when you were young? What did you enjoy?" Then he said, "I will bring out

> my old pictures and notes. I will show you next time." And he shared a lot of stories with me. And I was thinking, "Ahh, this is the way he lived. This is really who he is." . . . And by knowing how he lived and who he really was, I could have some idea how he took the explanation of treatment results from physicians and how he coped with it.

Nurses and physicians differ in how they determine and respect the autonomy of patients in their end-of-life care. The nurses' approach seems to be a long and indirect process. For physicians, however, asking about the patient's wishes is rather straightforward. They suggest several options and ask the patient or the family which option they want. It can be done in a single encounter, with one question and one answer. In contrast, nurses spend more time with patients, and their interest to know the patients' wishes is ongoing. Nurses recognize that patients and family could change their minds as the situation changes. Nurses also know that patients sometimes hesitate to express their honest treatment preference to their physicians, because they are afraid to hurt the physician's feelings and ruin their relationship. Thus, nurses continue paying attention to what a patient truly wishes from the early stage of their involvement onward. Another reason nurses take a more indirect approach to understand the patients' wishes is that they are not in a position to explain and elicit treatment choice directly from the patient. That is a physician's role; nurses cannot explain or decide what treatment choice should be used. If the physician talks to the family instead of the patient and never asks about the patient's own wishes, the nurse needs to indirectly explore the patient's true wishes. The nurses' concern focuses on the patient's actual desires throughout the illness trajectory.

Another nurse told a story in which the patient's wish was not granted and she regretted the way he died. It demonstrates the complexity involved in respecting a patient's wishes in real clinical situations.

> O: That was a patient with lung cancer, about 80 years old. He had advanced cancer, his albumin level went very low, and he also had some kind of skin disease in the groin area. His scrotum was ulcerative and swollen. His care was hard. Anyway, he wanted to go home. But because of his condition, it was a hard decision to make. He also said, "I don't want to go home unless I get much better." The family was also worried about his going home because he was living with his elderly wife. So he could not go home. [Pause] I regret that.

From a medical decision perspective, this patient's wish was clear: he wanted to stay in the hospital, receive treatment, and go home when he got better. From the nurse's perspective, he would not get better, he would not be able to go home as he wished, and therefore his wish of going home would never be granted. The patient knew his diagnosis was lung cancer, but he believed it would be cured by the chemotherapy. The nurse thought he did not believe he was dying. So the nurse could not know his real opinion about how and where to die. This patient had two conflicting wishes that made it difficult for the nurse to help him make the right decision for himself.

Sometimes patients themselves do not know what they want. Nurse N told a story in which she struggled to find out what the patient really wanted to do. She had an elderly female patient who was admitted to hospital for radiation therapy for bone metastasis from breast cancer. While she was receiving radiation therapy, the nurses tried to figure out pain management for her. But the nurses had trouble setting the goal for the pain management, because the patient could not explain what she herself wanted to do.

> N: All the nurses, including myself, were troubled with this patient. In general, when we ask the patients what they want to do, Japanese patients are not straight forward about what they want to do. Especially this patient, when I would go to see her for a vital check or something, she would ask the nurses to make all the decisions: "Is it OK if I get up? Is it all right to drink water?" She asked nurses' permission to do

> anything. It is OK to ask those questions. But when we asked her, "What do you want to do now? Do you want to reduce your pain? How much do you want to manage pain to make you able to do what? Do you want to go to the bathroom by yourself?" she did not tell us what we wanted to know. Her responses were something like, "What do you nurses think? Please don't push me so hard for an answer." Or "Don't press me." So we could not know what she wanted to do, how she wanted to spend the rest of her life, at all.

Because of the nursing value to respect patients' wishes and help accomplish them, nurses feel troubled if they are unable to identify what the patients' wishes are.

Comfort/Relief from Suffering

Similar to findings in other nursing studies (Doutrich et al., 2001; Wros, 1993; Yokoo et al., 1993), the nurses interviewed for this study identified one of the major moral concerns in end-of-life care as comfort and relief from suffering. Nurses often explained how bad they felt when they saw patients suffer. For several nurses, their worst experience in end-of-life care was watching patients suffer from shortness of breath and being unable to provide any effective relief. Interestingly, shortness of breath was the suffering mentioned most frequently, more than pain, in these interviews. This may be due to the characteristics of the population that nurse participants were serving. Approximately half of the participants were working or had experience working in respiratory units. Yet this also seems to resonate with some reports showing that pain management has improved over the last 20 years in Japan (Shimoyama, 2002; World Health Organization, 1996).

The suffering that concerned the nurses was diverse, including any kind of physical or psychological discomfort induced by illness, treatment, procedures, and relationships. Many nurses expressed difficulties and unbearable feelings in watching patients suffering from physical symptoms due to illness. Nurses tried to control or ease the suffering using medications and other sorts of comfort measures such as massage, heating pads, positioning, and fans. Often they negotiated with physicians for medical interventions to ease patients' discomfort. Unfortunately, some symptoms were unmanageable and some patients died writhing in agony. Sometimes the patients or family choose not to use medication to alleviate suffering. The patients may prefer suffering to the side effect of a declining consciousness level that impairs their ability to communicate with their loved ones. In such cases, although the nurses understand it is their choice, nurses feel an ethical dilemma, and they have a hard time watching the patients suffer.

Treatment itself can cause pain or suffering for the patients. In end-of-life care situations, the nurses raised questions about employing painful routine medical procedures and unnecessary examinations. "I did not do suctioning. . . . It is painful, he does not want to suffer, and his family does not want to see him suffer. I did not even check blood pressure," said one. Another nurse fought against a physician who wrote an order for a painful and risky lumbar puncture to rule out infectious peritonitis.

> N: The doctor said he was going to do a lumbar puncture on the terminally ill patient to find out if her peritonitis was cancerous or infectious. I asked him, "Are you really going to do this!?" If it was cancerous, there was nothing he could do. If it was infectious, he was going to use antibiotics. So if the only possible treatment was antibiotics, just giving her antibiotics was good. Why did he need to give her pain like a lumbar puncture?

In another situation, although the patient and family had decided on and signed a do not resuscitate (DNR) order, at the very last moment the daughter of the patient changed her mind and asked for heart massage.

> GG: When her heart stopped, she [the daughter] asked, "Please do heart massage." For us, the patient did her best and fought enough. We wondered why we should give her heart massage and make her suffer more. Anyway, because of the family request,

> the doctor did it, and we heard the sound of crushing lungs. It was an unbearable scene to watch.

No matter what kind of suffering they witness, the nurses' concern for patients' suffering was often expressed in emotional terms: "People who die with a great deal of suffering, it is painful to care for them and watch them"; "It was really painful, it was hard and even now it is painful [to take care of patients who have unmanageable suffering], sometimes"; "It was unbearable to watch"; "What was hard to see was that she could not eat although she loved to eat"; and "I felt very bad that he had to suffer." Nurses' responses to the morally concerning situations when a patient is suffering unnecessarily are nearly intuitive. It is almost as if they are actually feeling the patients' pain and suffering themselves. They sense it is bad and not right immediately, but often are unable to describe their response in logical terms.

Meaningful/Pleasant Time for the Patients

Another concern several nurses mentioned as particularly important in end-of-life care was that patients should have as much meaningful time as possible. The sense that there is limited time left for the patient changes nurses' perception of how the patient should spend time.

> IN: How do you think the care for terminally ill patients and non-terminal patients differs?
>
> M: What is the difference? Umm, how to spend time. I try to let the patient spend time in the best way that he or she likes. If they are patients for chemotherapy, I would focus on making them get better and discharged from the hospital without any troubles. For example, for a patient with hemorrhoids, I would not be concerned about whether he would enjoy traveling better after he fixes his hemorrhoid or not. But if it is a cancer patient with liver metastasis, because I want him to have as much meaningful and good time as possible, I would let him know that he can go home until the actual treatment starts if he wants, or tell him that he can get permission to go out to dinner or something with his family. If patients are in the terminal phase, I shift my focus to letting them have their own time and the life they enjoy as much as possible. I want them to live their lives as they are, not as a patient in a hospital.

The knowledge that a patient does not have much time left orients nurses to focus on helping the patient to conclude his or her life. A nurse said she was concerned about a patient who did not know his poor prognosis because “he is young. He has to take care of his business before he dies. To let him accomplish his life, we should convince his wife [who stopped health care providers from telling him his prognosis] to give him some idea what is going on." Another nurse was bothered that a patient was not able to talk to his beloved wife about all his feelings and his will before he died, because he did not know his time left was so short.

One nurse explained the goal of her care for dying patients: "The patient can have a comfortable day with something good. The patient can have something good; the patient can have an easy day today; the food tasted good today – it may be something small like that. Who knows if they have tomorrow? So I want them to spend this moment preciously. I don't want to let them say, 'I had a very hard day today.'" An example of helping patients to have a good moment is something as trivial as putting herbal lotion on jaundiced and itchy skin. The patient looked forward to and enjoyed the moment the nurse came to pat the lotion on her skin because it felt so good. It was one of the few pleasant moments the patient could enjoy while hospitalized with terminal illness.

Another nurse talked about a memory of giving good care by letting a dying patient smoke.

> L: A couple of days before he died, the patient's son visited him from a long distance. During his visit, the patient said, "I want to smoke." . . . We could not let him smoke in his room. At that time, we still had a little smoking area in the corner of the unit. So

> we pushed his bed there and he smoked a cigarette with his son. He said, "It tastes very good," and he looked very satisfied. I thought it was very good for him. . . . I had never seen him so relaxed or contented. His son had visited him, he could smoke a cigarette with his son, and he said, "It tastes good." I was happy seeing him enjoy, relaxed and satisfied.

This nurse could have said no when the patient said he wanted to smoke because she was busy and following the rules in the unit. Letting a very sick patient smoke in the hospital is not good from a health care provider perspective. But the nurse recognized it was more important for her patient to have a good moment with his son and enjoy his life. He did not have much time left and he would not have another chance to spend such a relaxing time with his son. Thus the nurse thought it was good care to allow him to have a meaningful and pleasant moment before he died.

This concern of letting a patient spend meaningful time overlaps with the concerns of regard for the patients' personhood and respect for the patient's wishes. Yet assisting the patients to have meaningful or pleasant time is an effort to add joy to their limited lives, whereas regard for the patients' personhood is more focused on perceiving and maintaining the patients as who they are. These nurses' efforts to promote the small joys of life may seem trivial compared to more important ethical issues such as decisions about use of life-prolonging procedures or DNR orders. As described in the section about respect for the patients' wishes, knowing the patients' end-of-life wishes and actualizing them involves physicians' orders and families' wishes also. Although the nurses are concerned to respect the patients' wishes about how they want to die, the nurses cannot grant these end-of-life wishes all by themselves. Thus, for the nurses who cannot grant the patient's large-scale end-of-life wishes, granting a patient's small-scale wishes, such as the man who smoked with his son, is one way to implement their moral concern of respect for patients' wishes. Moreover, the small pleasures that nurses provide may have more significant meanings for patients, whose world may be shrinking as their death comes closer. When nurses know a patient does not have much more time to enjoy his or her life, the patient's every single minute becomes precious. Holistically the nurses try to maximize the patient's quality of life within his or her limited situation.

Summary

These seven moral concerns, (a) not hurting the patients, (b) honesty, (c) isolation/loneliness, (d) regard for the patients' personhood, (e) respect for the patients' wishes, (f) comfort/relief from suffering, and (g) meaningful/pleasant time for the patients, were identified in the nurses' narratives of their practice for dying patients. They are moral because nurses make moral judgments, good or bad, about situations or acts, in accordance with these concerns. Although nurses are not able to describe why a situation is good or bad, they seem to know instinctively what is good or bad in each context. Because the situations in end-of-life care are complex most of the time, multiple concerns coexist in a situation and those concerns are interrelated, overlapped, and sometimes conflicting with each other. These concerns emerged through thematic analysis of the nurses' narratives about their end-of-life care practice. In order to understand why these concerns appeared to matter to the nurses, it is important and helpful to look into the background that help set the nurses' worldview. In the next chapter, the several background meanings that constitute these moral concerns are described. Also discussed are clinical situations in which moral concerns are embedded in practice.

Chapter V: Results and Discussion:

Background Meanings of Nurses' Moral Concerns and Ethical Practice in End-of-Life Care in Japan

In this chapter, the background meanings that constitute nurses' moral concerns and embody ethical practice in a particular context are illustrated. Background meaning is defined as "what a culture, subculture, family and personal life experience give a person beginning from birth. It determines what counts as real for the person. It is a shared, public understanding of what is. Background meaning is not itself a thing, like formal, explicit knowledge, rather it is what allows for the perception of the factual world" (Benner & Wrubel, 1989, p. 407).

Merleau-Ponty (1962) described the concept of background meaning using the analogy of light: you see what it illuminates, you would not see anything without it, and you don't see the light itself. The possibilities of how nurses view certain situations and respond to them are framed by their backgrounds (Benner et al., 1996). Each nurse has her/his own way to view the world that constitutes and is constituted by her/his own life experiences, determined by her/his family, community, society, and the culture in which s/he was born and raised. Perception of the world is unique for each person in the sense that no one has exactly the same life experience, yet it is also shared within a society because the community and culture surrounding a person affect how s/he perceives the world. Background meanings are important to understanding nurses' concerns and their practice, because the background meanings form how nurses view their situations in practice, set up what matters to them, and help implement their concerns into actual acts.

In interpretive phenomenological study the preexisting background meanings are customarily described before people's concerns and practices are illustrated. In the analysis process of this study, however, the nurses' moral concerns emerged first from their narratives, and in an effort to understand why these concerns matter to the nurses, the light that illuminates the concerns was revealed. From the early stage of the analysis, there were also some practices that stood out from others practices for me. The key to understanding the difference between these outstanding practices and other, ordinary practices also lay in the understanding of the background meanings of working as a nurse in a Japanese hospital for dying patients. In this study, therefore, the descriptions of background meanings come between the descriptions of nurses' moral concerns (Chapter IV) and their ethical practice (Chapter VI). The intention of this chapter is to fill in the backgrounds of the picture of the nurses' moral concerns in the previous chapter and give the readers an understanding of the contexts of the nurses' ethical practice in the next chapter.

The culture of the unit and the hospital where nurses practice, the people the nurses are working for, i.e., patients and their families, and the people the nurses are working with, such as other nurses and physicians, are the backgrounds of nurses' perceptions, concerns, and practice. Background meanings that relate to the Japanese nurses' moral concerns and their ethical practice in end-of-life care will be discussed with excerpts from the interviews to support and delineate how they relate to the nurses' perceptions. Because the background meanings related to ethical practice in end-of-life nursing care in Japan are vast, the discussion will be divided in three: cultures in nursing, terminally ill patients and their families in Japanese hospitals, and the nurse-physician relationship.

Cultures in Nursing

Nursing culture is an important background that forms the nurses' perceptions and practices directly and indirectly. There are cultures in groups of nurses in each unit as well as patterns and traits commonly seen among nurses in general. Several examples of unit cultures that appeared in the nurses' narratives will be introduced to portray the atmosphere and meanings of nursing culture in units, and they will be followed by an outline of themes in the narratives of nurses in all units: senior nurses, team consensus, and Western influence.

Nursing Culture in a Unit

Nursing culture within each unit is formed by the type of patients cared for, the mission of the unit, the system of nursing in the unit, and unit rules, including explicit rules such as job descriptions and more tacit rules such as the customary route to get certain orders. These conditions and characteristics of the unit are communicated among nurses and set a climate for nursing in the unit. The culture in a given unit not only tells how to practice nursing in the unit, but also frames what matters to its nurses.

Different culture in each unit. One nurse described her experience of making a nursing care plan for a patient right after she moved to a surgical unit.

> O: This unit is for acute care. I was originally working in a different unit where most of the patients had chronic disease. So we did not have many hustling situations like, "Early detection of abnormal signs! The priority is on prolongation of life!" We were more supporting patients' everyday life, encouraging the patients to be independent, and supporting their life. Therefore, the care plan was something like how to talk to the patient to encourage him, or how to intervene with the patient. [But in this unit,] I don't see that kind of care plan. Most care plans here are "Early detection of abnormal signs: Observe this, this, and this," or "Required procedures for this patient are blah,

> blah, blah." Well, this unit is mainly a surgical unit, so patients with internal medicine kinds of treatment are not the focus of the nurses' attention. . . . He was a very good patient, so I worried that he received only routine basic vitals checks and was overlooked by the nurses. That was when I had just moved from the other unit to here. I noticed the nurses in this unit focused on procedures, and everything runs around the physicians' order. So I tried to make my assessment and plan for this patient's care as explicit as possible.

The patterns or characteristics of the unit culture are hard for the persons who reside in the culture to recognize. Their view is limited to what usually matters to them in the unit, whereas outsiders or newcomers can see different things because they see it through different lenses. This newly arrived nurse had correctly identified that the focus of the unit was on saving the life of acutely ill patients. Nurses prioritized their care on the early detection of problems, managing all the medical procedures ordered by physicians, and saving lives, without much emphasis on supporting and helping patients to have independent lives. Nurse O had to spell out her nursing care plan for a patient with a chronic medical problem explicitly in order to make other nurses see how she sees the patient. She tried to shift the focus of care for this patient from interventions limited to medical procedures to care that would support his everyday life.

Another nurse explained that she had a hard time recognizing variances in the meaning of some terminology and practicing in a new unit where other staff nurses did not support her concern. In her story, although the patient, the family, and the physicians had reached agreement "to not do anything" when the patient's condition deteriorated, the level of "not doing anything" the nurse assumed was different from the level assumed by physicians in the unit. In her old workplace, "not doing anything" meant to do nothing but provide comfort care. In the new unit, "not doing anything" meant no CPR but included other active interventions such as high-volume oxygen supply and airway suctioning. When the physician ordered more aggressive intervention than she expected, the nurse was astonished because it was not what she had heard the patient wished. Although the nurse had long nursing experience and she was the chief nurse of the unit, she could not convince the physician that the treatment was not what the patient wished for, because she "did not have confidence, I think. The respiratory unit was a new area for me then, and there was no one who supported my idea. All the other staff nurses in the unit saw the interventions as common end-of-life care for patients with a DNR order. The other nurses did not see the discrepancy between the patient's meaning of "not doing anything" other than comfort measures and the actual care they were giving him under the name of "not doing anything" meaning no CPR. The nurses in this unit did not see the concern of disrespecting the patient's wish, although the nurse who was new to the unit could see it almost immediately.

Another nurse who is currently working in a palliative care unit described the effect of unit climate on the nurses' acceptable behavior at the patients' death.

> EE: When one patient died, he went through a very long process. I was very sad and I was crying with his wife. Then a senior nurse called me out from his room. In the surgical unit on night shift, each of the nurses was in charge of 16 or 17 patients. I was scolded, "If you are crying here, who is going to take care of the rest of the patients?" and she yelled at me like, "You cannot cry here!" It did not mean the senior nurse was not sad, but she said I had to switch my mode to keep doing my duty. Then I thought, in that unit, I was not allowed to cry and could not share the feelings of losing people in the unit.

In a surgical unit, the main goal is to provide surgeries safely and efficiently, and then send patients back home. The highest priority among the nurses' jobs in the unit is to carry out the prescribed medical orders to prepare patients for and assist them in recovery from surgery. The culture in the unit dictates that a nurse not show her feelings, particularly if it becomes an obstacle to carrying out the mission of the unit. This nurse could not agree with the unit culture, and several years later, she made a request to move to the palliative care unit, where she thought the mission of the unit was different and its culture would allow her to focus on more personal connections with the patients.

Unit culture sets nurses' perceptions and practices. For better or for worse, established culture in a unit binds nursing practice to the conventional viewpoints in the unit. The acculturated nurses who work in the unit are limited in their possibility of practice within the specific culture. A nurse recalled the conflict between her desire to support a patient and her family in carrying out their home remedy in the hospital, and the culture in the unit, which was unfavorable to the use of an "ineffective, unscientific" remedy.

> D: I was a brand-new graduate nurse at that time, so I was not involved in her care as a main nurse. I just did things like vitals checks and helped with personal care sometimes. Everyone [the nurses] wanted to avoid the loquat leaf remedy. They pretended not to see what the family was doing, and nobody tried to help them do the remedy. . . . They [nursing staff in the unit] pretended not to see it because it was an old wives' remedy and the family did it by themselves. There were negative feelings among the nursing staff about the remedy. Because it was not effective, it was just a

> waste, they [the nurses] did not want them to do it in the unit. So they told the younger nurses like me, "It is a waste," and there was a tacit rule not to give a helping hand to the family to do this remedy.

The culture among the nursing staff in this unit was that a home remedy is not effective and not appropriate in a modern hospital. The predominant view in the unit formed the view that nurses should not assist with the remedy. This limited nurses' involvement with this patient and her family's care. Since Nurse D was new and not imbued with the unit view about home remedies, she did the home remedy with the family for the patient. Both the family and the patient were very grateful to her. Yet, through this experience, she learned there was an unstated rule in the unit that most nurses followed.

Another example of nursing intervention limited by unit culture is shown in the struggles of a nurse with four years of experience to provide care based on her moral concern. Nurse CC had a patient who did not officially know her prognosis but seemed aware that her death was approaching. She was from a distant rural area and really wanted to go home one more time. In contrast, her children thought it would compromise their reputation in their local community if they brought her back home without giving her the most advanced treatment. Nurse CC was concerned about disrespecting the patient's wish, and felt the patient was spending meaningless time in the hospital for the sake of saving her family's face. Yet her intervention with this patient was restrained by the norms and culture in the unit.

> CC: I wanted to intervene [with the family], but I was not sure if it was good to step in or if it was jumping the gun. I have never seen anybody do that in this unit, telling the family the patient's thoughts and changing the family's decisions. I don't even know if it would be an OK thing to do. It may sound strange. It [nurses intervening in the family's decision by letting them know the patient's wish] just never came into the decision-making process. I have never seen that. It may not mean that I cannot do it, just because I have never seen it. I would also worry that it would lead to another issue. If I do that and something happens because of it, can I take the responsibility? If we know the patient's wish, I know we should act based on the patient's wish, but I just keep practicing as it is so far, although it troubles my mind.

This nurse has never worked in other units. She said she had never seen other nurses in this unit do anything to alter a similar situation. The normative nursing practice for this kind of situation in this unit is to follow the family and the physician's decisions, and not intervene with the family to convince them to listen to the patient's wish. Although the situation appeared unethical and Nurse CC felt "bad," her ability to implement her concern was restricted by the normative practice in the unit. Since she had never seen examples of other practice, so she did not know what to do and also wondered if these practices were acceptable. She had moral concerns in the situation, yet the norm in the unit limited her learning about ethical practice and the climate in the unit appeared to discourage her from taking a risk and acting in response to her moral concerns.

Rules in a unit frame what is good and what is not. Sometimes, unit rules set the tone and limits of nurses' practice and reinforce it by implying negative connotations to practice that falls outside of the limits. One nurse mentioned a unit rule requiring nurses to write an incident report if they communicated the diagnosis or prognosis to patients unaware of their condition. This requirement to write an incident report suggests that if a nurse communicates honestly with a patient, negative consequences could result. This, in turn, makes nurses hesitate to act based on their moral concern for honesty. It also conveys the impression to nurses that they have to work within the range of physicians' boundaries. The rules in a unit contribute to the formation of nursing culture, shaping a standard that determines what is good and what is not good nursing practice. Thus such rules could impair the nurses' ability to perceive moral concerns as well as their ability to implement such concerns in ethical practice.

Influence of Senior Nurses

One interesting finding in the interviews with Japanese nurses was that many mentioned the influence of senior nurses on their practice. Because seniority is one of the major systems ordering Japanese society, hierarchy within a group is often based on seniority. Senior members in a group are respected for their experience by the junior members in the group, and juniors learn and gain experiences by following seniors' practice (Tierney, 1994). Senior nurses are those with more experience in nursing, in the area of specialty, or in the particular unit. In Japan, most nurses go through the education system in the same order. Thus, the nurses who have worked longer are usually older and have more life experience, too. More experience does not necessarily indicate more expertise, but customarily older and more experienced nurses are respected for their experience and their practices are followed by the junior nurses.

Traditionally nursing has had a component of apprenticeship, and nurses are expected to learn efficient practice from senior nurses by watching them and being taught by them. A chief nurse with 15 years of experience responded to a question about how she gained the skills for becoming involved with patients:

> O: Sure, when I was a first-year, second-year nurse, I could not talk to the patients

> like this. How I learned it was, I learned from the senior nurses. They told me, "This is a good way to do . . ." and so on. And I actually experienced what they told me, and through the experiences I was convinced they were right. I have many many experiences like that, and the accumulation of that kind of experience makes me able to do this kind of practice.

Younger and inexperienced nurses generally respect and follow the senior nurses not only because they are more skillful in practice but because they know the customs and explicit and implicit rules for the culture in the unit and nursing. The culture of the unit is maintained and carried on by the senior nurses, who teach the junior nurses how to practice like they do. Because they are so influential for the junior nurses, advice or practice of the senior nurses shapes the junior nurses' views and practices. For example, Nurse CC had never seen any other nurses intervene to solve a patient and family problem. She could not learn how to solve the problem she perceived, because there was no one to show her. Nurse EE, described previously, learned from the senior nurse that she should not cry in the unit. Another nurse, who was asked by a terminally ill patient if he was going to get better, could not answer his question because of her concern about being dishonest. Yet "There was a senior nurse at the site, too. And she told me later, 'At that time, he [the patient] probably wanted you to tell him he was going to get better. I think it would have been better to tell him so.'" What this junior nurse learned was that not hurting the patient has higher priority than honesty in that sort of situation. Regardless of whether a practice is good or not, senior nurses set the normative practice in the unit and pass on the norms and culture of each unit to the junior nurses. Therefore, understanding the influence of senior nurses is important to explicating how nurses learn moral concerns and ethical practices.

Team Consensus

Another issue related to the culture among nurses that may reflect the larger Japanese society is the idea of team consensus. Japanese society places a high value on harmony and consensus, which creates pressure for conformity to group norms (Lebra, 1976; Nakayama, 1998; Tierney, 1994). Because of their strong sense of belonging and preference for collectivism, idiosyncrasy and dissension are avoided or suppressed by Japanese (Lebra, 1976; Tierney, 1994).

Some nurses expressed frustration or guilt that they followed the group consensus and did not take a certain action they believed would benefit their patient. Nurse L told a story about taking care of a dying patient who was not told he was dying at his wife's request. Because his wife wanted him to keep hope, she asked the nursing staff not to say anything to the patient that could indicate his deteriorating condition. Although the unit used a primary nursing system, Nurse L was not the primary nurse for this patient. The nursing care plan made by his primary nurse centered on not telling him any bad news.

> L: For example, I took blood pressure. Although the blood pressure started going down, like to high in the 90s, I told him "Ah, it is good," not saying anything more. I did not ask him about any of his concerns related to his life and death, just asked neutral things like, "How is your pain today?"
>
> IN: Why didn't you tell the patient the actual blood pressure? Why did you tell him, not a lie, but something not really true?
>
> L: Well, I was not the main nurse in charge of him. I just saw him from time to time because I was on the same [nursing] team. The wife made a request to keep up his sprit, and his nurse responded to the wife's request by saying, "OK, so we would tell him something like blood pressure like this." So I just followed her plan.

This nurse was concerned about not telling the patient his real condition and letting him die without sincerely talking with his wife. Although she disagreed with the primary nurse's approach, she followed it because the primary nurse knew the patient and the wife better and the primary nurse's care plan was the consensus on which the team agreed. There was a moment when Nurse L might have talked to the wife about different approaches. However, she chose not to talk to her because she thought it would be better for the health care team to maintain a united front. Another nurse in a similar situation also chose not to respond as she honestly felt she should, because "everyone had not reached a consensus yet."

Deference to the Primary Nurse

In units where a system of primary nursing is employed, having one nurse or a group of nurses designated as responsible for the care plan of the patients could result in limiting timely or spontaneous attuned care for the patients. A nurse remembered one patient with regrets. His family wanted him to go home, but the nurse noticed the patient did not want to go home. When the patient was discharged, the nurse thought the patient did not look happy and he looked like he wanted to say something. Because she was not his primary nurse or the nurse who made his discharge plan, she did not stop him. Next day, he was readmitted to the emergency room for choking and he died after several trials of intubations in the ER. The nurse said she did not intervene when he looked unhappy at his discharge because she felt she did not know the patient as well as his primary nurse, or as well as the nurses who made his discharge plan. She hesitated to overstep the primary nurses' judgment.

Another nurse, chief nurse in her unit, described a situation where she hesitated to tell her opinions and intervene when to do so meant she had to overstep the prerogatives of the primary nurses' judgment. As a leader in the nursing team, the chief nurse is in a position to encourage the primary nurses' autonomous and responsible practice. If she thinks the primary nurse's care plan does not best suit the patient's needs, she needs to intervene and mentor the primary nurse to improve the care plan. However, in this situation, the primary nurse who wrote a seemingly inappropriate care plan was a well-respected senior nurse in the unit. The chief nurse hesitated to point out her concern and intervene because she did not want her to lose face as a senior nurse.

Primary nurses are usually strongly autonomous in decision-making about care for their primary patients. Because the primary nurses are assumed to know their patients best, their care plans for these patients are adopted by the team. Once a plan becomes the consensus, due to the pressure for conformity and harmony within the team, even this chief nurse feels *enryo* (a type of self-restraint) and refrains from expressing disagreement. Needless to say younger nurses and even nurses at the same level are even more reluctant to question a primary nurse's judgment.

Western Influence in Japanese Nursing

Another characteristic of Japanese nursing culture that stands out in the nurses' narratives is a strong Western influence. The basis of contemporary Japanese nursing was established after World War II under the direct guidance of the American nurses in the occupation forces (Minami, 1985). The 1948 Public Health Nurse, Midwife, and Nurses Law, which defined the roles of nurses and provided a standard for the nursing education system, was strongly influenced by Western ideas of nursing. The reconstruction of the nursing system and nursing education led by U.S. nurses after the war molded Japanese nursing to a very Western orientation. Nursing practices in the United States were viewed as models, or the golden standard, and knowledge, technology, and theories have since been imported into Japan with enthusiasm (Minami, 1985). Numbers of nurses from the United States were invited as professors and taught in nursing schools in Japan. Many Japanese nurses have gone overseas to learn new and advanced ideas and techniques in nursing and brought them back to Japan. Textbooks published in the United States and translated into Japanese occupy a large part of the nursing section in Japanese libraries.

In her 1985 article, Minami expressed her concerns about Japanese nurses' enthusiasm for foreign knowledge. She argued that the assumptions and beliefs underlying the imported concepts have been accepted without examination and are causing conflicts between Japanese nurses' personally held traditional values and the new values imposed on the nurses as professional values. She also pointed out that Japanese nurses might not be aware of the conflict between their personal orientation and their professional one, because, although they are living in a culture and society with the traditional values, these traditional values are not clarified and cognitively transmitted in nursing value orientations.

Several narratives in the interviews support Minami's point. A surprisingly large number of the nurse participants mentioned or quoted theories, concepts, or ideas developed in the Western countries in their narratives. These included concepts in nursing theory such as "self-care," psychological models such as Maslow's hierarchy of needs, ethical principles such as "respect for autonomy" and "right," death and dying literature by Kubler-Ross and others, and prescriptive textbook-type literature about communicating bad news. Interestingly, although some nurses explained that the imported concept sometimes did not fit in their particular clinical situations, no one expressed her awareness of the gap or clarified the source of the gap. One nurse described a discussion in a unit nursing conference about a patient who was in denial of her bone metastasis and subsequent prognosis of not being able to walk:

> AA: Talking about topics such as the patient wanting to walk again, we don't let her have great expectations but also help her keep hope. So we don't say, "You will walk

> again." Instead we say, "We hope you will be able to walk." That way, she has some hope. At the conference, we all talked about how to talk to her. But many of us felt that keeping unwisely silent or responding by saying, "Why do you think so?" so-called textbook-like responses, is just dodging the question. So as a result, when the patient says she wants to walk, we now often say, "Yes, that would be good."

What she called “textbook-like responses” are those commonly written in the textbooks as communication strategies with dying patients. Most of these textbooks are either translations of English textbooks or based on literature developed in Western countries, where the background social system and culture regarding information disclosure and communication style are very different from in Japan. Therefore, it is no surprise that prescriptive responses developed in the context of another culture do not fit within the Japanese nursing context.

None of the nurses questioned why the textbook approach did not work in this situation; instead they kept going with their modified approach. Several other stories indicated the existence of gaps between applied imported concepts and actual clinical situations. Yet no further clarifications were pursued regarding what caused the misapplication of the imported concepts. Doi (1973) claims that value orientations that were developed in another culture and introduced into Japan pervade Japanese culture through a process of identification and assimilation. Thus, the original features of the value might be modified and changed. The nurses' attitude of disregarding the gaps and continuing with modified use of the concepts appears to be a part of the assimilation process undertaken almost unconsciously.

The strong influence of Western nursing since the foundation of the contemporary nursing system should not be ignored when exploring the thoughts and practices of Japanese nurses. Postwar nursing education has been consistently based on imported nursing philosophy, accompanied by such Western values as individualism, independence, and autonomy. These values are embedded in Japanese nurses' professional value orientation. The translated terms for the Western values are a part of the jargon used in Japanese nursing, and Japanese nurses may frame their concerns and describe their practice using these translated words. However, these values may not match with the value system the Japanese patients and their families hold, or even with the nurses' personal value systems, because values are fostered in the culture and social structure where people are raised.

When the nurses experience the discrepancy between their strongly Westernized professional ideas and patients', social, or their own personal value orientations, the nurses respond in one of two ways. They either keep the imported concept intact and save it for abstract discussions, or they assimilate the idea with modification to something suitable within a Japanese context. In the latter case, the nurses may not be aware that they are interpreting the concept differently from its original meaning. Assimilation is not necessarily wrong adaptation. Yet, since Western influence is so deeply embedded in Japanese nursing professional values and the nurses have subliminally assimilated it into their everyday clinical practice, the assimilated values need to be carefully and consciously examined in order to understand the uniqueness of Japanese nursing (Davis 2002, Minami, 1985). Acknowledging Western influence among Japanese nurses helps to uncover the Japanese nurses' real moral concerns that are not embellished by foreign concepts, and to understand their ethical practice in end-of-life care better.

This section has described how social rules and multi-layered relationships among nurses create a culture in nursing, and how this culture then shapes what nurses perceive and what they can do. The culture among nurses in a unit can limit not only practice but also views and what matters to the nurses. Through acculturation, junior nurses fit into the unit culture. When senior nurses teach a unit's conventional practice and viewpoints, this could limit new possibilities for nursing practice. The value on group consensus and hesitancy to exceed the prerogatives of primary nurses are also characteristics seen among the nurses that cast limitations on their practice. The Western influence on Japanese nurses' professional values, which may overlay and cover uniquely Japanese nursing values, was also discussed. Some of these background meanings in nursing culture will be reviewed further in Chapter VI to shed light on the nurses' ethical practice.

Terminally Ill Patients and Their Families in a Japanese Hospitals

The terminally ill patients and their families for whom the nurses are working also construct another important set of background meanings for end-of-life nursing care. Who patients and their families are, and what their relationships are with the nurses, both influence nursing concerns and practice. The patients and their families in this study are portrayed only through the nurse participants' perspectives: no actual patients or their families were included in the study. The following characteristics of patients and their families appeared to have prominent implications for end-of-life nursing care in the interviews: (a) patients with cancer, (b) patients in the end-of-life stage, (c) patients within the Japanese culture, (d) patients' relationships with health care providers, and (e) families of a terminally ill patient in Japan.

Patients with Cancer

The participants were asked to discuss all terminally ill patients they cared for regardless of the type of illness. However, because cancer has been the number one cause of death in Japan since 1981 (Health and Welfare Statistics Association, 2000) and one out of four Japanese dies from cancer, many of the patients mentioned in the interviews were dealing with cancer. Due to the high mortality rate, diagnosis of cancer has been perceived as a more significant threat to life than almost any other disease diagnosis. Traditionally Japanese physicians have only rarely disclosed the diagnosis of cancer directly to a patient because they were afraid that it was like giving the patient a death sentence. This would be too cruel for patients (Kiba, 1993; Mizuno, 1990; Ohi, 1997; Tanida, 1994, 1998). Instead, physicians tell the diagnosis to the patient's family and obtain surrogative consent for treatment. Alternatively, physicians may ask the family's opinion about whether to tell the patient the true diagnosis. In any event, they then follow the family's decision (Asai & Fukui, 1997; Kiba, 1993).

As new and more advanced treatments for cancer are developed, and as the concept of patient rights and informed consent has spread throughout Japan, the number of situations where physicians reveal the diagnosis of cancer to patients has increased (Asai & Fukui, 1997; Hattori, 1991; Kiba, 1993). Although disclosing the prognosis of advanced cancer is not yet common, this change in practice was also evident in the interviews in this study. More physicians have begun to disclose a cancer diagnosis to their patients because of their fear of being sued for providing false information. They are also motivated to reveal a cancer diagnosis to convince patients to agree to aggressive treatments with severe side effects (Asai & Fukui, 1997). However, when a cancer becomes untreatable and the patient is terminally ill, physicians stop providing information to the patient because they feel it is cruel to tell the patient that there is no more treatment.

The nurses' stories about end-of-life care included terminally ill patients with a broad range of disclosure levels: from patients who did not know their diagnosis to patients who knew everything, including their prognosis and their approaching death. Davis, Konishi, and Mitoh (2000) trace this broad range of disclosure practice to situational ethics, which is characteristic in Japanese culture. According to them, information disclosure and decision-making in Japan are practiced case by case, depending on the relationship between the patients and their families. Because people are not independent individuals for Japanese but rather are interrelated with their family, the decision-making is determined within the family relationship.

This case-by-case approach for information disclosure adds great complexity to nursing practice. Although a group of physicians working together in the same unit tend to practice a similar level of disclosure, the nurses may have to deal with more than one dying patient. One may know everything about his diagnosis, while the patient in the next bed may not know anything. When the unit culture and the hierarchical nurse-physician relationship bind the nurses to communicate with the patients within the range of disclosure the physicians have set, nursing practice and communication with the patients are complicated by these different levels of disclosure. Most of the nurses were able to recall in interviews whether the patients knew their diagnosis, whether they were told their prognosis, how much they were told, and if the disclosure was limited, who limited it. This recall indicates how critical it is for the nurses to know the level and rationale for each patient's disclosure status in order to care best for them.

Patients in the End-of-Life Stage

Several nurse participants said they found caring for terminally ill patients stressful and tiring. End-of-life nursing care is overshadowed by the knowledge that in the end, the patient will still die. One nurse in a palliative care unit said, "The goals of hospital are treatment and cure, in general. So for us [nurses caring for dying patients], we cannot get a sense of accomplishment." She suggested that nurses need to shift the goal of their care for dying patients from outcome to process. According to her, when the death of the patients is inevitable, helping patients to live meaningful lives until the moment of death is a worthwhile experience for their nurses.

Another large factor that makes end-of-life care stressful and difficult for nurses is the seriousness of the issues they face in giving the care. Death and dying are not easy topics. Death raises an existential question for the people around the dying patient, asking the meaning of life. The nurses are no exception. Their work places them as witnesses, supporting the patients as they struggle to discover meaning in their lives and in their deaths. Significant strength is required to continuously face the angst of dying patients.

Nurses also accept a heavy responsibility in helping patients to complete their lives in the best way possible. One nurse expressed simply that "terminal care requires a lot of care and attention. It almost makes me nervous." She thought everything, every single minute, became so precious and important for her dying patients that she had to be very careful and attentive to them. She felt nervous because it was an enormous responsibility to help the patients to fulfill their lives as they wished while letting them have a meaningful time at the end of their lives. Pressure especially increased when there was no time left to try again if something went badly.

The topic of death and dying is sensitive, and it is almost taboo to talk about death in Japanese society. Some people do not want to use any words related to death because they believe that to speak of death will bring it about. Regardless of the degree of prognosis disclosure, the topics of impending death or preparing for death are regarded as ominous by the patients and even more so by their families. However, some patients feel an urge to express their concerns regarding their life and death. They want to make decisions about wrapping up their life and completing unfinished business. The sensitivity of the topic affects the nurses' practice of communication with the patients as well as their families.

Patients in Japanese Culture

Another characteristic of the patients that has implications for ethical nursing practice is their cultural background. All but one of the patients who appeared in the nurses' stories were Japanese. Although each patient is different and has a unique set of values, it is worth understanding some of the dominant Japanese traditional values that may have implications for nurses' moral concerns and ethical practice.

Insider and outsider. In Japan, there is a long tradition of group consciousness with a strong sense of belonging to a group (Lebra, 1976; Okuno et al., 1999). Groups vary in size and nature, but most often the family is the most fundamental group to which the patient directly belongs, especially at the end of life. The notion of group consciousness draws a clear distinction between the "inside" *(uchi)* and "outside" *(soto)* of the group and places boundaries on family privacy. Because of this strong group orientation, Japanese are often said not to have an identity as an individual (Lebra, 1976; Doi, 1973). Their identity is defined in relationship to the others in the group to which they belong. They do not exist outside of the framework the group provides. Therefore, patients do not have personal privacy within their family; rather, privacy discriminates outsiders from insiders of the family. Because a patient belongs to his or her family and there should not be any boundaries between family members, it does not violate the patient's privacy to reveal the diagnosis and prognosis to family members without permission from the patient (and even without telling the patient first). Telling the prognosis first to the family is in accord with the cultural presumption that the family members and the patient are one entity and there is no individual distinction or difference of interest between them. The family members are expected to function as the rational, cognitive part of the patients, who would be shocked and become irrational to know they are dying.

On the other hand, it is not acceptable for outsiders to cross the boundaries of family privacy. For example, a nurse who intervenes to facilitate family relationships in order to accommodate a patient's wishes could be viewed as violating the family privacy. Certain types of caregiving provided by outsiders are not socially acceptable because such care is a private matter inside the family and not outsiders' business (Okuno et al., 1999). Since Japanese nurses also share the notion of inside and outside, they are sensitive both about how much to intervene in family caregiving and when to withdraw and leave the family their privacy. Nurses, therefore, sometimes intentionally avoid intervening in family conflict regarding end-of-life decision-making, although family care and coordination with respect to their patient's wishes are professionally their concern.

Omakase: Leaving decisions to others. Another traditional value, *omakase,* has important implications for the end-of-life decision-making. The Japanese word *omakase* means leaving every decision to others. Okuno et al. (1999) analyze this concept as having two dimensions: "One is a person's peaceful, relieved feelings of trust in leaving the decision to people who accept that person unconditionally"; and the second is "a positive behavioral adaptation to meet others' pride or self-esteem in order to obtain their emotional and functional support" (p. 312). *Omakase* is seen as a positive coping style for those who are not usually in a position of control within a particular social system (Tierney, 1994). The persons given the authority to make decisions gain pride and self-esteem because the person relinquishing authority depends on them. Thus, those in control are implicitly bound by the moral obligation to serve the best interests of that person in return. Several examples of *omakase* were seen in the interviews, when patients left (or were assumed to leave) the decision for end-of-life care to either their family or their health care providers.

Okuno et al. (1999) conclude that Japanese, especially the elderly, are deeply embedded in their families, and traditionally it has been family members who make important decisions, usually the husband, father, or eldest son, and not the patient (Tierney, 1994). By leaving the decision to the family, the patients can maintain the pride of their family decision-makers, and the decision-makers feel the obligation to serve by doing the best for the patient. This relationship was very well illustrated in a story about a patient with ovarian cancer. Her husband asked the physician not to tell his wife about the diagnosis of ovarian cancer, which seemed to have a devastating image for this couple. The wife never questioned her treatment or her disease throughout several series of chemotherapy and into the terminal phase. The husband was the decision-maker. He wanted her to stay in the hospital and keep trying chemotherapy regardless of the side effects, which caused her enormous discomfort and suffering. At the end, the patient developed severe abdominal distress. She asked her husband, not her physician, to get her some comfort measures such as sedation, then passed away.

The nurse remembered this case very well because she was not sure whether following the husband's wishes was good for the patient. As a nurse who placed value on comfort, she had a hard time watching the patient suffer from the treatment her husband chose. The nurse also did not want to disrespect the patient's own wishes. But since the health care professionals did not communicate with the patient directly, they did not know her true wishes. According to the cultural pattern of decision-making, the patient might have been peaceful and relieved to leave all decisions to her husband. Indeed, the patient asked her husband, the decision-maker she relied on, to make her comfortable at the end, instead of asking the physician directly. But the nurse did not know whether or not going through multiple chemotherapies with uncomfortable side effects was what the patient really wanted. Nurses are taught the concept of respect for individuals in nursing school, because nursing education is strongly influenced by the Western view of the person as an autonomous and independent being. This situation where the husband made decisions while the patient was still competent seemed to conflict with the concept of respecting the autonomous individual.

Because it was typical decision-making practice at that time in the unit, the nurse did not talk to the physicians about her concerns for the patient's suffering and the potential disrespect for the patient's wishes. The nurse could not even talk with the patient about her feelings, because she was afraid that asking might make the patient suspicious about her diagnosis. Although the nurse tried to tell the husband the patient was suffering from the side effects, the husband could not stop himself from seeking further treatment that he thought was in the best interest of the patient. After the patient's death, her family visited the unit to thank all the unit staff. The nurse remembered that they looked very satisfied and happy despite the patient's intense suffering at the end.

The nurse questioned how care that caused such great suffering was seen as good care from the patient's family's perspective. This case remained in the nurse's memory because of the perplexing impression it left. Her Western-influenced nursing values of respecting individual wishes and providing comfort conflicted with the larger Japanese cultural values in which a wife should leave all decisions to her husband and feel relieved that her husband did what he thought best for her. Interestingly, although the nurse was troubled by this conflict, she assumed the interdependent relationship of this couple was natural, accepted that the husband's decision was in the best interest of the patient, and did not pursue the patient's wishes. This appears to confirm that cultural values do influence nurses' practice, for better or worse, and that these values are often taken for granted by the nurses who were raised and live in the same culture.

Japanese patients also tend to leave decisions regarding medical treatment to physicians. Because physicians are professionals and the experts in medical treatment, Japanese patients are relieved to leave decisions regarding medical treatment to in experts' hands. By trusting and leaving all decision-making to physicians, the patients support the physicians' pride and self-esteem and, in return, they expect to obtain the best services from the physicians.

The negative side of *omakase* behavior appears when the patient has doubts about the physicians' decisions. One patient with liver metastasis from prostate cancer was not told his metastatic condition because of his wife's strong request. He was told only that his liver had some problems, for which he would receive minor treatment. He therefore studied about treatment for liver disease in general. Because the patient acted depressed and frustrated, a nurse asked his concerns. The patient expressed his doubt about the appropriateness of the treatment he was receiving. The nurse asked if the patient had asked the question directly to the physician, and the patient said no: "He said it might be impolite to tell the professional doctors his [nonprofessional] opinions about treatment. Moreover, he said he was afraid to ruin the relationship with the doctor by questioning his expertise." Although this patient decided to ask the physician about his treatment, he changed his mind again and eventually did not ask the physician anything. The nurse observed that the patient not only felt bad questioning the physician's expertise but was also afraid to hear any bad news by pressing the doctor for an answer. The patient chose to put all decisions into the physician's capable hands and thus avoided a situation where he would have to make difficult decisions by himself.

Omoiyari: Japanese-style empathy. *Omoiyari* is another popular Japanese characteristic often seen as background in nursing care. According to Lebra (1976), *omoiyari* refers to empathy; specifically the ability and willingness to feel what others are feeling, to vicariously experience their pleasure or pain, and to help them satisfy their wishes. "The ideal in '*omoiyari*' is for Ego (the self) to enter into Alter's (other's) *kokoro*, 'heart', and to absorb all information about Alter's (other's) feelings without being told verbally" (Lebra, 1976, p. 38). This form of empathy is manifested as anticipation and accommodation of the other's need or desire and by avoiding whatever might cause discomfort for the other. In contrast to American empathy, which is shown by giving the other freedom to choose what he or she wants or likes, Japanese empathy takes care of the other's wants without asking (Aida, 1970; Doi, 1973).

In general, *omoiyari* is highly regarded virtue in Japanese society, and it is particularly critical in nursing as nursing is a helping profession. All nurses are expected to have *omoiyari* and to be kind and benevolent with keen sensitivity to anticipate and optimize patients' comfort. This is done not only by providing pleasure but also by preventing displeasure. Lebra (1976) observed that, in order to not hurt the other's feelings, Japanese tend to be circumspect and reserved. Some Japanese nurses' acts, as revealed in the interviews, were expressions of culturally appropriate empathy, preventing displeasure for the patients by anticipating how the patients would feel when they were told their gloomy prognosis.

Ohnuki-Tierney (1984) extended argument to say that any deviation from empathetic care by nurses is likely to hurt the patient, because anticipatory, almost preventive, empathetic treatment is culturally embedded and naturally expected of the nursing profession. As a result, Japanese emotions appear to be fragile and extremely vulnerable to the slightest insensitivity. Further, if the person is not comfortable or displeased, the one who attempted to provide empathetic treatment would be depressed because his or her empathetic concern with the person's comfort was not successfully practiced. The nurses are aware that Japanese patients often expect to be protected from bad news such as malignant prognosis by the *omoiyari* of the health care providers. The nurses anticipate that insensitively disappointing this expectation by telling the truth, without anticipating and preventing the suffering the patient would feel, could hurt the fragile patient. Also, the nurses are afraid to be seen as nonempathetic.

Another noteworthy peculiarity of the Japanese form of empathy is its reliance on implicit, nonverbal, intuitive communication. As mentioned above, the ideal *omoiyari* is to feel what others are feeling without being told and to then help them satisfy their wishes without being asked. The Japanese do not place value on words, because words could imply more than, or other than, what was expressed. In addition, Japanese believe that only an insensitive, graceless person needs a direct and complete verbal message (Aida, 1970). A mature, sophisticated person in society should be able to anticipate another person's feelings. This presumption is reasonable only in a society in which every member shares similar values and feelings. This is true in Japanese society, which has been for a long time geographically small, secluded, and with a homogeneous population. Because of this cultural presumption established by a long history, patients and their families expect nurses to be empathetic and able to understand their feelings and prevent their discomfort without being told verbally or directly.

These are some examples of cultural characteristics embedded in the Japanese patients and their families. Yet, in modern Japanese society, it is also true that not everyone shares the same cultural values about relationships. Because of the education system changes after World War II and the strong emphasis of the U.S. occupation forces on individualism and equality, people born after the war seem to have different values than the older generation. They understand the notion of individual rights as a concept, although they may still live amidst cultural expectations for interdependence. In the postwar educational system, expressing personal thinking and feelings are encouraged. Therefore, the degree to which an individual patient carries the traditional values varies depending on age, whether the area is rural or urban, and each individual's life experiences. Although the traditional norms and values described here may not apply to all Japanese patients, discerning these cultural backgrounds of both patients and nurses is critical to understanding the nurses' moral concerns and practice in Japan.

Patients' Relationships to Health Care Providers

Patients' relationship to physicians. Another factor that contributes to the cultural background is the patient's general relationship to his/her health care provider. Like most social relationships in Japanese society, the physician-patient relationship is hierarchical, with the physician in a superior position. As described previously, the patient hesitated to question the physician because he feared ruining his relationship with his physician.

Narratives by other nurses also included comments that indicated the physician's highly authoritative status in Japanese society. Often, patients view physicians as professional, authoritative, and omnipotent in the health care system. Physicians are respected in Japanese society because of the long history of higher education and the excellent reputation of a professional occupation. They assume a paternalistic role within the health care system. Physicians are perceived to have the authority to make all decisions relating to patients' health issues (Tierney, 1994). Nurses refer most decision making to physicians, reinforcing the public view of physicians as omnipotent, solo decision-makers within the health care system (Stein, Watts & Howell; 1990).

Since physicians are professionals and the experts in medicine, it is considered outrageous that patients or lay persons would question them or express their opinions to the experts. This perception can sometimes lead patients to tell the doctor they feel much better as the result of a physician-directed treatment, although they might tell the nurses that they don't feel any better. Similarly, patients may tell the nurses what they do or do not want in terms of treatment, but in front of the physicians, they are obedient to the physicians' suggestions. Within a hierarchical society, flattering the physician or deferring totally to the physician's advice and choice of treatment without expressing any personal opinions or desires appears to be a coping style for patients who are not in a position of control. By fulfilling the physician's pride and self-esteem, they are able to obtain, in return, the medical services they need.

Although the national health insurance system does not restrict which physician the patient can choose, patients usually stay with one primary physician throughout the course of illness. Once patients have their primary physician, they are loyal to that physician and attempt to maintain a good relationship with the physician at any cost (Ohnuki-Tierney, 1984). Although recently the number of medical lawsuits is increasing, Japanese patients remain reluctant to assert their equality and tend to stay in a subordinate position to keep a harmonious relationship with their physicians.

Nurses are taught that patients are the center of care and are on an equal level with any health care provider. However, nurses also know from experience that the patients do not view themselves as equal with the physicians, but often feel that physicians are superiors whom they must obey. Thus, nurses enact the role of advocates for their patients, because the patients are intimidated by the physicians and unable to express their opinions and wishes.

Patients' relationship to nurses. In contrast to the highly respected status of physicians in Japanese society, nurses' social status remains comparatively low. Although nurses often have intimate, sincere relationships with the patients, they are not based on respect for nurses' professional knowledge and expertise. The relatively low social status of nurses is thought to be due to the subordinate status of women in the society. Nursing is regarded as predominantly a women's job, and indeed 97% of nurses in Japan are women (Society for Study of Issues in Nursing, 2001). Nursing has been perceived as typical women's work that does not require any specialized knowledge or skills, something any woman can do without formal education. Until the last two decades, most nursing education programs were located in diploma schools. In Japanese society, the image of nurses was as physician's handmaidens with little academic education, rather than independent, well-educated autonomous professionals (Tierney, 1994). As the number of baccalaureate programs in nursing increased and higher education for nurses became readily available, nursing began to gain status as a professional occupation. Yet physicians are still viewed as the leaders in the health care system and nurses are viewed as their assistants.

Another factor that affects the status of the nurse in Japanese society is age. The average age of nurses engaging in clinical work is 36.4 years old (Japanese Nursing Association, 2002). In Japan, where seniority constitutes another social hierarchy and people respect others according to their age, young female nurses are not viewed as respected, mature, reliable professionals. The patients are often older than the nurses and have more life experience. Therefore, although the patients may feel sincere and close affection for a nurse, similar to what they may feel for their daughters, they do not expect young nurses to be a resource for discussing serious life and death issues. Several nurses expressed concern that they were not viewed as capable professionals by their older patients. GG is a 26-year-old who has four years of nursing experience.

> GG: I really want them to live as they wish until they die. I want them to die as they wish. But it is hard to help them to accomplish it. The patients who are dying are most of the time much older than me. They have a much longer history in the society, have established social status, and have been taking bigger responsibilities in the society. So it is impossible for me to understand all of that. I don't have enough life experience to understand and consider all of the responsibilities and implications they carry. Although I want to talk with them and help them to accomplish their life, I wonder if they would think, "It's a waste of my breath to share my concerns with a young chick like her," or, "There is nothing she can do to help me."

Another 26-year-old nurse described how difficult it is to elicit patients' real concerns.

> G: The people we deal with are not children. They are grown-ups. So they cannot

> throw their feelings and emotions straight at nurses who are their children's or grandchildren's age. I wish they could express their feelings more freely because they are in crisis and we are professionals there to help them. But they have to keep their dignity as mature grown-ups.

These two nurses exemplify awareness of a social norm that seniors should not act childish by openly expressing their feelings in front of junior members of the society, and that older patients believe younger people are too inexperienced to help them.

Physicians are respected, even if they are young, because of their professional authority and because they tend to be men. In comparison, nurses, who are primarily female and often young, are not viewed as strong professionals nor seen as having much authority. Patients, particularly older, male executives, proud of their high social status, may not perceive nurses as reliable resources for help with "important and serious" matters.

> W: There are some patients who do not want the nurses' intervention. They are usually men who work in government agencies and highly ranked positions. Men in their 50s or 60s, in the prime of life, tend to see us as just young chicks and don't want us to be involved in their care. . . . I think many of them want to talk to their primary physicians directly. In contrast, the patients in their 70s and 80s are mellowed down,

> and they will talk to us. But men in their prime tend to want to talk to the people in authority.

These concerns and stories about patients who spurn the nurses because of their youth were often expressed by younger nurses with less than five years' experience. Some nurses explained that they even use their age, gender, and junior status to demonstrate their respect for the patients' personhood. They play the role of junior members in the society to remind the patients what they have accomplished in their lifetime and to encourage them as mature adults to maintain their pride in their rich life experiences.

Although the nurses were frustrated by patients who would not rely on them as dependable professionals, not many of them try to persuade patients that they are capable of helping the patients with their quality of life. Instead, the nurses tend to let the patients choose the person with whom they feel comfortable communicating. If a patient prefers to talk to the physicians rather than the nurses, the nurses arrange it. The nurses think that everyone has a personal preference as to what to share with whom. Even among the nurses, it is not necessarily the primary nurse that patients feel most comfortable expressing their wishes or complaints to. The nurses do not mind whom the patients appear to respect most and with whom they communicate, as long as they are able to learn the patients' concerns and wishes through the persons the patients feel comfortable with.

The nurses are often proud that they know the patients better than any other health care professionals. This is usually the case because the nurses spend the largest amount of time at the patients' bedside and provide most of the direct, often very personal care to the patients, which leads to close, intimate relationships between nurse and patient. Because of the non-authoritative status of nurses and their maternal, friendly manner, seen as characteristically female, many patients feel at ease and are able to communicate with the nurses, revealing their sincere concerns and wishes. Conversely, in Japan, the primary physicians, who make the primary diagnosis, may have lifelong relationships with their patients extending through the trajectory of the illness (Ohnuki-Tierney, 1984). Thus, the physicians may have known their patients longer than the nurses, who meet the patients only when they are admitted to the hospital.

Nursing care is based on two-way interactions rather than unidirectional intervention from the nurses to the patients. Since it is reciprocal, nursing practice cannot be understood fully without an idea of how the patients view the nurses, what their expectations are of the nurses, and how they interact with the nurses. In that sense, exploring the patients' perceptions of their relationship to nurses is meaningful as a background. It must be clarified here that the discussion in this section is strictly from the nurses' perspective. In this study of nurses' ethical concerns and practice, the focus of interest is on nurses' views about how the patients perceive their relationships to the nurses, not on the patients' actual perceptions. For example, the perception that some patients disregard the nurses because of their age, gender, and nonprofessional status may be only what the nurses perceive and not the patients' actual thoughts. However, because the nurses do perceive these things, they affect nursing practice.

The patient-physician relationship is important background in another sense. In the hospital, patients are living in a web of relationships that includes not only the nurses but also physicians and other health care providers. In terms of medical treatment for illness, which is the reason patients have come to the hospital, physicians have the most power. The patients strive to maintain good relationships with their physicians precisely because the physicians have the power to determine their treatments. A part of nursing practice is case management, facilitating patients' relationships with multiple health care providers and allied resources. Thus the nurses' knowledge about individual patient-physician relationships forms a part of the background for the nurses' concerns and their practice.

Families of Terminally Ill Patients in Japan

As mentioned previously, the families of terminally ill patients play a major role in the end-of-life care within the Japanese health care system. According to anthropologist Ohnuki-Tierney (1984), the illness of one member of a family is an affair for the entire family, not for the individual patient. This is true especially when the illness is serious and close to the end of life. Family is the most fundamental group to which a patient belongs, and the cultural assumption is that a family is one entity. Therefore, there are no boundaries within a family, and close family members, usually the spouse, parent, children, or siblings, are assumed to be proxy decision-makers for the dying patient. Although the patient may be competent to make decisions, the physicians tell the family first about the patient's condition and ask their opinion about how much they want the patient to know.

The physicians assume the family will take the responsibility for decision-making because the family ought to know the patient best. They should know whether the patient can bear the very bad news of impending death or will give up hope. They should know if the patient is the kind of person who wants to know everything and make choices by himself or who leaves all decisions to others. As suggested previously, it is characteristic of Japanese society that individuals do not have much of a separate identity. There is not much privacy within the family group and strong privacy boundaries exist instead to separate the family unit from outsiders. It is therefore reasonable for physicians, as outsiders, to ask an insider's opinion about the patient's state of mind. Group consensus is very important in Japan, and the family needs to be consulted and come to a group decision that most of the members agree on. As a member of the group, the patient is expected to be happy and follow the group decision, with or without knowing what the decision was.

As described in many of the stories in the interviews, there are cases in which the patients' wishes are different from the decisions made by the family. Since Japanese nursing education is strongly influenced by Western nursing values, Japanese nurses' concern for respecting patients' wishes is more focused on the patient as an individual, separate from the family. Yet, because the Japanese nurses interviewed also live within the same culture, they understand and to a certain degree share the cultural norm regarding the role of a family as a proxy for the terminally ill patient. Thus, although the nurses are concerned with respecting the patients' individual wishes, their actual practice may be in conflict with that concern and they end up yielding to the family decision.

Who takes the representative proxy role among the family member is also an interesting issue. The responsibility of the family proxy is enormous. Historically such a big responsibility is assumed by the patriarch of the family. If the patient is a woman, her proxy is her husband, father, oldest son, or brother (Tierney, 1994). If the patient is a man, his proxy varies depending on the family. Often his wife is the primary proxy, but if she is old, too young or has always taken a submissive role in the family, the eldest child or other patriarchal figure in the family becomes the representative of the family who talks with the physicians. In two stories, it was the wife of the patient who made a clear and strong request to the physicians not to reveal the prognosis of impending death to her husband, explicitly because the husband would not handle the bad news appropriately. As Ohnuki-Tierney (1986) points out, women are often in charge of the health care of their family members with full responsibility for the patients, whether the patient is an infant or an adult man. Because these wives were in charge of their husbands' health and very sure that they knew what was good for their spouses, they were confident proxies. Therefore, although the person who acts as the representative of the family to discuss end-of-life decision-making with the physician may be the patriarch of the family, the actual decision may be made by a matriarch of the family who has full responsibility for the health care of the family.

Daily visiting by the family is common in Japan. As both Lebra (1976) and Ohnuki-Tierney (1984) observed, it was once typical for someone in the family (most of the time a woman) to stay in the hospital 24 hours a day to care for the patient's everyday needs. If there was no female relative to take this role, a subprofessional nurse *(tsukisoi)* was hired to substitute. Lebra wrote, “The existence of such a role indicates the deficiency of hospital facilities in meeting patients’ non-medical personal needs. It also suggests the Japanese patient’s inclination toward total dependency, necessitating such an overall caretaker" (p. 64). Both of their observations took place in the 1960s and 1970s, and the current hospital care system is different. The custom of *tsukisoi* may still exist in small rural hospitals, but since the 1980s most large urban hospitals have provided nursing care that includes personal care for each patient. The three hospitals from which the nurse participants were recruited provide comprehensive nursing care and allow family to stay with patients outside of visiting hours only when a patient’s condition is critical. Yet, as a residual from the custom of *tsukisoi* and the underlying assumption that the patients are totally dependent when they get sick, families are accustomed to visit the patient almost daily.

Usually a female relative visits the patient daily to check on the patient’s everyday life in the hospital. The family caregiver is not necessarily the family decision-maker. For example, the family decision-maker may be the eldest son, but the family caregiver may be the elderly wife of the patient, a daughter, or the daughter-in-law. Caring for her parents-in-law is an expected role for a wife.

Because the family caregivers visit almost every day and play a large part in the patients' life in the hospital, the nurses have more of a chance to develop a relationship with these persons and tend to include them in the care for the patients. The nurses' care for the patient sometimes extends to the family caregivers, too. The interviewed nurses often expressed their concerns for the family caregivers in addition to the patients. Some nurses thought it was a good case if family members were satisfied and happy that they had provided the best care for their loved ones, regardless of the patient's own experience. In these cases, the recipients of the nurses' care seem to be the family members rather than the patients.

Because of the borderless Japanese family relationship, the health care providers assume that the family decision-making is more important than the patients' individual wishes. That is, if the family members are happy and satisfied, it is good for the patients, as well. Needless to say, not all families follow the traditional cultural norm of family decision-making. In contemporary Japan, typically in urban areas, traditional extended families with close bonding are decreasing and nuclear families are increasing. People's views of family, the individual, and the relationship between the two are also changing as the structure of the family changes. There is more diversity in family relationships, which range from the traditional group-oriented family relationship to more individual-oriented relationships. But the traditional family relationship remains important.

Although not often described nor explained in the nursing literature because the content of Japanese nursing literature is predominantly imported, nursing care for Japanese patients in actual clinical settings requires a sense of the role of family in the culture and society of Japan. Most nurses understand the traditional patient-family relationship through their professional or personal life experiences. Their descriptions of the patients, their family relationships, and nursing interventions with the families indicate that the nurses take into consideration the traditional patient-family relationship as a baseline family relationship in Japan. Family involvement was mentioned in many stories about end-of-life care in the interviews, which implies the importance for the nurses of involving the families in end-of-life care. In order to understand the nurses' concerns and practices, it is therefore meaningful to explore the Japanese patient-family relationship to understand the insights the nurses have about the families of terminally ill patients in Japan.

These characteristics stood out in the interviews as prominent background meanings framing the nurse participants' moral concerns and ethical practices in end-of-life care. Because everyone is different, what constitutes the backgrounds of the patients and their families and what backgrounds of the patients or the families have significant meanings for the nurses vary in every situation. In addition, the bases of the background meanings for the patients and their families are not limited to those mentioned above.

Nurse-Physician Relationship

As background for nursing practice, the relationship between the doctor and the nurse cannot be overlooked. Although they are two dominant health care providers in the Japanese health care system who are sharing the same worksite, nurses do not tend to see their relationship as friendly or equal (Aroskar, 1985, Benner, Tanner & Chesla, 1996; Kojima, 1997; Stein, Watts & Howell, 1990). Compared to the U.S. health care system, the more formal hierarchy of Japanese society is reflected among the multiple professionals in Japanese health care. Physicians occupy the highest position in the system, and nurses and other disciplines are subordinate. In Japan, the heads of hospitals are physicians, and therefore physicians are often the employers of the nurses, too. In addition, nursing education was historically placed under the medical system, and nursing is often viewed as a dependent occupation directly belonging to medicine. As the system for nursing education has changed, education was separated from governance by hospital owners, and the number of baccalaureate nursing programs increased. These college and graduate-level nursing programs emphasize independent autonomous practice as a professional, not as a subordinate of physicians.

However, actual nursing practice in clinical settings seems to be far from the independent autonomy that nurse scholars envision. In part this is due to the legal definition of the nursing role in Japan. The Japanese nurse's role in law is "assisting medical treatments, and care for patients during convalescence" (Article 5, The Public Health Nurse, Midwife, and Nurse Law, 1948). Licensed physicians are the only people who can provide medical treatments, thereby restricting related nursing practice to physicians' orders. Legally, Japanese nurses are obligated to both physicians and patients. Moreover, even many nursing care practices for ill or injured patients, such as bathing, diet, and rest, are often included as a part of the medical regimen and require physicians' orders if the patient is hospitalized. Therefore, nurses cannot be independent from physicians' orders (Kojima, 1997).

Although it was not the focus of this study, physician involvement in nurses' practice was evident in many of their narratives of end-of-life care. Their relationship to physicians will be discussed in three dimensions: (a) how and why nurses and physicians collide, (b) why nurses follow physicians' orders, and (c) nurses' strategies for dealing with physicians. Examples of narrative data and commentary illustrate how the nurse-physician relationship affects nursing practice.

How and Why Nurses and Physicians Collide

I: He had metastasis, bleeding, his kidney was going bad, his kidney started failing to function. We wondered how much chance of survival he had. But I remember that they [physicians] decided to do everything. Because he was hospitalized for the purpose of detailed examination for paralysis in the first place, his family requested full procedures to save him. He was drowsy and we could not confirm his wishes. The doctors were like, "We will do everything, needless to say." I wondered how likely he was to survive, with intubation and everything. They said, "Without doing it, we'll never know [if he can make it]." That is true, but. . . . In our unit, we usually do everything until the very last minute. I don't know why, but they [physicians] do [everything].

IN: So when nurses ask the physicians why they do that, what do they say?

I: They say, "Because we don't know the cause, we just do everything until the end." I was like, "Huh?" I really cannot accept that. Because we don't know the cause, we do everything, and then we may find something. But by the time we find something, it could be too late. Sometimes, the reasons the doctors give me absolutely do not make any sense. During the very terminal phase, patients sometimes want to eat this or that. But the physicians' order is NPO [no food per oral]. "What? He is terminal!"

> I will think. "Doctor, does he have any chance to survive? Do you think he can go home?" I will ask. The physicians do not think he can recover or go home either. But if I tell the doctor, "The patient wants to eat ice cream," the doctor will say "No!" I ask why, and he will say, "He would aspirate." I have quarrels with them sometimes, saying, "Why can't he eat ice cream?" Although he is at the very end of his life, doctors will say, "As a doctor, I cannot allow him to do that [eat ice cream and take the risk of aspiration]." I wonder if they have a different view. I wonder, for them [the physicians], if treatments have the most priority. But I cannot stop thinking that this is the end of his life, we don't know how long he can live, so why shouldn't we grant his little wishes?

This narrative includes several aspects of nurse-physician relationships. Ideally the nurse and the physician are two discrete professionals who have their own goals and missions. But typically in hospital settings, both are serving the same patients. When two different groups with different viewpoints and different goals work in the same place for the same patients, it can lead to collisions, with each group competing to see whose values will dominate. Conflicts between nurses and physicians are usually settled by the traditionally supported superiority and legal authority that physicians have in Japanese society, as demonstrated in this excerpt.

The narrative indicates the area where both nurses and physicians have interests and responsibility: the patient. In the situation Nurse I described, the physicians' priority is to find out the cause of the patient's problem and treat it, even if the patient is terminally ill and there is no possibility for survival because treatment comes too late. The nurse's concerns here were respect for the patient's wishes and comfort.

Another example of conflicting interests appears in the second half of the narrative. Although nurses claim that caring for people through supporting their lives is a nursing responsibility, and this view is assured by the Japanese law, this nursing practice is often restricted by medical orders in hospital settings. Patients' fundamental everyday life care in the hospital, such as bathing, diet, rest, and activity, all requires physicians' orders. Usually physicians leave this care in nurses' hands. If everyday life care has any implications for treatment or disease status, physicians step in and write orders as a part of medical regimen. In the narrative above, the judgment of whether to allow the patient to have ice cream was in the physicians' domain. While the nurse was concerned about letting the patient have a pleasant time at the end of his life, she could not act on her concern because of the dietary restriction from physicians, whose concern was prevention of any adverse events that might threaten the patient's life.

The physicians' and nurses' different viewpoints appeared in other interviews as well. "The doctors in my unit do not have much interest in patients as persons. They are very much interested in treatment though," said one nurse. She found it easier to work with these physicians most of the time, because they let nurses do nursing care related to the patient's personal life as they liked unless it had any implications for treatment. Another nurse said that in her unit, the physicians and nurses share the same goal for the patients in the end-of-life care situation:

> U: About the patients in this unit, we don't have the situation [in end-of-life decision-making] where the physicians and the nurses have different opinions. The patients go to heaven anyway, so let them go without too much suffering. It is good. This is the opinion of the doctors in this unit, and our [nurses'] opinion, too. Then the family also says, "Don't let him suffer." Then it goes very smoothly, just watching. We don't stop IVs, but take out other tubes. Everything else just goes naturally.

The following short episode from another nurse describes the different approaches of the nurse and the physician to a patient's terminal illness, and how the difference caused conflict between them.

> S: It was recurrence of her cervical cancer five years after the treatment, and it wasn't that the physician was negligent in following her up. For us [the nurses], there was not much choice, so we thought we should focus on helping her to live a good life until the end. But the physician said he could not tell her [that she had recurrent cancer] because it made him feel like he was abandoning her. Maybe, I guess, he did not want to be a bad guy as a physician.

The nurse's approach to the patient at this stage of illness focused on having meaningful time. In contrast, the physician's focus was on the recurrence of the cancer that he had not conquered. As a physician, he felt a responsibility to keep her under his medical care and not give up her treatment, instead of letting her choose how she wanted to live the rest of her life. Because of this view, the physician did not reveal the prognosis to the patient, which resulted in limiting nurses in their practice.

Another area of nurse-physician conflict in end-of-life care is symptom management. Nurses are usually the ones who stay close to the patients and see them suffer. In addition, nurses are often the ones who carry out the physicians' prescriptions to alleviate symptoms. Nowadays, most symptoms are managed with medications, and prescribing medication is physicians' domain. Although physicians must write the prescriptions, symptom management relies heavily on nurses' ability to evaluate and intervene. Because they closely watch patients and how they respond to interventions, nurses often have a clear idea what method works best to alleviate a patient's symptoms.

> B: There was a patient who could not sleep at night because of the pain. I would tell his physician, "Doctor, if it is cancer pain, what do you think about using morphine?" but it takes a lot of strength, it takes a lot of courage. It is not so bad here [in this unit], but we did not have an easy atmosphere for talking to physicians in the unit where I used to work. There were many times physicians reacted like, "Why do I need to be told about a prescription for morphine from a nurse?" So, to say that to the physicians, it takes a lot of courage. But if I don't talk to the doctors, it is cruel to the patients. Because the patient has so much pain that he cannot sleep at night, we have to tell the doctors regardless of how much we [nurses] are dumped on by physicians. So we collect all the courage we have and go to talk to the physicians. Well, of course, not all doctors are like that. There are some doctors who listen to us and say, "OK, let's start the meds," too.

This situation exemplifies what Bishop and Scudder (1990) call the in-between situation of nurses. As they quoted from Engelhardt's 1985 article, nurses are the "people in-between" because their practice needs to meet demands from two powerful individuals: the patient and the physicians. Bishop and Scudder argue that the physician has power from his authority in health care, based on his greater knowledge and technical skills in medicine and his legal right to prescribe drugs and perform lifesaving procedures, and "the patients have the right to decide what they will allow to be done to them" (p. 20). But in Japanese society, where not many patients acknowledge their right to make decisions about their medical care, the in-between situation for nurses occurs between the physicians and the nurses' sense of moral obligation toward the patients. In other words, the patient's right is embedded in Japanese nurses' moral concerns as a taken-for-granted assumption, and the nurse's concerns lead her to step into the physicians' domain of medication prescription.

In summary, nurses and physicians are separate professionals and often have different goals and concerns, yet both groups serve the same patients. When the practice of one group restrains the practice of other group, the two professional groups collide. Then they have to find out how to compromise.

Why Nurses Follow Physicians' Orders

No narratives in the interviews described a nurse who disregarded a physician's order to execute her practice. When physicians' orders conflict with nurses' concerns or restrain the nurses from acting upon their concerns, nurses either defer to the physicians or try to negotiate with them. When nurses defer to the physicians, some resent it and feel powerless, while other nurses accept it without difficulty as a rule in the health care system.

There seem to be several reasons why nurses' follow physicians' orders. The most frequently mentioned reason was that nurses should not step in the physicians' domain. For example, providing medical information and treatment options to patients and their families is a physician's role. Nurses can only repeat what the physician has already disclosed, without disclosing any more information. The strong sense that physicians limit what nurses can tell their patients and families was expressed in narratives such as the following:

> CC: It was difficult to explain to the family [about the patient's condition and prognosis].
>
> IN: What do you mean it was difficult?
>
> CC: First of all, it is physicians who explain [to family] primarily. So I think I should not tell anything that deviates from that. I should not explain what I think ahead of the physicians. If the physicians have told [only] this much, I should stay in that range.

In this case, the physician's explanation to the family did not agree with the nurse's understanding of the situation. The physician's explanation made the family think the patient would recover, whereas the nurse knew the patient was terminally ill. Therefore, when the family asked Nurse CC about the condition of the patient and what would help the patient to recover, she had a hard time staying within the physician's explanation and giving her opinion without contradicting what the physician had said.

Many other narratives suggest an unwritten but clear rule that patients and families should not be told any information regarding their conditions, prognosis, or treatment options that the physicians have not already disclosed.

> S: Fortunately, for this patient, all the timing [to move to a hospice facility] worked out well. So I think she was able to have a very good time at the end of her life. That is why I remember her well. I think it would be best if we could provide that kind of care [hospice care] in here, too. But not many patients are able to collect enough and appropriate information about hospice, and it is difficult for physicians to give information about that [hospice] to patients, too. And nurses cannot give information that the physician has not told the patients.

> I: I wish they [the physicians] would tell the family about the disadvantages of doing that [intubations and putting the patient on the respirator], too. But somehow, they

> manage to lead the family in the direction of doing everything.
>
> IN: When you see such a situation, and as a nurse, you can see the adverse effect of the intervention, do you talk to the family about your concerns?
>
> I: I talk to them some, it does not mean we [nurses] don't talk to families regarding that. But if it is a decision about treatment, it becomes the physician's domain; our involvement, the involvement of the nursing side, becomes weak.

These two narratives provide examples of how the nurses view the physicians' domain as something they should not infringe upon.

Even when the nurse has a different idea about what information may benefit the patient or the family, based on her knowledge about them and her moral concerns, the nurse often feels she cannot give her opinion without consulting or obtaining permission from the physician.

> IN: A while ago, you said these are not things nurses could tell patients, if the physicians had not told them. But is it bad for nurses to talk about these things, not the treatment choices, but other kinds of options [such as hospice],and possible or potential ways of spending meaningful time, to patients when the physician have not?
>
> S: That is something I really have trouble judging. But I think I cannot tell them

> without notice to the physicians. I think it would be OK for nurses to tell patients these things, when both of us [nurses and physicians] acknowledge that we have different views. Telling patients just based on my judgment, without notifying physicians, is not a team approach, I think.

Although this nurse implied she would tell her opinions to the patient after notifying the physician, regardless of the physician's response, she did not have stories in which she actually put this view into action as she rationalized it here.

Many nurses perceive the physician's authority as sacred, and feel they should not or cannot intervene in such physicians' domains as information disclosure, treatment decision, and medication prescription for symptom management. Through experience, the nurses learn that the physicians' authoritative domain is hard to violate. For example, the following nurse learned from how the physicians responded to her question regarding pain medication.

> B: There are bad feelings when they respond. I may say too much. Probably I should stop just saying, "The patient cannot sleep well because he has pain." I wonder if I have a bad habit of saying too much. I go too far, like "How about pain medicine? If it is cancer pain, what do you think about morphine?" If someone told me that, well, I am not a doctor so I really can't tell, but I would listen to her, so I [as a doctor] don't

> have any trouble [hearing it]. But for the doctors, they may think it is discourteous or impertinent that nurses say something to them. I often wonder. So I always hesitate to say something to the doctors. I think it is good if we, doctors and nurses, can talk normally and understand each other's opinions, but the reality is like what I described. I feel there is a hierarchy, thus there is hesitation and diffidence. I feel bad—it is just temporary, but it is an unpleasant feeling. They respond by hurling rude words, and it is unpleasant.

Experiences in which the nurse was intimidated made her hesitate to negotiate with the physicians. Now, she does not want to confront them with her opinion. Another reason nurses are often reluctant to ask physicians to disclose more information to the patients and families that will facilitate nursing intervention is the perception that the physicians will not change their approach even though the nurses ask for it.

> R: It may be just me. The way I said it might not be good either. Anyway, when I asked the physicians, they did not respond as I asked or they told me straight off, "No way!" without hearing my side of the story. Because of these experiences, I started to think that it is useless to talk to the physicians.

Some other nurses said they follow the physicians' orders for the benefit of the patients. One nurse talked back to a physician when she found out he had ordered an unnecessary painful examination for a dying patient. But the physicians did not change their order "once they've decided" to do the procedure, and the nurse chose to assist for the sake of the patient's comfort, not because she agreed with the physicians' decision.

> N: Why did he need to give her pain? . . . "Isn't she dying?" I told him straight. But the doctors do it anyway. Once they've decided, they do it. I told them I refused to assist with the procedure. But I have to assist them, because I know I can make it easier for the patient.

Another nurse did not explain a patient's suffering condition to the family members as this would have contradicted what the physician had told them, both to protect the family and the patient, and to protect the physician. When this patient's respiration dropped suddenly, he was intubated and put on a respirator, which was against his wish, but in accord with the family's wish and appropriate treatment according to the physician.

> Q: I wanted to explain that [this condition must be very painful for the patient] to the family. But I did not tell them because I thought it would be hard for the family, because it meant negating everything we were doing [in accordance with the family's wish] then. So it was a big dilemma for me. I just tried to convince myself, "It is good,

> because the family think it is good." The doctor told the family, "He does not look like he is suffering" or "He looks comfortable." I could not say something that was dead against what he said. If I did, the family would distrust medicine. . . . I thought it would be cruel to the family to have the physician for an enemy. After all, it is physicians who give treatment. So if the nurses set them up to make an enemy of the physician, it would be against the patient's interests.

The relationship between the family and the physician was complicated by the dishonest and defensive behavior of the physician, who was afraid of a lawsuit by this family. The nurse tried to cover the physician's inappropriate explanations to the family by restating them again in terms of benefit for the patient within the range of what physician said, although she did not agree with his explanation. She covered the physician's poor practice based on her concern of protecting the physician, the health care team, and the hospital from a lawsuit. She said, "I think it is not good we are sued." It is interesting that her concern of protecting the physicians and hospital reputation was seen in the ANA Code of Ethics up until the late 1950s as nurses' responsibility (Arosker, 1985). There may be a tacit moral rule in nursing culture that nurses ought to protect the physicians and their health care team.

Another reason why the nurses defer to physicians' decisions is their respect for the knowledge physicians have. A nurse told a story about being unable to stop a physician from poking a dying patient every day to check blood gas data, because she could not refute his medical knowledge.

> Q: I asked him, "Doctor, please stop it." But he said the patient would be more comfortable if the blood gas level was adjusted.
>
> IN: Is it more comfortable?
>
> Q: I don't know. It may be something like blood infusion makes patients with anemia feel better although they may look like they are unconscious. I wonder, maybe. If he says so with that much confidence, I cannot [say any more]. I did not study medicine, so I am in a weak position to talk back. I cannot talk back to him just with nursing observations. I wonder if it might be more comfortable if the data improved. It might be true, if he said so. But do we need to go that far? Well, I also know it is not my decision how far we should go. If the patient really gets comfortable, it would be a good thing though.

Compared to nursing, medicine has a much longer, more prestigious history as a science and an academic discipline. To enter medical schools, students must have much higher scores on their entrance exams than for many nursing schools. As a result, there is a general belief that medical education is superior to any knowledge nurses have. Therefore, the nurse felt that if the physician was speaking based on his knowledge from medical school, any knowledge from her experiences and observations were inferior.

Some other nurses also mentioned they yield to the doctors because of their knowledge and experiences in practice.

> AA: If I ask why we use a certain medicine, or is this medicine really necessary, the doctor will give me his reasons and his thoughts behind the prescription. And he is in his 40s; he has much more experience than me. So I tend to defer to him. I have my opinion, but so does the doctor. I am still inexperienced and cannot see the bigger picture, so I listen to the doctor and would be convinced.

Another nurse described how she yielded to the physician's decision when the physician had a longer relationship with the patient and knew the patient better than the nurses did.

> M: For some patients, like liver patients, the doctors have a long relationship with their patients, like for 10 years, 20 years. So the physicians may know the patient and the relationship between the patient and his family much better than we [the nurses], who meet the patient for the first time during his hospitalization. So I think sometimes, the decisions the doctors make are based on their better knowledge of the patient and

> the families, and may be better [decisions].

The nurses defer to the physicians' practice even though their moral concerns contradict the physicians' orders. The reasons they defer vary. Some nurses learn from bitter experience that they would be intimidated or ignored. Other nurses give up because they know the physicians won't change orders simply because of a nursing request. Nurses follow physicians' orders for the sake and benefit of the patient. Nurses also feel responsible to protect physicians and the health care system they belong to. Finally, nurses follow physicians' orders out of respect for the knowledge physicians have.

Nurses' Strategies to Deal with Physicians

In the narratives from the nurses in this study, the nurses always yielded to the physicians' orders and practiced within their restrictions. They also approached physicians with their concerns in an attempt to advocate for their patients. Because the nurses intrinsically accept the social status difference between themselves and physicians in the health care system and recognize they should not directly express opinions that infringe on the physicians' domain, they use several strategies to deal with physicians.

> P: I often have a clear idea what I want them to do. For example, it may be time to change Lepetan to morphine. But if I say it directly, it will hurt their feelings. There

> are still many doctors like that. They don't want to be told what to do by a nurse. Therefore, depending on the doctor, sometimes we negotiate indirectly from the side. If the doctor can listen to nurses as just one opinion and talk, we may ask straight though. [Pause] Yes, it varies with the doctor's character. For some doctors, even if he has the same opinion as the nurse, if the nurse initiates the idea first, he rejects the idea just because the nurse addressed it first. Things like this happen. So it is a complicated matter. . . . In my opinion, from my experience, although it depends on each doctor, after all, it is easier to be heard if I say it indirectly rather than directly. I agree, telling them straight is best, but we have to keep good communication with them, too. If we keep telling only our opinions, it will not go well. I guess I am concerned that our communication becomes worse [if the nurses keep telling only their opinions]. Even with an indirect manner, as far as we understand what the physicians are thinking and they listen to us a little bit, I think it is fine.

The same nurse talked about a combined strategy of laying siege to physicians while timing and repeating requests: "If I talk to the doctor one on one, it is rarely heard. But if we talk with all the staff together, the physicians tend to accept better." To this end, the nurses held a conference with all staff members, a nurse manager, and all the levels of physicians involved in a particular patient's care, especially the physicians who have authority to make decisions about the patient. Although they might ignore just one nurse's opinion, physicians tend to listen to nurses' group opinions. If the needed change were not urgent, the nurse said she would take time to negotiate with the physician, starting with dropping some hints, nudging the physician gently, then continuing to report the situation where the nurse thought the physician needed to modify his order.

Nurses sometimes try to communicate with physicians by talking their language. One nurse's detailed description about how she managed to have a physician come to the unit to change an order and talk to the patient's family on a weekend shows her effort to see the patient in the way a physician would see him. She set up the situation to make him feel he needed to come in by using the objective language that the physician spoke.

> H: When I was working night shift, he had more shortness of breath [SOB], accordingly his oxygen needed to be increased. I called his primary physician at 7 o'clock in the morning and told him about SOB. Their meeting [where the physician would explain to the family the patient's condition and the fact his death was close] had been scheduled for 14:00 [2 p.m.] that afternoon, but I thought we could not wait until then. I called the family before calling the physician, told them his condition

was getting worse and asked them to come in 9 a.m. instead of 2 p.m. Then I told the primary physician that the family was going to come in at 9 a.m. I asked him, if it is possible, please come in around 9 o'clock and see his breathing and give us an order. . . . When I called him, he said he would come in 9 o'clock. He is the kind of doctor who does not come in most of the time, but he came.

IN: How did you bring it up?

H: Well, I reported the patient had seven liters [of oxygen] the day before. At that time he did not have SOB, but the primary physician was in the unit then and said he might develop atelectasis and heart failure. He left after he ordered prednisone. The patient went through evening shift with seven liters of oxygen. During the night, he became unable to cough out sputum, so I did suctioning. With suctioning, he dropped to the 70s [oxygen saturation]. After the suction he had prolonged shortness of breath, and because he did not recover, I increased the oxygen. I could not hear the air in his lungs well. His volume of urine decreased. I reported those objective facts. I also mentioned changes in the ECG monitor, and I also guessed that he [the physician] would take an X-ray. And I said he ordered prednisone, but the order was for 14:00 every day. I did not know why it was a fixed time, but I thought if he was developing

> atelectasis or pneumonia, prednisone would help a little. I wanted to ask about that, so that I waited until 7 o'clock and called. I reported the conditions and obtained the order for an X-ray and immediate prednisone and antibiotics drip. In addition, I told him that I would look out for the effect of prednisone, but please come in soon. Because there was no DNR (do not resuscitate order) and confirmation from the family, I judged we could not wait until 14:00, and asked them to come in early. There was nothing we could do without the family. I confirmed the time the family was able to come and told the time to the doctor.

It is very interesting to note the differences between how the nurse described the condition of the patient to the physician and how she described her experience of caring for this same patient. In her story about her care, her focus was more on the patient's subjective sufferings and feelings, how to make him comfortable, and how to respect him as a person. Her report to the physician, however, was limited to objective data designed to appeal to the physician and prompt him to make a decision. She waited to call the doctor until it was a reasonable time. She called the family and asked them to come in earlier than scheduled, before she called the physician. By timing and facilitating everything for the physician, she set up the physician to do the things she wanted him to do.

In addition to trying to use the same language to communicate with the physicians, some nurses said they would talk to physicians using the words of the patients or their families.

> O: How to deal with the physicians? I would tell them, "The patient said he wanted to do this." The nurse is just advocating for the patients' way of thinking. Don't tell them the nurses want to do this. Tell them, "The patient wants to do this," or, "The family wants that." Having told them what the patient/family wants, ask the physicians, "Do you choose what they want, or chemotherapy?" Nowadays, the physicians are getting weak, trends in medicine are changing. So the physicians do not force them to do chemo if the patients or the families don't want to.

Her point was that the physicians may not like what is suggested by the nurses, but they would listen to requests from patients or their families.

Some other nurses chose to ask senior nurses, the chief nurse, or a nurse manager to negotiate with the physicians. Particularly, younger and inexperienced nurses think physicians would pay more attention to more experienced nurses.

> AA: In our unit, nurses are confident about our thinking. The nurses know how to convey our opinions: assess the timing, who is the best person to tell them [the

> physicians], whether it is better to break it down into several times, whether it is better to wait and see, and so on. Especially the nurse manager and the sub-manager, they are really good at it. We, younger nurses, see how they deal with it, then we learn whether it is something I can tell the doctors by myself, or if it seems to be difficult, then I would ask senior nurses to tell the doctors.

Senior nurses are respected for their clinical experience not only by younger nurses but also by the physicians, particularly young and inexperienced physicians such as residents. Therefore, suggestions from the senior nurses are often accepted with respect. Chief nurses and nurse managers often have a little bit more authority than the staff nurses because of their administrative and leadership position in nursing. Some physicians attend more to the suggestions or opinions from those nurses because of their respect for the title. The nurses are aware of the authority that experience and titles add. They utilize the additional power of some members within the nursing group in order to negotiate with physicians more effectively.

Despite the claim of nursing independence from medicine, the fields of practice overlap. After all, both nurses and physicians serve the same patients. In addition, Japanese law places nursing in a subordinate position to medicine. In such a social context, the nurses defer to the physicians' decisions and orders, while they also continue to negotiate with physicians to alter medical decisions for their patients' benefit using various strategies to find common ground between the physicians' goal of practice and the nurses' concerns. Without understanding the background meaning of the nurse-physician relationship, therefore, it is difficult to fully grasp what it means to be a nurse in a Japanese hospital and the context of nursing practice.

Summary

The purpose of this chapter was to describe significant background meanings in order to understand the nurse participants' moral concerns and practice through their narratives. Because nursing care is developed and provided within a web of relationships with the persons the nurses are working for (the patients and their families) and the persons they are working with (health care providers such as other nurses and physicians), the meanings these people have for the nurses are the critical backgrounds. Therefore, the backgrounds discussed in this chapter were divided broadly according to the people involved. Of course, the relevant backgrounds are not limited to the issues mentioned above. Japanese culture and the society in general make up the larger context of the phenomena, yet to keep the background meanings close to the specific focus of this study, general description of the

Japanese ethos was avoided. Instead, cultural and social characteristics that directly describe related background meanings of each human relationship were included.

Narrative data were used to illustrate why certain issues appeared as significant backgrounds in this study and how these backgrounds related to interpretation of the nurses' concerns and practice. Without comprehending the meaning of a nurse's relationships with colleagues, patients, patients' families, and other health care providers, it is impossible to apprehend what nurses' concerns are and how they dictate practice. In the next chapter, nurses' ethical practices are described. Nurses' ethical practices are derived not only from the moral concerns described in Chapter IV but also from the background meanings that determine what the nurses do, as discussed here.

Chapter VI: Results and Discussion:

Nurses' Ethical Practice in End-of-Life Care in Japan

In this chapter, ethical nursing practice in end-of-life care will be explicated from the nurses' narratives about everyday clinical experiences in Japanese hospitals. The nurses' moral concerns were uncovered in Chapter IV, and the backgrounds that shape what matters to them and how they practice were described in Chapter V. However, during this study the actual interpretation and understanding of the concerns, background meanings, and practices did not happen in this linear order. Because nurses' moral concerns, not abstract ethical principles or general justifications but what really matters to them in the clinical situation, can be grasped most vividly in the actual actions taken in a particular situation, many of the moral concerns discussed in Chapter IV were extracted from interpretations of moral practices in the narratives. Further deliberations about why a situation matters to the nurses and why they employ certain acts clarified the prominent background meanings undergirding the nurses' views. Understanding of the background meanings in turn opened more possibilities for other interpretations. This endless, circular interpretation process is called the hermeneutic circle.

The hermeneutic circle appears in the writing of this study, too. On a larger scale, it is possible to see that uncovering concerns from practices, as described in Chapter IV, is one arc in the circle, and the second arc in the circle is understanding of practices by projecting the concerns and backgrounds, which is going to be undertaken in this chapter. Smaller-scale circles also reappear in this chapter. My interpretations are a series of circulatory projections and uncoverings in the narratives of practice and its contexts, rather than a dissection of the phenomena into pieces. Therefore, my interpretation of nurses' ethical practice will be best laid out by following the same reflective circulatory process.

Ethical Practice in End-of-Life Nursing Care

Ethical practice in this study is defined and captured as nursing practice in which the nurse felt she had done good or acted rightly. “To do good” means the nurse has contributed to the good of others, particularly of the patients or their families. “To act rightly” means the nurse has carried out the actions that she is expected and obliged to take. However, because most acting in the world occurs in a smooth, nonreflective way, the nurses’ acts are often immediate responses to a situation. They may not have cognitive reflections about their ethical practice (Benner, Tanner & Chesla, 1996; Benner & Wrubel, 1989).

Thus, in an attempt to solicit the ethical practices socially embedded and often taken for granted in the nonreflective moral culture of nursing, the nurses were asked to tell their stories about experiences when they felt good or bad, right or wrong. Although terms such as "nursing ethics" and "ethical practice" were used in the title of the study and the written informed consent shared with the participants, these terms were not used in the actual questions during the interviews. Instead, the nurses were asked to describe "memorable experiences" in the sense of good/bad or right/wrong, and these stories have been interpreted and extracted with considerations of their ethical meanings in nursing, their backgrounds, and their contexts. If the outcomes when the nurses felt good had nothing to do with the presence of the nurses, the narratives were not regarded as stories about ethical nursing practice. What makes certain practice "ethical" will be discussed extensively in this chapter with the aim of understanding nursing ethics in end-of-life care in Japan.

Many of the narratives describe practices that incorporate the notion of ethics, that is, good/bad and right/wrong, in nursing specifically related to end-of-life care in Japanese hospitals. In an effort to capture the complex and often nonreflective nature of ethical practice, two paradigm cases that typically explicate the ethical practices will be presented followed by an interpretive analysis. Various supportive and counter exemplars will be added for further illustration and to expand the reader's understanding beyond the paradigm cases cited.

Paradigm Case: Taking Her to a Hot Spring

This is an account from a 27-year-old nurse about a patient who was most memorable for her.

> DD: It was a lady about 50 to 60 years old, she had a daughter who was about the same age as me, and she was always there with the patient. I don't remember what her exact diagnosis was though. Her symptom was general fatigue and she lay in bed almost all the time. Usually patients have many complaints, like suffering and so on . . . but about this person, the only thing she worried and complained about was BM [bowel movement]. She said to us, "I want laxatives this much today," or something like that so many times that nurses tended to think, "She only talks about BM, she is fixated on such a trivial thing." The nurses took her too lightly, like "OK, OK." . . . But I thought it was kind of cute [laugh]. I also wondered if she might have any other concerns or anxiety that she was not clear about by herself, and therefore she worried about BM so much. So I tried to listen carefully to her complaints about BM. Then she said something like, "I have never been listened to like that before." Because she had never been taken seriously and always told, "OK, OK," she said, "I am so happy [to be listened to]." Then she started to open her heart to me. We got

along well and became close. But her condition started failing. Around that time, she wanted to go on a little trip to a hot spring with her family for the last time. She kindly asked me, “I want to go to a hot spring in Hakone. Can you go with us?” She was really going downhill very quickly. She became unable to stand up, and she was not in a condition to go on a trip. But she had hope, and she was making a plan, who will drive, who is going to ride in whose car, which hotel to stay in, what dinner we would order. . . . Because she was making the plan with her whole heart, although I knew it would be impossible, I told her, “I can take a day off on this date, so let’s go on the trip together.” Usually a nurse doesn't go on a trip with her patient, but I promised her I would. About the night after the day when she was making all the plans, her conscious level started dropping, and within the next couple of days, we sent her off [she passed away]. So I have this memory about this person. Her daughter was there all the time, and she said, “It was very good she [her mother] had someone she could have a heart-to-heart talk with. We are very glad she came to this hospital.” That was the most memorable patient and thing that happened. . . .

IN: . . . How did you listen to her complaints about BM?

DD: How? Maybe something like, “You worry about it, don’t you? I know it does not

> feel good. It is not fun to spend all day worrying about it, so let's talk about it whenever you feel you need to." It was just a usual conversation, but I think I tried to acknowledge that she worried about it, and tried to think it was important because she thought it was important. Although, for us, it was not a major problem, it was not a big deal symptom at all.

The family of this patient had been very defensive at the beginning and prone to make cutting remarks about health care providers. The nurse guessed that they had had unpleasant experiences in the former hospital where the patient was admitted. For most of other nurses, the defensive attitude of the family was a more prominent problem than the patient's complaints about a minor problem such as her BM. Eventually, when the family saw the patient was happy and got on well with the staff in this unit, they loosened up. The nurse also talked about the patient's death.

> DD: I was able to take care of her when she died. She talked about the trip a lot. After she became unconscious, I said to her family that it was good she had a hope to go to a hot spring with her family. She was surrounded by her family and I was there, too. After she died, she died really quietly, I just thought of letting her to go to the hot spring. Then when I called the resident doctor's home to ask for a pronouncement of

> death for this patient, I asked him if he had any hot spring bath salts in his house. He searched hard in his house, and we, I, with her family, gave her a hand bath, foot bath, and bed bath with the bath salts he brought. We all felt good that she could "go to the hot spring" and said goodbye to her. One more thing, she wanted to go to the chapel [in the hospital], and I was thinking of taking her there. But when I asked her, she said, "I don't feel good today, so not today." Then that night, she became unconscious. So she could not go to the chapel. We talked about it and thought it would be nice if she could go there, too. I thought we might be able to take her there even on the bed after she passed away. But at that time, the door was locked and we could not do that [laugh]. Something like that, even though it was a bit late, the family was able to grant what she hoped for and what she wanted. There was a very good atmosphere. At that time, for the very first time, her daughter, who had been very defensive [against health care providers], said to me in tears, "My mother was very happy to meet you." I felt so reassured and happy when she said that.

This paradigm case includes many aspects of ethical nursing practices. The nurse felt good that she was able to connect and build a good relationship with the patient, that the patient was able to have hope in her very last days, that the patient's wish was granted, and that the family was happy because the patient was happy in this unit. Nurse DD was able to bring the physician into her caring activity. Her concern for this patient's complaints about BM was not restrained by the team consensus of the other nurses.

Now, looking at this story as a paradigm case of ethical practice, my question is, what makes this nurse's practice for this patient ethical? How did this ethical practice happen? When I asked the nurse what was good in this case, she was able to explain why she felt good by identifying several moral concerns she had and how her practice satisfied these moral concerns. Nurse DD was concerned about the loneliness the patient felt when her concern about BM was not taken seriously, about respecting her personhood, about respecting her wish to go to a hot spring, about letting her have meaningful time by supporting her hope, and so on. But simply having these concerns would not necessarily lead to her particular actions. Other nurses in the same unit might have had the same moral concerns as Nurse DD, but they might not implement the concerns into ethical practice, actions that result in "good" consequences. Moreover, some nurses' concerns were not the same as Nurse DD's. What is required to implement moral concerns into ethical practice, and even prior to that, what is required to identify the most significant moral concern regarding a particular patient in a particular situation?

What makes this story so ethically prominent is this nurse's involved care for the patient and keen attunement to the needs of this patient. While other nurses took the patient's complaints about BM "lightly," Nurse DD attended to the patient's complaints, listened to her, and understood and acknowledged that the concern was important for her although it might be trivial from the nurses' health assessment perspective. The nurse was not standing outside and judging the patient's symptoms and physical condition objectively. Rather, she was involved and engaged with this patient, and tried to understand the meaning of the patient's complaint from her side. The nurse's active listening happened spontaneously in response to the cry from the person.

Later in the interview, the nurse mentioned that in general she was concerned for people who feel loneliness, and she suggested that the patient had attracted her attention because she was left out from other nurses' attention as "a patient with minor complaints." Yet from her narrative account, it is obvious that she was not deliberatively concerned about the patient's loneliness when she took her action. It was a natural reflexive response that happened in the situation.

This personal connection due to the nurse's involved care became the key that opened the patient's heart to the nurse. The patient even overcame her fixation on her BM and was able to focus on other aspects of her life, to live meaningfully with hope. Seeing the patient trusting the nurse and being happy in this hospital, the family of this patient, who had been defensive against the health care providers, became happy for the patient and were also able to develop a trusting relationship with the nurse. The solution to the concern other nurses had about the defensive family was also embedded in this nurse's intervention based on her engagement to the patient. These consequences originated from the nurse's acts and demonstrated the notion of good inherent in nursing.

When the patient was planning to go on her trip, again, although objectively the nurse thought that the patient would not be able to make it, she stayed connected with the patient and responded by respecting her wish to go to the trip. Telling the patient they would travel together while the nurse knew she should not go and the patient would not be able to make it may seem dishonest. But in this involved, engaged relationship, the nurse's prime concern was to respect the patient's last wish, not strict honesty.

Another prominent act in this account was "letting her go to the hot spring" when she died. Some nurses might not have thought of giving a bed bath using a hot spring bath salt, or not taken the time to ask the physician to look for the bath salts. Others might have dismissed the patient's and the family's wish as already overdue or impossible given the limited facilities in the hospital. But Nurse DD made it possible to grant the patient's wish even after her death, and that also fulfilled the family's desire to grant the patient's last wish to go to the hot spring. Since she was connected to the patient as a person, even after her death, she still respected the patient as a person, which led her to respond to the patient's and the family's wish by inventing an alternative. Because the nurse understood the meaning of "taking her to the hot spring" for the family and "going to the hot spring with the family and the nurse" for the patient, Nurse DD could meet their needs meaningfully. The nurse acted with a spontaneous reflexive response in the situation. She was not thinking analytically; rather she was moved by the compelling urge to care for this patient. The nurse felt very good about what she did and about the daughter's words.

Paradigm Case: He Died As He Wished

This story was told by a chief nurse with 15 years of end-of-life care experience. A part of her story was quoted as an exemplar of nurses' concern for respecting patients' wishes in Chapter IV. The patient was about 70 years old, and he was dying from interstitial pneumonia. He had been told his pneumonia was progressive a long time previously, and he did not want to die in suffering from shortness of breath. Therefore, the patient had talked with the nurse and the physician and asked them to manage his shortness of breath by medication, regardless of its side effect of respiratory depression and drowsiness, when his death became imminent. When there was no other treatment to alleviate his symptoms and his death was very close, the physician let him know. The patient then spent some time with his son and wife before asking Nurse O to give him morphine and relieve his breathing difficulties. He died as he wished with care from the nurse. Although this nurse gave all credit for the "good" in this story to the strong-willed patient and his family who respected and supported the patient's wish, the nurse's skills also helped this patient accomplish his life as he wished.

When this patient was told by his physician that his death was approaching and it was time to start morphine, he chose to talk to Nurse O and ask her if she agreed with the physician. He asked her opinion because he regarded this nurse as a person who knew his wishes and had promised to help him not suffer as he died. He knew she would respond to his last wish and advocate to accomplish it. Therefore, it was not just the patient's and his family's personalities that made this "good" ending happen. It was the nurse's skilled involvement and her attentiveness to the patient as a person that allowed the patient to clarify his wish and express it explicitly so that the nurse and other staff could respect it.

She said she had never had another patient who had no hesitation to talk about his death and made his wishes so explicit. But this patient's act of expressing and clarifying his wishes could not happen without someone to express his thoughts to. In the interview, this nurse mentioned that some other nurses in the unit were astounded by the eloquence of the patient, who was unusually outspoken about his death, and by the almost brutally explicit conversation between this patient and Nurse O regarding how he wanted to spend the last moments of his life. Nurse O was able to establish and engage in a relationship with this patient, whereas the other nurses were daunted by his clear attitude toward his death and backed away from the relationship. Nurse O explained how she got involved with this patient.

> O: He used to ask me, "It must be really hard for you, too, to keep listening to my thoughts, what I am thinking about my upcoming death." But I told him how I felt, "No, rather than feeling difficulty, I am very honored to hear your thoughts. I am even encouraged by you. You make me feel I am a reliable, accountable nurse for you, and that empowers me, that makes me want to try harder." . . . When he was admitted to the hospital, I introduced myself as his primary nurse, and told him, "I am the nurse who is responsible for your nursing care until the time you discharge." Probably

> because of the way I introduced myself to him, he started telling me things like, "This is my thought." . . . He started with, "I have interstitial pneumonia and. . . ." Then I thought, "This person really wants to be understood as who he is." And he told me the history of his life with the disease.

From the very early stage of their relationship, Nurse O immediately tuned into the patient and picked up his need to be understood as a person. Nurse O developed her relationship with him by listening and sharing a lot of thoughts with this patient. She did not run away and stayed connected when he discussed his thoughts about how he wanted to die. Rather, she communicated her willingness to listen to him and appreciated who he was.

This nurse's skilled ethical practice in this story makes a distinct contrast with some stories other nurses told that they did not feel "good," but rather felt difficulty or hardship. For instance, recall the excerpt used to illustrate the moral concern of not hurting the patient in Chapter IV. Young Nurse V, with three years of experience, was confronted by a patient whose lung cancer was progressing and whose lower extremities were paralyzed because of bone metastasis. The patient had been told his diagnosis but not his prognosis. The patient asked many nurses, including Nurse V, if he was going to die and how he was going to die.

> V: I said, "I don't know if you are going to die. Nobody knows that."

> IN: So what did the patient say?
>
> V: He said, "Yes, I guess that's right. Nobody knows." Then he asked me, "How do patients like me die?" I asked, "What do you think about how you will die?" He said something like, "I don't have any respiratory symptoms at all now, like pneumonia or fever. So I have no idea how I am going to die from here." But I couldn't say, "You may die of pneumonia," or so on. When he said that he might die of pneumonia or deteriorated breathing function, all I could say was, "Well, I guess you may."

This nurse was concerned about hurting the patient's feelings by telling him how he was going to die. In this narrative account, it is clear that Nurse V kept a distance from this patient. Because she was so afraid that he was going to ask her something she should not say and that she might end up hurting him unnecessarily, she could not listen to and respond to his questions. For a moment, she thought this patient really wanted to know what was going to happen to him. But she did not respond to this intuitive grasp of what he really wanted.

Another nurse (T) described backing away from a patient who kept talking about his unrealistic hopes for his treatment: "I could not keep up with him, it got harder to keep my mind going along with him. So before it appeared on my face, I needed to get away from him quickly." Because she was uncomfortable and felt dishonest encouraging his unrealistic hope, she wanted to run away from him, and she felt like she was "touching a time bomb" when she talked to him. This nurse also kept a distance from the patient and did not connect with him.

Nurse O, who displayed skilled involvement and engaged practice in the care for the patient who died as he wished, later in the interview described how she would respond to patients who talk about their death, quite differently from these young nurses.

> O: Uh-huh. Everyone [young nurses] says they are afraid of terminal care.
>
> IN: Uh-huh. They often say so. What do you think they are afraid of?
>
> O: Well, I guess they dislike death. Also, they [nurses] are afraid to answer questions from patients when they become terminal.
>
> IN: Umm, they are afraid when the patient asks, "When am I dying?"
>
> O: Yes, yes. If they say that . . . Everyone dies someday though.
>
> IN: Are they afraid because they worry what they say may hurt the patient?
>
> O: Yes. A couple of days ago, I was asked by a patient, "I wonder how much longer I can live?" What he said . . . "Nurse O, it seems like I'm coming to the end." He said something like that in the middle of a super-busy time in evening shift. I said, "You said you are coming to the end, but so many things can happen in a person's life. Do you think your time is coming?" It is a kind of funny response though [laugh]. "You

think so? You don't feel good?" I asked, then he said, "Well, I don't feel good. My abdomen bulges and is uncomfortable." Even though he put it like that [his death is coming], he was suffering from the bulged tummy. So I talked with him to find out the method to get rid of his abdominal discomfort. I told him that is our [nurses'] job. Then, after that, he did not say anything like, "I am gonna die, I am gonna die." There are a lot of messages behind his little complaint. There may be a time when he really wants to talk about it [death]. If so, he would not say, "My abdomen bulges," but he would tell me maybe something like, "It is very hard, and I think death is approaching." But in this instance, he said it was his tummy, so I responded to that. When I told this story to the staff [nurses], they said, "How could you say such things unconcernedly!?" [Laugh] They say "unconcernedly," but I said that with concern. So I told them, "I am fine with that. I am all right with that." If the patient responded he was concerned about his imminent death, then I would say, "You feel like that. What is happening?" I would ask. Although it is so busy, if the patient sends me some signs he wants to tell me now, it is a more important thing to do. I told them it is a matter of readiness to listen to the patient. Then, they [young nurses] said, "Wow! You reached to the province of god" [laugh].

Here, she described clearly how she tunes into the patient and listens carefully to understand the meaning behind his words. Then she responds to the patient's needs.

Because she is a chief nurse in the unit and often mentors the younger nurses, she told me what she often tells her junior nurses when they have difficulties developing involved relationships with patients.

> O: When a patient throws a ball to you and you throw a fake ball back, the patient will not throw a real ball back to you again. If you respond to them with a lip comfort, they will not tell you their real thoughts. If you want to know the patient's true mind, you have to stand on the same level with them and have to tell them your true mind, too. . . . Younger nurses asked me, "What would you do if the patient is shocked and depressed or starts crying because you tell them your thoughts?" I told them, if the patient cries, the only thing I can do is apologize. The way I speak might be rude. But you can restore the relationship if you stay there. . . . Moreover, if the words come out from your honest caring mind as your sincere opinion, it usually does not hurt the patient.

Nurse O encourages the younger nurses to step in further rather than withdrawing when they confront the patient. Only by stepping in and becoming involved with the person can nurses build a connection with the patient and grasp the patient's authentic needs, which allows the nurses to be truly the advocate of the patient. Interestingly, Nurse O's description in this excerpt resonates with the discussion Gadow (1980), an American nurse, presents in her article about existential advocacy as a philosophical foundation of nursing. She points out, "Regarding the *patient* as a 'whole' would seem to require nothing less than the *nurse* acting as a 'whole' person" (p. 87). The clear difference between Nurse O's practice and Nurse V and T's practices in the exemplars was that Nurse O was involved with the patient as a "whole" person whereas Nurse V and T withheld themselves from the patients for various reasons.

Practical Skills in Ethical Practice

Through interpretive analysis of the two paradigm cases and some contrasting exemplars, it becomes clear that certain skills are required to carry out ethical practice. The nurses do not seem to be deliberating the moral concerns involved first, then choosing their actions based on these concerns. Rather, the nurses' ethical practice is spontaneous and nonreflective in the situation. The ethical practice results from the nurses' skilled abilities to be involved in, to tune into, and to respond to the situation. Without these three skills, the nurses are not able to implement concrete ethical practice, even when they have conscientious moral concerns. These skills are subtle and unstated, but they permeate nursing care for dying patients. The three skills are intertwined and hard to distinguish from one another, but the following sections try to delineate these skills further.

Involvement

From the paradigm cases and contrasting exemplars, it seems that an involved relationship with the patient and engagement to the situation are a vital part of ethical practice. Yet, for professional societies, getting "too involved" is always viewed as taboo and professionals are warned not to be overly involved with their clients (Benner, 1994; Gadow, 1980). Professionals are encouraged to keep a distance from their clients, since objectivity and distant rationality are thought to be a "professional" attitude (Schon, 1982). In addition, the institutional pressure for efficiency and the workloads given to nurses not only discourage nurses but make it more difficult for them to engage with each patient (Benner, 1994).

A story from Nurse EE, which appears in the section about nursing culture in Chapter V, illustrates the institutional pressure on nurses that limits their ability to build engaged relationships with their patients and families. When Nurse EE was working in a busy surgical unit, she was crying with the patient's family when a patient passed away. But she was called out from the patient's room by a senior nurse and scolded that she should not cry there because she had to take care of the other 16 to 17 patients she was responsible for in that busy evening shift. Typically in general units, where patients require various level of care, the nurses have to deal with a wide range of patient needs. Some of them are time-demanding, such as care for post-surgical patients and patients receiving strictly timed chemotherapy, and some of them are time-consuming, such as listening and talking to the patients about their end-of-life options. To fulfill the mission of the units, which is usually providing medical treatment and cure for the patients, the nurses often have to suspend care for the dying to care for the curable patients. Time constraints posed by the different care goals and heavy workloads prevent the nurses from engaging fully in care for each patient. Other nurses in general units also talked about their difficulties finding enough time to talk to and get involved with dying patients, because their time with a patient is often cut short by nurse calls from other patients or other tasks which have higher priority in the unit.

Too much involvement could become problematic when a nurse cannot separate herself from the patient. There are three stories in the interviews in which the nurses' acts could be called overinvolved. In these three stories from two nurses, the nurses clearly took extra steps to get involved with a patient or a patient's family. They were aware that they had poured themselves into the patients more than usual. But there is a difference between their acts and the skilled involvement that makes nursing practice ethical. Involvement does not mean total immersion in the patients, exceeding the domain of nursing. In overinvolvement situations, the nurses take responsibility beyond their role as nurses.

One example of an overly involved relationship was a nurse with a young female patient. The nurse felt pity for the patient who was dying at such a young age and did not have close family members or friends to take care of her. Because their ages were similar, the nurse offered to be her "friend." Instead of helping the patient to rebuild or improve her relationships with her family and friends, she volunteered to take the role of friend beyond the role of nurse. Then the patient asked her to go out with her as a friend to have a haircut and take a photograph for her own funeral, and the nurse accompanied the patient. Afterwards, this nurse was given a warning from a nurse manager in the unit that it was not appropriate to go out with a patient as a friend.

How did this act of going out to the hair salon and photo studio with the patient differ from the nurse in the paradigm case who promised to go to a hot spring with the patient? First of all, Nurse DD's relationship to the patient in the paradigm case was as a nurse, not as a family member or a friend. She was able to make judgments as a nurse and was aware that the patient's condition would not allow an actual trip. If the patient had been fortunate enough to be able to make the trip, Nurse DD probably would have accompanied her as a nurse from the hospital if it were necessary, but not as a friend. The difference was that Nurse DD in the paradigm case assumed her responsibilities as a nurse, while the other nurse offered a relationship other than nursing. Skilled involvement means engagement to the patient as a nurse and it is required to understand the patient as a whole and advocate for the patient's authentic life. When the involvement exceeds the domain of nursing, the acts are no longer nursing interventions.

Interestingly, the three stories about seemingly overly involved relationships all happened in a palliative care unit. Because of the time constraints and institutional pressure described previously, nurses in general units tend not to have as much opportunity to be involved with the patients. On the other hand, in a palliative care unit where the mission is to provide comfort care and support the patients' personal lives until their deaths, the nurses are encouraged to become involved with the patients and the environment allows the nurses to be involved. Therefore, nurses in a palliative care unit may tend to be more involved with the patients, and their willingness may sometimes mislead the nurses to become overly involved beyond their nursing role.

Being in Tune

Being in tune is another important skill in ethical practice. It means tuning into the patients to listen carefully to their real message. This attunement happens only when the nurses are involved with the patients and actively try to listen to the patients' voices. To build an involved relationship, the nurses also have to be able to identify the patients' needs and respond to them. Just listening and picking up the tune of the patients does not do anything by itself; the nurses have to respond to the patients on the same wavelength, and that forms the involved relationship. Therefore, involvement, being in tune, and responsiveness appear intertwined and inseparable.

In the first paradigm case, the nurse first connected with the patient when the nurse picked up on her complaint about BM and was able to listen to the patient's experience carefully. Her tuned response to the patient ultimately developed a close connection between them, but in the meantime, she was able to tune into the patient because she was committed to caring for her.

In the second paradigm case, it was also the nurse's attuning that opened the channel for the communication between her and the patient and built a trusting relationship. When the patient started talking about his history of illness, Nurse O quickly picked up that "this person really wants to be understood as who he is." Nurse O was able to do that because she was fully engaged in her care for the patient and was present as a whole person. As Nurse O explained to the younger nurses, she was able to respond anytime to patients who wanted to talk about their death, because she was ready to listen to their voices. Her statement "I am ready" indicates she is facing the patients with her entire being and not withholding anything from them. The patients' true messages may not be exactly what they are saying. To grasp the true meaning of the patients' words, the nurses have to tune into the patients. Nurse V in the counter exemplar was withholding herself because she thought the patient did not know what she knew about his prognosis, and she did not want to tell him and hurt him. She was not facing him as a whole person, but was ready to "run away" instead of listen. Therefore, when the patient asked her how he would die, although she had a moment to tune into his real desire to know, she backed away from listening to what he really meant.

Responsiveness

The third skill for ethical practice is the ability to spontaneously respond to a patient's needs. As shown in the paradigm cases, responsiveness is displayed in spontaneous reflexive acts derived from the nurses' involved relationship and tuning. In the first paradigm case, responsiveness is seen when Nurse DD listened to the patient's concern about her BM, and when she had the idea of giving a bed bath with hot spring bath salts to the deceased patient and actualized it. These acts happened as consequences of her involved relationship with the patient and her being keenly in tune with the patient's true wishes. In the second paradigm case, Nurse O listened to the patient's thoughts, trying to understand who he was, and answered the patient's questions honestly to let him die as he wished. Acts in response to the patients' needs seem to be spontaneous, not the result of logical deliberation, because most of the time, the nurses cannot explain why they act.

Another good example of a responsive act can be seen in the following story. Nurse BB has four years of nursing experience and three years' experience in end-of-life care. In her unit, linens are routinely changed only once a week, and patients do not receive a daily bed bath. Although Nurse BB was not the patient's primary nurse and had not known the patient much before, she was in charge of the patient the two days before he died. The day before the patient died, she changed all his bed linens and gave him a full bed bath with his wife, although it was not the designated linen change day or his bed bath day. The patient's wife was very pleased that the patient and his bed looked refreshed and clean. The nurse remembers this episode as a small but good thing she did for him, because his wife was pleased and the next day the patient died in a clean, tidy bed. In the interview, when I asked

Nurse BB why she did that even though it was not the designated day for linen changes or his bed bath, she answered, "I just thought it would be good to change it. . . . I had a kind of hunch it [his death] would be that day or sometime soon. So at that time, I just thought it would be better being [i.e., dying] in a clean bed rather than in a messy bed and untidy." She could not describe her reasons any further: she just thought it would be good and she did it. Although she had not been involved in the long-term care for this patient before this day, when she was in charge of the patient, she quickly tuned into the patient's and his wife's unspoken need for a clean and tidy environment for his death and smoothly responded to this need.

Development of Practical Skills

It is interesting to see how the nurses acquired these three practical skills for ethical practice. Some nurses exhibited these skills in their stories, while other nurses did not have stories that showed these skills. There are also some nurses who have stories explaining how they learned the skills.

The two nurses in the paradigm cases were not aware of their use of skills in the actual practice scenes. Their skills are the extension of their smooth, seamless everyday movement as nurses. When I, as an interviewer, asked questions, they deliberated before they could explain their actions to me. Nurse O in the second paradigm case explained eloquently how she became involved and talked to the patients by sharing a story of a patient who said to her, “I think my end is coming,” in the middle of a busy evening shift. But she admitted that she could not talk like that to the patients when she was a beginner nurse. She said she had learned and gained the skills of how to be involved and how to communicate with the patients from listening to senior nurses and experiencing what they said for herself.

Another nurse (U) told a story about how she is developing the skills. When she was a new graduate nurse, she observed a senior nurse, who came into a patient’s room to help Nurse U and was able to listen to the patient’s woes and concerns and let him open his heart just by talking briefly with the patient. At the time, Nurse U was new at everything and too busy just completing her tasks without mistakes. But she could not forget what the senior nurse did. As she gains more experience in the unit, she tries to pay more attention and to listen to the patients more carefully. “Now, I would try to listen to his thoughts and feelings, rather than try to find things to do for him. I may not be able to solve the problem right away, but I would think about what he is trying to say, why he is saying that.” Nurse U recently had a patient whom she was able to become involved with, and the patient opened up to Nurse U because of her willingness to listen and her presence as a whole person.

Another nurse also had a similar experience of watching a senior nurse employing skilled ethical practice when she was a first-year nurse. Through her own experiences of dealing with the patients in the unit and watching other nurses' practices, she noticed the importance of facing and responding to the patients as a whole person. The nurse described a recent experience in which she intentionally pushed herself to tell her honest opinion to a patient. Although the relationship between this nurse and the patient did not result in a significant story, the nurse was making an effort to develop her skills of involvement, being in tune, and responsiveness.

In an article about development of ethical expertise, Dreyfus and Dreyfus (1991) explained that, in order to acquire ethical expertise, one must respond to ethical situations in the way the ethical expert does and experience how good or how bad it feels to succeed or fail to act ethically. That is exactly what these two nurses are doing. They are trying to respond to the ethical situations as the senior nurses would respond, and are experiencing satisfaction or regret at the outcome of their actions. On the other hand, one nurse had no episodes to relate that included ethical practice. Although she expressed her moral concerns in her stories, she said she did not know how to translate her concerns into actions, because she has never seen any other nurses in her unit doing so. She could not learn the practical skills because she did not have any models to follow.

Overall, the Japanese nurses' acquisition of the skills for ethical practice seems to fit the skill acquisition model for the development of ethical expertise (Benner, 1984, 1994a; Dreyfus & Dreyfus, 1991; Dreyfus Dreyfus, & Benner, 1996; Rubin, 1996). It is interesting to see how the nurses recognize the skills and try to learn them, and then once they acquire them, the skills become a natural part of their practice and are not consciously observed. Although a part of process of skill development was identified as the result of interpretive analysis, the purpose of this study was not to explore their developmental process. Therefore, the sampling method and analytic process do not allow further examination of the development of the Japanese nurses' ethical expertise.

Ethical Sensitivity

As the moral concerns were explicated and practical skills in ethical practice revealed through analysis, it became clear that something makes the nurses morally concerned and compels them to learn these practical skills. This is nurses' sensitivity to the ethical issues in a situation and their urge to do something about them. It is this sensitivity that makes the nurses aware of the existence of moral concerns in a situation. It is this sensitivity that moves the nurses to be involved, tune into, and respond to the patients. It is this sensitivity that compels a nurse to improve her/his skills and to be a good nurse. This sensitivity occurs as an urge to do something in response to the ethical imperatives from the patients. First, it appeared in the narratives to be a variety of the skill of responsiveness. But later it became apparent that this sensitivity transcends the concrete, contextually well-tuned action in response to the patient's needs. Rather it is the ability to sense the ethical imperatives from the patient.

Responsiveness driven by ethical sensitivity is expressed in the following short comment by a nurse: "I still regret that I could have done something better. Although I understood the patient's mind, I did not make a movement right away." She regrets this case very much because she did not respond to the patient's ethical imperative for her help. This sensitivity to the ethical imperatives from patients is the driving force for ethical nursing practice. Many nurses' ethical practices are derived from this urge of "cannot help doing it." Many nurses expressed their feeling of "ought to do something" in the face of patient's peril.

Nurses in Japan, in general, seem to be eager to learn good nursing practice and to be good nurses. The underlying force driving the nurses to improve their practice and skills is ethical sensitivity. The compulsion to respond to the patients' ethical imperatives moves the nurses to recognize other nurses' ethical nursing practice, admire it, and try to learn and improve their own practical skills. Without this compulsion towards good nursing, the nurses cannot develop the skills for ethical practice.

Although ethical expertise requires experience, not all experienced nurses had gained skills for ethical practice. One nurse has 24 years of nursing experience, but she did not have any stories including ethical practice. She said she was not good at talking and listening to the patients. Thus she listens to the patients only when they make it clear that they want to talk to her. This is different from attuned listening as an ethical skill. And she may respond to the patients' verbal requests, but not because of the compelling urge to bring good to the patients. In her narratives, she mentioned some moral concerns, but they were more like norms she consciously tries to follow. This nurse's narratives did not include contextually sound moral concerns, ethical practices, or accounts indicating her ethical sensitivity: no compelling feelings to do something at a patient's imperative; no gratification at meeting a patient's authentic needs; and no bitter regrets at being unable to bring good to patients. Seemingly this nurse either never developed her ethical sensitivity or lost it somewhere in her nursing career as something unnecessary. This nurse's narratives stood out from other nurses' narratives, but until the theme of ethical sensitivity emerged, it was unclear what made this nurse different.

Ethical Practice: Moral Concerns, Practical Skills, and Ethical Sensitivity

Nurses' ethical practice requires three ingredients: moral concerns, practical skills, and ethical sensitivity. Nurses' moral concerns were explicated in Chapter IV, the practical skills that make ethical practice happen have been identified and discussed, and ethical sensitivity, which drives nurses to be ethical, was just mentioned. In this section, I would like to outline the bigger picture of ethical practice in end-of-life nursing care in Japan, comprehending the interrelationship of moral concerns, practical skills, and ethical sensitivity.

Moral concerns and practical skills are intimately related in ethical nursing practice. Involvement, being in tune, and responsiveness enable nurses to deliver ethical practice in real clinical situations. Without these skills, nurses are not able to express their moral concerns in effective acts, even when a nurse has strong moral concerns. For example, one nurse had a moral concern about a patient's loneliness when she saw him dying alone in his room. Because of his rapid deterioration, the physicians' judgment about his prognosis fell behind his progression, and neither the patient nor his family had been told that his death was very close. Therefore, he was dying that night without knowing it and without his family present. The nurse noticed and was concerned about him dying lonely, but she did not know what to do. She did not know how to be connected with him and how to help him be less alone. Another nurse expressed her concern about a patient who wanted to go home but whose family wanted her to stay in the hospital to receive the most advanced treatment. Yet, since the nurse had never seen anybody intervene and provide ethical practice in such a situation, she did not know how to do so. Even when nurses have moral concerns, if they do not have the skill of tuning in to pick up the patient's immediate needs, skilled involvement to establish a connection with the patient, and the ability to respond to the needs, their moral concerns will not be implemented through action.

Practical skills allow nurses to recognize the most prominent moral concerns for patients, too. In the first paradigm case, while other nurses were concerned about the patient's defensive family, Nurse DD's engagement with the patient made her concerned that the patient was left out, and made her respect the patient's personhood by listening and attending to the patient's worry. In the contrasting exemplar, Nurse V was concerned about hurting the patient by telling him about his approaching death. But if Nurse V had been tuned to the patient's authentic need and facing the patient as a whole person, she might have seen the patient's other, more important concerns. These practical skills help the nurses to recognize the concerns most meaningful for the patients.

Although the practical skills of involvement, being in tune, and responsiveness are required for ethical practice, they do not suffice by themselves. The moral concerns listed in Chapter IV are values held by Japanese nurses who are taking care of dying patients. For some nurses, these are more prescriptive, normative values taught in nursing school. For other nurses, they are concerns felt, learned, and established through their own experience. When those who have a given set of nursing ethical values encounter a situation where their values raise questions, the skills of involvement, being in tune with, and responsiveness are the tools to solve their concerns. These skills are meaningless without moral concerns. For example, if nurses who are learning the skills identify situations where their taught ethical value of respecting the patient's wish is neglected, they employ the skills of attunement and involvement to understand the patient's wish and respond to it. If they had no moral concern in the situation, they would not use the skills.

On the other hand, for those who learn the moral concerns from their own experiences, the skills of involvement, being attuned, and responsiveness exist before the moral concerns. Moreover, these nurses become aware of the moral concerns through the skills. Their fundamental everyday commitment and tuning to the patients make them aware that something is important for the patients. Once nurses are aware of the patient's ethical imperatives, the nurses' ethical sensitivity urges them to respond. They learn from experience that they have to respond to the patient's voice, because if they dismiss it, it remains in their mind more vividly and leaves a bitter aftertaste.

When the nurses are involved and well-tuned to the patients, everything may go smoothly. Because these skills are practical, as the nurses acquire and master the skills, they become part of nonreflective everyday practice. Thus the nurses do not recognize the use of the skills. The involved relationship and the nurses' well-tuned responses may prevent ethical issues from emerging at all. In these cases, the nurses just feel good about their care because it was good for the patient. In the second paradigm case, Nurse O thought it was a very good experience because "the patient was great." Because her skilled interventions were so smooth, no ethical disruptions occurred.

The relationship among the moral concerns, the practical skills, and ethical sensitivity are complex. The skills can be the tools that implement moral concerns into acts. Meanwhile, the skilled involvement and tuning uncover and construct the nurses' moral concerns as well as preventing the breakout of moral concerns. Nurses' ethical sensitivity underlies both and compels nurses to look for the patient's good and respond to the patient's ethical imperatives.

Searching for Nursing Ethics in End-of-Life Care in Japan

The intention of this study is to explicate nursing ethics in end-of-life care in Japan from the nurses' narratives about their practice. Instead of applying an ethical framework borrowed from Western bioethics, ethical values inherent in Japanese nursing care for dying patients and how they are embodied in nurses' actual practice in the cultural and social context are explored. From the interpretation of the nurses' narrative accounts, this ethical practice was explicated as an intricate web of moral concerns and practical skills driven by ethical sensitivity. The skills and moral concerns identified in this study are active ingredients of ethical practice, but not a complete explanation of nursing ethics in end-of-life care in Japan. More fundamental ethical questions lie beneath these skills and concerns. Why do nurses care about these moral concerns? What is the force driving the nurses to be ethical? These are fundamental questions for nursing ethics. Although ethical sensitivity as compelling force was discussed briefly, it requires further focused inquiries. How do nurses develop or learn ethical sensitivity? Is it a virtue found in the individual nurse's personality? Is it a trait inherent in nursing as a profession? Explication of nurses' moral concerns and their practical skills are the first steps for the exploration of nursing ethics in Japan.

In the interpretive analysis in this study, the focus of ethical practice and moral concerns is on patient care. Yet, as a profession within the health care system and in the larger society, nursing has some ethical responsibilities other than patient care, too. This section touches on some of these other issues related to nursing ethics. The first issue is nurses' ethics regarding hospital rules. As employees in an institution, nurses have an obligation to follow the rules and ethical norms of the institution. But several nurses mentioned occasions when they broke or overstepped the rules to serve a particular patient's needs. As the nurses become involved with and tuned to the patients, sometimes their concerns may override a social norm and make cases for exception.

In one nurse's story of the first experience when she felt a good connection with a patient, she cared for a woman who was dying from an abdominal tumor. The patient could not eat because the tumor mass was obstructing her stomach and colon. Nurse JJ decided somebody sit with the patient at every mealtime to keep her company and tried to make an atmosphere in which the patient could enjoy the meal. Although the patient could not eat much, she looked forward to meals because someone came to her room and shared the meal with her. This patient always wrote down the names of the nurses whom she had meals with on the day and she died holding a piece of paper with the nurse's name on.

JJ: [At mealtimes] because the patient herself could not eat, she brought food out

> from her refrigerator and told us, “Please eat this, please eat that.” She asked her family to bring fruit to the hospital. Her family thought that the patient was eating it, so they kept bringing in more fruit [laugh]. But in reality, it was we who were eating her food, not the patient. But the patient was watching us eating her food very happily. Fundamentally, I thought it didn't look good that the nurses were eating the patient’s food in front of her while the patient could not eat. But if that made the patient happy, if she could enjoy her mealtimes because of that, I thought it might be OK.

As Nurse JJ thought, nurses eating the patient’s food does not look right. It goes against professional morals and the norms for nurses’ behavior. But in this context, because her involved and tuned relationship made her certain how important having meals with the nurses was for the patient, the social norm yielded to her concern for letting the patient have pleasant time.

Similarly, in the first paradigm case, Nurse DD's promise to go to a hot spring with the patient is not acceptable behavior for a health care professional. Yet, based on their relationship and in the context, it could be seen as an ethical practice. Another nurse, M, who let an alcoholic patient drink liquor before his death, respected his personhood and the meaning of his life enough to break the rule against alcoholic beverages in the hospital and overrode the norm among health care professionals. Another nurse let a patient use a vacant private room to spend a night with his girlfriend for his last birthday. The patient could not afford a private room, so the nurse provided a private place for this dying patient and let his girlfriend stay with him just for one night without leaving a record for charge.

The nurses know that these rules and norms exist to protect patients and to treat all patients equally. But when the nurses are involved with the patients, their perspective shifts to see what the patients see and feel how the patients feel. Then they start to see what would protect a particular patient, what would harm a particular patient, and what kind of intervention is equal treatment for each patient in the true sense. They break the rules not because they disagree with the rules. They break the rules to serve their underlying values more truthfully in consideration of the patient as a unique person. And the practical skills of involvement, tuning, and responsiveness allow the nurses to see the truthfully ethical way to serve the patients.

The nurses' practice of overriding the rule or norms situation by situation may be seen as inconsistent and unreliable. It may also be seen as the situational ethics that is widely known as a characteristically Japanese approach (Lebra, 1976). But the nurses are not making judgments based on their whims. They have moral concerns, and their judgments are consistent with their moral concerns. These moral concerns do not necessarily conflict with the underlying values of the hospital rules or professional norms. But when the nurses are involved with and tuned to the patients, rather than judging them from a distance, sometimes these concerns have different applications in practice than is prescribed by rules or norms. Involvement and tuning clarify the meanings of the concerns for the patients and help the nurses to interpret their concerns into real acts that respond to the patients' needs.

Therefore, breaking rules is not always unethical, and most of the time nurses take risks and break the rules or norms because of their contextually tuned moral concerns and their urge to do good in a particular situation. Unfortunately, there are times that breaking a rule with seemingly appropriate moral concerns and tuned response turns out to be unethical. The nurses need to be aware that nursing ethics encompasses not only the good of the patient but also the good of other patients, patients' families, the community, and nursing as a profession. The overriding of norms and rules narrated in the interviews is mostly justified as ethical practice from the standpoint of individual patient care. Yet when nursing ethics is discussed, it is important to consider the other ethical responsibilities nurses have.

Another issue related to nursing ethics is the importance of distinguishing ethical issues in nursing from other non-nursing ethical problems, such as clinical problems or issues in the system. There are some situations where a nurse has both the moral concerns and the skills for ethical practice, but the nurse does not feel good about the outcome care in the situation. For example, Nurse N tried to stop a physician from performing a seemingly unnecessary lumbar puncture on a dying patient.

> N: The doctor said he was going to do a lumbar puncture on the terminally ill patient to find out if her peritonitis is cancerous or infectious. I asked him, "Are you really going to do this!?" If it was cancerous, there was nothing he could do. If it was infectious, he was going to use antibiotics. So if the only possible treatment was antibiotics, just giving her antibiotics was good. Why did he need to give her pain like a lumbar puncture? "Isn't she dying?" I told him straight. But the doctors do it anyway. Once they've decided, they do it. I told them I refused to assist with the procedure. But I have to assist them, because I know I can make it easier for the patient.

In this situation, she was connected to the patient and she knew this test was not what the patient wanted. She advocated for the patient, but the physician decided to do the procedure anyway. Because the nurse was concerned about the patient's pain and committed to relieve the pain as much as possible, she eventually assisted the physician doing the painful procedure although she believed it was unnecessary. The nurse ended up feeling bad because she could not prevent the unnecessary suffering.

This is an ethical situation nurses often face (Yokoo et al., 1993), where nurses feel difficulty that they are caught in the middle (Izumi, 1997). In the study done by Yokoo and her colleagues, it was suggested that nurses often do not think their practice was ethical unless the outcome was good. For example, Nurse N, who could not stop a seemingly needless lumbar puncture, thought her practice was "not good" because the outcome of the situation was an unnecessary painful procedure for the patient.

But from the findings of this study, I would argue that this nurse's practice was in fact ethical. The nurse was involved, tuned to the patient, had a moral concern for the patient's suffering, and she acted on that. She stayed involved to care for the patient throughout the procedure. But the hierarchical relationship between physicians and nurses, and physicians' discretion in treatment decision-making, resulted in an outcome that went against the nurse's values. In a situation like this, the ethical question should be raised at the system level, not about this nurse. This issue needs to be resolved between the two different professions, i.e. nursing and medicine, not within the nurse. It is also an issue for the system whose structure permits this ethical conflict to occur. Nurses are often placed in a position where they have to suffer from being unethical, because they do not have the authority to take direct action to solve a conflict. Clarifying the ethical values inherent in nursing and what makes nurses' practice ethical is helpful to delineate the boundary of nursing ethics and to distinguish ethical conflicts due to different professional values in systems.

Summary

In this chapter, nursing ethical practice was explicated and three practical skills required for ethical practice were identified. These three skills (involvement, being in tune, and responsiveness) are intertwined, and they both implement and construct moral concerns. Nurses learn these skills by observing others, hearing their explanations, and experiencing for themselves the truth of their role models' explanations. Yet, most critically, an underlying compelling force is necessary to orient the nurses towards good in nursing. Without ethical sensitivity, nurses would not be motivated to learn the practical skills and could not be aware of moral concerns.

This study is a first step towards identifying the nursing ethics in end-of-life care in Japan. These findings are neither comprehensive nor exclusive. Yet uncovering the Japanese nurses' ethical practice and providing a language to explain it is a beginning. The findings from this study will make nurses aware about the possibilities of what they *could* do in terms of ethical practice and help them clarify and communicate their ethical values and judgment in their own words.

Chapter VII: Summary, Implications, and Conclusion

Summary of the Study

Purpose of the Study

The purpose of this phenomenological study was to describe and understand nursing ethics in end-of-life care in Japan. The specific research questions were:

1. What are the moral concerns inherent in nursing care of dying patients in Japan?

2. What are the ethical practices, skills, and behaviors that reveal these moral concerns and thus the ethics of Japanese nurses in end-of-life care?

Procedures and Analysis

The participants of the study were 32 Japanese nurses (all female) who had more than one year of end-of-life care experience, from three large urban hospitals in Japan. Individual interviews were conducted in which the nurse participants were asked to describe their memorable experiences in care for dying patients. All interviews were conducted in Japanese, the participants and my native language. The interviews were tape-recorded and transcribed verbatim. The data for this study consist of the interview transcripts, field notes kept during the interviews, and a personal journal kept through the analytic process. Data were analyzed through reflective interpretation, identification of major themes, coding and retrieval of data according to an interpretive plan, and reflective writing based on paradigm cases and exemplars illustrating the major themes and issues (Wros, 1993). All the Japanese transcripts were reviewed with the Japanese dissertation committee member, and nine out of 32 interview transcripts were translated into English and reviewed with the doctoral advisor and American nursing colleagues who are experienced interpretive phenomenological researchers.

Findings: Nurses' Moral Concerns

Seven moral concerns were identified in the interviews. They are (a) not hurting the patients, (b) honesty, (c) isolation/loneliness, (d) regard for the patients' personhood, (e) respect for the patients' wishes, (f) comfort/relief from suffering, and (g) meaningful/pleasant time for the patients. These concerns are often interrelated, overlapped, and sometimes in conflict with each other. The meanings of each concern need to be understood in conjunction with related background meanings in the culture and society.

The first concern of not hurting the patients is different from the principle of nonmaleficence commonly used in bioethics, in that the nurses try to avoid anything that might cause psychological discomfort for the patients. *Omoiyari,* or empathy, is a highly ranked virtue in Japanese culture, particularly for nurses because they are mostly women and helping professionals. *Omoiyari* means the quality of anticipating and accommodating the needs of others and preventing their displeasure. The patients, in turn, expect to be protected from displeasure by the nurses' empathy. Causing displeasure to the patients is thus equivalent to hurting the patients, which is morally bad for the nurses.

The nurses were also concerned about being honest to the patients. The general virtue of honesty becomes the nurses' concern because it is the foundation of an involved relationship. When the nurses cannot share their honest thoughts with the patients, the nurses have to keep a distance in order to hide their opinions and cannot face the patients as a whole person. The distance caused by dishonesty makes nurses uncomfortable because they are not building a good nurse-patient relationship.

In addition to the psychological distance between nurses and patients due to dishonesty, the nurses are also concerned about the patients' psychological and physical isolation from their families. The theme of isolation and loneliness as nurses' moral concern was prevalent in the nurses' narratives about their end-of-life care practice. This prevalence shows the nurses' strong belief that no one should die alone.

The nurses' two concerns of regard for the patients' personhood and respect for the patients' wishes are closely related, yet the nurses seem to differentiate them in their actual practice. In respecting personhood of the patients, their focus is on supporting the patients to be themselves on the everyday care level. On the other hand, nurses' concern of respecting the patients' wishes tends to focus on end-of-life decision-making. Respecting how the patients wish to die could be seen as a part of respecting the patients' personhood. But in practice, respecting the personhood can be dealt with within the nursing domain, whereas respecting patients' wishes regarding end-of-life decision-making is related to the physicians' judgments of treatment options and is affected strongly by physicians' decisions. Thus these two concerns are differentiated in terms of the goals and the required nursing practice. Respecting patients' personhood means helping the patients to live as who they are until their death, and nurses often have full discretion to do this in their practice based on their tuned knowledge about the patients as persons. The goal of respecting the patients' wishes involves helping them to die as they wish, which often requires negotiating with the physicians.

Providing comfort and relief from suffering is another major moral concern the nurses showed. The nurses seem keenly aware of patients' pain and suffering not only from their illness and symptoms but also from their medical procedures and treatments. The nurses provide care to alleviate suffering as much as possible, but their interventions are often limited by the prescriptions of the physicians. Because of their involved relationship with the patients, the nurses' responses to the patients' suffering sometimes become so emotional that they have difficulty describing it in logical terms to convince the physicians to prescribe appropriate medications. The nurses sense that pain and suffering is "not good" immediately, and being unable to relieve the suffering and witnessing the patients suffer makes them feel powerless.

The last moral concern extracted from the nurses' narratives was letting patients spend meaningful and pleasant time. This concern is similar to respecting the patients' personhood to some extent. Yet it is framed by the nurses' awareness of the short time left to the dying patients. The nurses want the patients to spend the time they have left as meaningfully as possible. This may involve helping the patient to wrap up his or her life, or it may involve letting the patient have a pleasant moment and feel happy to be alive.

Some of these moral concerns exhibited in the nurses' narratives of their end-of-life care are seen in the nursing literature and described as nurses' ethical values or concerns (Doutrich et al., 2001; Wros, 1993; Yokoo et al., 1993). Other concerns are rather unique. They are "moral" concerns because the nurses judge their situations or acts as good or bad in accordance with these concerns. Although the nurses are not often able to describe why, they seemingly know instinctively whether or not each situation or act is good or bad.

Findings: Ethical Nursing Practice

Having moral concerns does not necessarily make the nurses' practices ethical. In order to carry out moral concerns in practice, the nurses need to be involved in the situation, be in tune with the patients' authentic needs, and respond to those needs. Involvement, being in tune, and responsiveness are interrelated and often inseparable from one another in practice. The involved relationship could be induced by the nurse's acts in response to a concern for the patient in a situation, or the nurse's involvement could lead the nurse to be responsive. In addition, the most prominent and meaningful moral concern for a particular patient in a particular situation can be grasped only through skilled involvement and keen tuning. An involved relationship with the patient allows the nurse to be attuned to the patient and reveals the most significant concern for the patient.

These skills are similar to what were identified as nurses' ethical comportment or characteristics of "good nurses" in studies conducted in the United States (Benner, 1994; Benner, Tanner & Chesla, 1996; Bishop & Scudder, 2001; Dreyfus& Dreyfus, 1991), although they have not been discussed in the Japanese nursing literature. However, several nurses interviewed described their experiences of learning and acquiring these skills by watching senior nurses' practice and through their own experiences of success and failure. This indicates that the nurses intuitively recognize that these skills are important to provide "good," i.e., ethical, care to the patients, but they did not explore the skills explicitly because of their intangible nature. This finding of the existence of practical skills and the process of their acquisition beg for further research to clarify the ethics embedded in actual nursing practice.

In addition, there seems to be an underlying driving force, which was named ethical sensitivity in this analysis. Ethical sensitivity is a compelling force moving the nurses to care about their moral concerns and make them want to do ethical practice. Because of their ethical sensitivity, the nurses are able to see and hear the cry of patients and are compelled to do something to bring them good.

Limitations

Although the methodology for this study was appropriate for its subject and goal, there were some limitations. One of the limitations of the study was due to the sampling method. Purposeful sampling was intended to capture the gross picture of end-of-life care across the different types of clinical settings. Yet time, resources, and geographical distance constrained the recruitment of nurses to a specific geographical area, types of facilities, and convenience sampling of the participants. The number of institutions that are accessible to outside researchers was another limitation that emerged during the recruitment process. These limitations resulted in a convenient sample of three large urban hospitals to recruit participants from and excluded independent hospice care facilities, home care institutions, and rural or small hospitals. The participants of the study are volunteers who responded to the letter of invitation to the study. Therefore, the participants may have more interest in nursing ethics in end-of-life care than nurses generally. For these reasons, the participants of this study are assumed not to be representative of the population group, and the findings from the 32 participants in this convenient sampling cannot be generalized. However, the purpose of phenomenological research is to enhance understanding of the experiences of the participants and explicate the practical knowledge and skills embedded in these experiences, not make predictions in the bigger population. The findings that emerged from this study should be shared with other nurses to enhance their insight into ethical nursing practice in end-of-life care and to fuel further discussions on this subject.

Another limitation of this study was the retrospective design of the data collection through interviews. In order to capture the practical knowledge and skills that are already a part of practitioners' everyday, often taken-for-granted practice, narrative accounts about actual situations they experienced and observations of their actual practice are thought to be the most valid sources of data (Benner, 1994; Benner, Tanner & Chesla, 1996). In this study, due to feasibility constraints, only interviews to collect narrative accounts were conducted and no observations of actual practice were employed. That limits the findings of the study to the concerns and skills that remained in the nurses' memories. In addition, the findings also rely on the nurses' abilities to articulate their practice. In Japanese culture, where explicit words are not trusted much and people are proficient at reading the implications behind the words from the context, not only nurses but the Japanese in general tend to be not explicit (Doutrich, 1993). Moreover, in order to maintain harmony and not stand out from the group, Japanese do not show off their success stories. Although the researcher provided a safe environment for participants to share their own experiences, including good and bad, without the fear of being judged by others, the unfamiliarity of telling explicit stories of their experiences and culturally cultivated hesitation to share their success stories might limit the capacity of the nurses to explicate their practices. Although there is a strong argument to support the value of narrative accounts as valid sources for identifying practical knowledge and skills (Benner, 1994; Benner, Tanner & Chesla, 1996; Dreyfus & Dreyfus, 1991), observation of the nurses' practices would have expanded and deepened the understanding of the practice, and the findings about their moral concerns and skills might be more thorough.

The third limitation is related to the process of analysis. All of the data collection took place in Japan during short periods of stay. Although some early interviews were transcribed and reviewed with the Japanese advisory committee member in Japan and the themes that emerged from the preliminary analysis were built into the next interviews to pursue further, most of the analysis did not take place until my return to the United States. Thus the themes that emerged from later interviews or later analysis could not be pursued for further clarifications from the nurses.

In addition, because the interviews were conducted in Japanese, the primary analysis was carried out mostly based on the Japanese transcripts. The excerpts that explicate the themes were translated into English and shared with the American advisory committee only when the interpretation moved beyond the primary analysis and several core themes had emerged. Although approximately half of the interview transcripts were originally intended to be translated from Japanese to English, it became clear after translating a couple of interviews that the narratives in the interviews are so value ridden and context bound that the literal translations of the words are not only meaningless but also invite misinterpretation. Therefore, the planned preliminary interpretive session with the American advisor was abandoned, and validation of preliminary analysis based on the raw narrative accounts relied totally on the Japanese advisor.

The last limitation of this study is the inexperience of the researcher. Although I had some experience of doing qualitative research, this was my first study using interpretive phenomenology. In this kind of research, the researcher serves as the instrument to collect and interpret data (Benner, Tanner & Chesla, 1996; Packer & Addison, 1989). I have experience taking care of dying patients in Japanese hospitals, and have actually worked in one of the hospitals recruited for this study. Although I have experience with the participants' situations, inexperience conducting interviews and analysis and too much familiarity with the situation could generate a blind spot for me. For this reason each dissertation committee member was chosen to bring different viewpoints to the analysis. In addition, the dissertation committee served to monitor, direct, and supplement my more inexperienced work.

Implications

The findings from this study have various implications for nursing. The descriptions of the concerns and skills could stimulate nurses to reflect on their values and their everyday practice and clarify the possibilities and responsibilities inherent in their practice. The study could also inform nurses about ethical issues surrounding their care for dying patients. In addition, it is hoped that this study will contribute to the general body of knowledge concerning nursing ethics, particularly in Japanese society. These potential contributions will be discussed in four different areas: philosophy, practice, education, and research.

Implications for the Philosophy of Nursing Ethics

In Japan, nursing ethics has been discussed as a part of virtue ethics or bioethics. Virtue ethics is derived from the history of conventional nursing practice and argues that nursing ethics is based on the personal virtues of nurses (Hashimoto, 1964; Shibata, 1970). As nursing developed its role as an autonomous profession, this view of nursing ethics heavily reliant on the nurses' personal characters has been questioned and found inappropriate as a professional ethics. More recent discussions on nursing ethics in Japan place it under the umbrella of bioethics and apply a principle-based approach to describe and justify nurses' ethical judgment (Fry, 1989; Kojima, 2002; Shimizu, 2000; Shirahama, 2001).

However, the findings from this study suggest that nurses in clinical practice are not necessarily using bioethical principles to make judgments about ethical practices. Rather, their concerns are more embedded in their actual practice, and their actions are directly derived from these concerns. That observation is coherent with some of the findings in the existing literature, which indicate that nurses respond to ethical issues intuitively and emotionally rather than rationally, and that application of principle-based ethics to nurses' everyday ethical concerns is difficult (Cooper, 1991; Doutrich et al., 2001; Parker, 1990a, 1990b; Taylor, 1997). Moreover, Japanese hold different social values from those in Western countries, where the philosophical values underlying principle-based ethics developed. Therefore, it is understandable that there are discrepancies between principle-based ethics and the descriptions of Japanese nurses' everyday ethical practice.

The interview narratives from the nurses caring for dying patients provide rich description of nursing practice in end-of-life care in Japan. The interpretations from the rich descriptions reveal a unique set of moral concerns the Japanese nurses have in their actual care, and skills that make the nurses' practice ethical. These findings suggest that Japanese nurses' care for dying patients is not framed by principles based on Western values. The Japanese nurses' ethical practices, compelled by their involved relationships, being in tune with patients, and responsiveness, seem to be more similar to caring ethics, which was also developed in the United States (Benner, 1994a; Benner, Tanner, & Chesla, 1996; Gilligan, 1982; Noddings, 1984). Although caring ethics is developed from women's perspectives, Japanese nurses are mostly women, and women in the two cultures seem to share many similar values, the existence of different cultural values in the United States and Japan makes me hesitate to adopt the caring ethics approach to frame nursing ethics in end-of-life care in Japan. Some Japanese nursing leaders raise concerns about accepting foreign ethics without examining their underlying values (Katada, 2002; Minami, 1985; Teshima, 1998). Davis (1998, 2002), a nurse ethicist, also raises questions about the universality of Western-developed ethics and points out the possibility of different interpretations of ethics across different cultures.

What we need to do to find and establish the ethics true to Japanese nursing is make the effort to uncover and extract the values and acts that exist in the actual practices of Japanese nurses. The findings from this study contribute to a foundation for discussions and explorations of nursing ethics in end-of-life care in Japan through this inductive process. As Gilligan's work (1982) focused on females' experiences of ethical issues uncovered different voices and contributed to explicating a new approach to ethics, these findings from the actual experiences of Japanese nurses should clarify the components of existing nursing ethics in end-of-life care in Japan. There may be similarities or overlaps between Japanese nursing ethics and caring ethics, virtue ethics, or even principle-based ethics. But we cannot conclude that Japanese nursing ethics in end-of-life care is the same as, similar to, or very different from nursing ethics developed in Western countries until we can clarify and examine the Japanese ethical values.

This study is a preliminary step toward explicating Japanese nursing ethics in end-of-life care from the perspective of practicing nurses, but further questions need to be addressed in order to clarify the ethical value system and to develop the findings into a theory of nursing ethics. First of all, what are the motivations or driving forces compelling Japanese nurses to do ethical practice? There are some episodes in the interviews where the nurses were moved to act in response to the needs of the patients, saying, "I could not help doing that." There are some stories in which the nurses felt strong regret about not being able to actualize their concerns and advocate for the patients' good. These compelling forces underlying the nurses' ethical practice emerged only in the later interpretation process. Therefore, these stories were not followed up to explicate the ethical driving force underneath. In the next study, these episodes need to be explored further to understand the motivational component of nursing ethics. The nurses' developmental process of ethical comportment also merits extensive inquiry, because it will cast light on the structure of nursing ethics. For that purpose, more systematic sampling to include nurses in various stages of ethical development is required.

These findings will also stimulate further discussion of universal nursing ethics versus cultural relativism, and will contribute to the development of ethics as a philosophical foundation for professional nursing. Eventually the value of nursing ethics can be examined and deliberated in relationship to bioethics and other ethical approaches.

Implications for Nursing Practice

The findings from this study will contribute to nursing practice in three main ways. First, nurses will be more aware of their ethical practice and its underlying values, which will extend the possibilities of ethical practice for dying patients and their families. Second, the explicated moral concerns and skills will give nurses terms to describe their practice and their values to patients, their families, and other health care professionals. Nurses will thus be able to vocalize their roles in the health care system more explicitly. Third, the findings will help nurses to distinguish ethical problems in nursing from clinical problems and ethical problems outside of the nursing realm.

This study will make nurses aware of the ethical aspect of their everyday nursing care for dying patients. Nurses often do not view their practice within an ethical framework, because, for them, ethics is something abstract and unrelated to their everyday practice (Doutrich, 2001). This indifference to ethics is mostly a reaction to Western-developed, principle-based ethics, which does not have much application to their daily practice. The findings from this study, on the other hand, are extracted from actual nurses' experiences and clarify their ethical practice and what is important in nursing practice using nurses' words. Nurses will be able to relate to these ethics, because they already exist in their everyday practice. Using these articulated concerns and skills, the nurses can reflect on their practice, be aware of its ethical aspect, and judge practices for themselves. When they face a situation where their ethical practice breaks down, instead of just feeling powerless and troubled, nurses will be able to identify their concern in the situation and employ skills to actualize the concern. By tuning to and developing involved relationships with patients, the nurses will be able to find creative ways to respond to the patients' authentic needs and describe them to others.

The second contribution of this study is the development of vocabulary to describe nurses' ethical values and moral responsibilities in the health care system. Since the nurses respond to ethical issues so intuitively and sometimes emotionally, the nurses' ethical acts have not been described, and therefore not acknowledged in the health care system and in the larger society. Among nurses, it might be possible to acknowledge ethical practice and learn from another nurse's acts. But health care professionals from different disciplines, patients, and their families, who do not share the same background meanings, will not be able to understand the ethical values existing in nursing unless they are put into words. Although the terms require some more refinement, the nurses' moral concerns and skills uncovered in this study will add vocabulary that will help nurses to explain their concerns, ethical judgments, and ethical practices.

Often the ethical issues nurses face in health care institutions are due to the different values and goals of the people involved in the situation. To consolidate these different standpoints and serve the good of the patients, nurses need to be able to express and share their concerns with others involved in the situations. Since nurses did not have the language to explain their concerns and practice to other disciplines, either nurses' moral concerns were not considered in ethical discussion among health care professionals, or nurses had to alter their concerns to fit into the borrowed language of bioethics to share them. By gaining the language to describe their concerns clearly, nurses will be able to participate in ethical discussions and argue their opinions with other disciplines. This does not mean that nurses' expressed opinions about the ethical issues are always the right ones. But as professionals in the health care system, nurses have to accomplish their expected role as advocates for the patients by participating and expressing their concerns within health care teams. With a language to describe their practice and concerns, nurses will become more efficient communicators to advocate for the patients. The vocabulary developed from this study will empower nurses by offering a language to explain their ethical practice and be heard by others. This will eventually strengthen the voice of nurses in ethical health care situations. When nurses are able to see the authentic needs of the patients from their involved relationship and convince others of these needs, ethical conflict stemming from the different views of different professions will be minimized and patients will benefit.

The third and last implication of the findings for nursing practice is related to the ability to distinguish issues in nursing ethics from clinical problems and ethical problems beyond nursing. Davis (2002) points out that nurses often dismiss ethical problems in nursing as clinical problems. For example, pain management difficulties may be viewed as a clinical problem when the nurse's knowledge and skills are inappropriate. But pain management could be an issue of nursing ethics, if the nurse does not learn the knowledge and the skills because she does not care about the patient's suffering. Conversely, like the exemplar at the end of Chapter VI, a situation where a nurse feels unethical may not involve a nursing ethical issue but rather an ethical issue in another discipline or even a problem in the system. Nurses are often confused about the nature of a problem and therefore unable to take appropriate actions to solve it. Having a clear idea of what nursing ethics is in relation to their practical sense in the clinical setting will help the nurses to distinguish ethical problems in nursing from others and help them to be more efficient in resolving problems.

Implications for Nursing Education

Although nursing ethics is a major part of nursing philosophy and has a critical role in nursing education, ethics was not included in the nursing curriculum in Japan for a long time. When ethics did appear in the curriculum, it was usually general descriptions of principles in bioethics and discussions based on these principles about euthanasia, abortion, DNR orders, or brain death and organ transplant. These principles are sometimes interpreted and related to nursing, but ethical judgments in these issues are not part of nursing practice. As a result nurses often have to face clinical ethical problems without ever having had the opportunity to deliberate the ethical values in nursing practice.

Some Japanese nurses seem to learn ethical practice from their clinical experience.

As explicated in the findings, from their own experiences and/or watching senior nurses, they learn what is good nursing and what is not. This intangible practical knowledge and skills are passed down to younger nurses as inherent good in nursing without being articulated. Some of the moral concerns found in this study could be interpreted as the principles of bioethics, but most of them seem more like uncovered ethical values and skills derived from the wisdom of these ethically experienced nurses whose practice the junior nurses are modeling.

Therefore, the findings from this study will provide a good foundation for teaching nursing ethics to students. The nurses' moral concerns and skills explicated in this study will provide educational guidelines about ethical practice for nursing students as well as practicing nurses. Because these concerns are actual concerns faced by nurses in the clinical end-of-life care setting, they will help nursing students to learn about real ethical issues. By describing what the moral concern is in a situation and how ethically experienced nurses act in such a situation, nursing students and junior nurses can learn how to see a situation from an ethical point of view and how to respond ethically (Dreyfus & Dreyfus, 1991).

A list of descriptions of nurses' moral concerns in end-of-life care and the practical skills that make them aware of and implement their concerns in actions means having a concrete tool to describe nursing ethics. Although a part of the ethical skill acquisition process was outlined from some of the nurses' narratives in this study, the whole picture is not yet known. To develop effective and meaningful education in nursing ethics, further study is required to explicate the acquisition of ethical practice.

Implications for Nursing Research

This study is a beginning of phenomenological exploration of nursing ethics in end-of-life care in Japan. To date, nursing ethics in Japan has been discussed mainly within a framework of principles in bioethics. Several Japanese nursing leaders expressed their concerns about framing nursing ethics in Japan with borrowed theories based on culturally different values (Katada, 2002; Minami, 1985; Teshima, 1998). However, no study has attempted to uncover the ethics inherent in Japanese nursing practice, particularly care for dying patients. Use of naturalistic inquiry, particularly the interpretive phenomenological approach, was appropriate to uncover and understand nursing ethics that are embedded in practice and often difficult to articulate. The findings of this study suggest several directions for future research. Although some of the suggestions have already been made in earlier sections of this chapter, all suggestions for future study will be summarized and presented here.

First, an extended study including a more diverse group of nurse participants would be revealing. In this study, the participants were limited to the nurses working in selected inpatient units in large city hospitals. Therefore, the findings from this study may reflect the culture of large city hospitals. All participants were self-selected, so it is assumed that the nurses who participated in the study have more interest in, and therefore more awareness about, nursing ethics than those nurses who did not participate. Considering the small proportion of male nurses in the entire nursing population, it may be reasonable that there were no male participants in the study. However, given the significant resemblance of the found values in Japanese end-of-life care nursing ethics to caring ethics, which is characterized by its feminine perspective, it would be interesting to explore Japanese male nurses' moral concerns and skills. In order to capture the bigger picture of nursing ethics in end-of-life care in general, nurses in other types of clinical settings should be included in the study.

Second, observation of nurses' practice in addition to the interviews is recommended. Observation of practice would supply broader descriptions of the unconscious, taken-for-granted, and therefore more fundamental ethical practice. Observations followed by interviews regarding the practice just observed would help the researcher to understand the practice further. In particular, a study to pursue the underlying ethical motivations of nurses will be indispensable to explicate the large picture of nursing ethics and such a study would benefit from data combining observations and narrative accounts about the observed practice.

Third, the findings from this study uncovered ethical nursing practice from nurses' perspectives, but are they ethical from the care recipients' perspectives? Does the nurses' seemingly skilled ethical practice really contribute to the patients' good? To answer these questions, the study would need to extend its scope to the patients and their families and explore their expectations of the nurses' ethical obligations and their experiences of nurses' ethical practice.

Because this study is a beginning of inquiry for nursing ethics in Japan, there are numerous possible future directions. The scope of study should also extend to nursing ethics outside of end-of-life care, such as home care, chronic or acute care where the goal of care is not peaceful death, pediatric care, psychiatric nursing, and so on. Comparison and integration of the findings from these studies will be important to uncover and expand theory related to nursing ethics.

Conclusions

This study was designed to uncover and understand nurses' ethical values and practices in end-of-life care in Japan. Although Japanese nurses are often self-effacing and devalue their practice by humbly saying, "We are not doing a great deal," or, "Our practice is 30 years behind U.S. nursing," I am always impressed with their devoted and compassionate care for their patients, particularly dying patients. Their practice may seem to be 30 years behind American nursing if it is evaluated with American criteria. But Japanese nurses are practicing in a different social structure and value system. Because of various social and system restrictions, these nurses' efforts to do "good" for their patients may not be actualized as much as they intend. But this outcome might not mean the nurse was "not good" or unethical in the situation. Japanese nurses need to explicate the ethical values existing in their own practice instead of borrowing and applying an ethical value system developed in a different cultural and social background.

Japanese nurses in end-of-life care have their own ethical values, which are revealed as moral concerns. Their moral concerns are implemented as ethical practice through involved, attuned relationships with patients and intuitive compelling responses to patients' authentic needs. Their culturally enhanced skill of being in tune with patients makes it possible to grasp their authentic needs without forcing them to speak up, and skilled involvement allows the patients to assume the level of interdependence or independence they find comfortable within the nurse-patient relationship. The responsiveness the nurses exhibit implies underlying ethical obligations that compel the nurses to do “good” for the patients.

The aim of phenomenological research is to uncover and understand the practices, meanings, concerns, and practical knowledge of participants engaged in that world (Benner, 1984; Benner, Tanner & Chesla, 1996). The interpretive account generated must be plausible and increase the understanding of the phenomena. The findings of this phenomenological study need further validation in the nurses’ actual practice and also need to be examined for commonalities and differences with nursing ethics in other cultures. Yet, as a novice researcher, it has been a rewarding experience to step into the participants’ world and explicate and understand the nursing ethics inherent in their practices.

References

Aida, Y. (1972). *Conscious structure of Japanese [NIHON JIN NO ISIKI KOUZO]*. Tokyo: Kodan sha.

American Nurses Association. (2001). *The Code of Ethics for Nurses*: American Nurses Publishing.

Aristotle. (1941). *Basic works of Aristotle*. New York: Random House.

Aroskar, M. (1985). Ethical relationships between nurses and physicians: Goals and realities - A nursing perspective. In A. H. Bishop & J. R. Scudder (Eds.), *Caring, curing, coping: Nurse, physician, patient relationships* (pp. 44-61). University, AL: University of Alabama Press.

Asai, A. (1995). Should physicians tell patients the truth? *Western Journal of Medicine,* 163, 36-39.

Asai, A. (1996). Barriers to informed consent in Japan. *Eubios Journal of Asian and International Bioethics*, 6(4), 91-93.

Asai, A. and T. Fukui (1997). Ethical issues in Japanese clinical setting in 1990's: Attitudes and experiences of the Japanese. *Eubios Journal of Asian and International Bioethics,* 7, 39-43.

Astrom, G., Jansson, L., Norberg, A., & Hallberg, I. R. (1993). Exprerienced nurses' narratives of their being in ethically difficult care situations: The problems to act in accordance with one's ethical reasoning and feelings. *Cancer Nursing, 16*(3), 179-187.

Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press.

Benner, P. (1984). *From novice to expert; excellence and power in clinical nursing practice.* Menlo Park: Addison-Wesley Publishing Company.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science, 8*(1), 1-14.

Benner, P. (1994a). Discovering challenges to ethical theory in experience-based narratives of nurses' everyday ethical comportment. In J. F. Monagle & D. C. Thomasma (Eds.), *Health care ethics: Critical issues* (pp. 401-411). Geithersburg: An Aspen Publication.

Benner, P. (1994b). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practice. In P. Benner (Ed.), *Interpretive phenomenology:*

Embodiment, Caring, and Ethics in health and illness (pp. 99-128). Thousand Oaks: SAGE Publication.

Benner, P., Tanner, C. A., & Chesla, C. A. (1996). *Expertise in nursing practice: Caring, clinical judgment, and ethics.* New York: Springer Publishing Company.

Benner, P., & Wrubel, J. (1989). *The primacy of caring: Strerss and coping in health and illness.* Menlo Park: Addison-wesley.

Bishop, A. H., & Scudder, J. R. (1990). *The practical, moral, and personal sense of nursing: A phenomenological philosophy of practice.* Albany, NY: State University of New York Press.

Bishop, A. H., & Scudder, J. R. (1991). *Nursing: The practice of caring.* New York: National League for Nursing.

Bishop, A. H., & Scudder, J. R. (2001). *Nursing ethics: Holistic Caring Practice* (2nd ed.). Boston: Jones and Burtlett Publishers.

Budan, L. (1994). *Caring practices in families of persons with AIDS.* Unpublished doctoral dissertation, Oregon Health Sciences University, Portland, Oregon.

Carse, A. L. (1996). Facing up to moral perils: The virtues of care in bioethics. In S. Gordon & P. Benner & N. Noddings (Eds.), *Care giving: Readings in knowledge, practice,* *ethics, and politics* (pp. 83-110): University of Pennsylvania Press.

Cooper, M. C. (1989). Gilligan's different voice: a perspective for nursing... paradigm for moral deliberation. *Journal of Professional Nursing, 5*(1), 10-16.

Cooper, M. C. (1991). Principle-oriented ethics and the ethic of care: a creative tension. *Advances in Nursing Science, 14*(2), 22-31.

Crigger, N. J. (1997). The trouble with caring: A review of eight arguments against an ethics of care. *Journal of Professional Nursing, 13*(4), 217-221.

Davis, A. (1998). Development of Nursing ethics: Are there universals? *International Nursing Review.*

Davis, A. J. (2002). Global influence of American nursing: Some ethical issues. In A.J. Davis (Ed.), *KANGO RINRI: RIRON, JISSEN, KENKYU [Nursing ethics: Theories, practice, and research].* (pp.37-45). Japanese Nursing Association Publishing Company, Tokyo: Japan.

Davis, A., Aroskar, M. A., Liaschenko, J., & Drought, T. S. (1997). *Ethical dilemmas and nursing practice* (4th ed.). Stanford: Appleton & Lange.

Davis, A. J., Konishi, E., & Mito, T. (2000). Rights and duties: Ethics at the end of life in Japan. *Eubios Journal of Asian and International Bioethics, 10*(1), 11-13.

DeVos, G. (1960). The relation of guilt toward parents to achievement and arranged marriage among the Japanese. *Psychiatry, 23*, 287-301.

Doi, T. (1973). *The anatomy of dependence* (J. Bester, Trans.). Tokyo: Kodansha International.

Doi, T. (1974). Amae: A key concept for understanding Japanese personality structure. In T. S. Lebra & W. P. Lebra (Eds.), *Japanese culture and behavior* (pp. 145-154). Honolulu: The University Press of Hawaii.

Doutrich, D. (1993). *The international educational experiences of Japanese nurses.* Oregon Health Sciences University, Portland.

Doutrich, D., Wros, P., & Izumi, S. (2001). Relief of suffering and regard for personhood: Nurses' concerns in Japan and the USA. *Nursing Ethics: An International Journal for Health Care Professionals, 8*(5), 448-458.

Dreyfus, H. (1991). *Being-in-the-world: A commentary on Heidegger's being and time, division I.* Cambridge, MA: MIT Press.

Dreyfus, H., & Dreyfus, S. (1991). Towards a phenomenology of ethical expertise. *Human Studies, 14*, 229-250.

Dreyfus, H. L. (1994). Preface. In P. Benner (Ed.), *Interpretive phenomenology:*

Embodiment, caring, and ethics in health and illness (pp. vii-xi). Thousand Oaks: SAGE Publications.

Dreyfus, H. L., Dreyfus, S. E., & Benner, P. (1996). Implications of the phenomenology of expertise for teaching and learning everyday skillful ethical comportment. In P. Benner & C. A. Tanner & C. Chesla (Eds.), *Expertise in nursing practice: Caring, clinical judgement, and ethics* (pp. 258-279). New York: Springer Publishing Company.

Engeldhardt, H. T. J. (1985). Physicians, patients, health care institutions - and the people in between: nurses. In A. H. Bishop & J. R. Scudder (Eds.), *Caring, curing, coping: Nurse, physician, patient relationship* (pp. 62-79). University, AL: University of Alabama Press.

Erlen, J. A., & Frost, B. (1991). Nurses' perceptions of powerlessness in influencing ethical decisions. *Western Journal of Nursing Research, 13*(3), 394-407.

Ferrell, B., Virani, R., Grant, M., Coyne, P., & Uman, G. (2000). End-of-life care: nurses speak out. *Nursing, 30*(7), 54-57.

Fischer, C. T. (1987). The quality of qualitative research. *Theoretical and philosophical physcology, 7*, 2-11.

Fowler, M. (1997). Nursing's ethics. In A. J. Davis & M. A. Aroskar & J. Liaschenko & T. S. Drought (Eds.), *Ethical dilemmas & nursing practice* (4th ed., pp. 17-34). Stanford: Appleton & Lange.

Fry, S. T. (1989). Toward a theory of nursing ethics. *Advances in Nursing Science, 11*(4), 9-22.

Gadow, S. (1980). Existential advocacy: Philosophical foundation of nursing. In S. F. Spicker & S. Gadow (Eds.), *Nursing: Images and ideals* (pp. 79-101). New York: Springer Publishing Company.

Gadow, S. A. (1985). Nurse and patient: The caring relationship. In A. H. Bishop & J. R. Scudder (Eds.), *Caring, curing, coping: Nurse, Physician, patient relationships* (pp. 31-43). University, AL: The University of Alabama Press.

Gardner, K. (1985). *Quality of care for the terminally ill: an examination of the issue.* Chicago: Joint Commission on Accreditation of Hospital.

Gilligan, C. (1982). *In different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Glasser, B. and A. Strauss (1965). *Awareness of dying.* New York, Aldine Publishing.

Gordon, S., Benner, P., & Noddings, N. (1996). *Caregiving: Readings in knowledge,* *practice, ethics, and politics*. Philadelphia: University of Pennsylvania Press.

Gramelspacher, G. P., Howell, J. D., & Young, M. J. (1986). Perceptions of ethical problems by nurses and doctors. *Archives of Internal Medicine, 146*, 578-579.

Grundstein-Amado, R. (1992). Differences in ethical decision-making processes among nurses and doctors. *Journal of Advanced Nursing, 17*, 129-137.

Grundstein-Amado, R. (1993). Ethical decision-making processes used by health care providers. *Journal of Advanced Nursing, 18*, 1701-1709.

Hashimoto, B. (1964). *KANGO RINRI [Nursing ethics]*. Tokyo: IGAKU SHOIN.

Hattori, H., Salzberg, S., Kiang, W.P., Fujimiya, T., Tejima, Y., and Furuno, J. (1991). The patient's right to information in Japan - Legal rules and doctor's opinions. *Social Science in Medicine,* 32(9), 1007-1016.

Health and Welfare Statistics Association (2000). KOKUMIN EISEI NO DOUKOU (Statistics of national health status). *Journal of health and welfare statistics*, 47(9).

Heidegger, M. (1962). *Being and time* (J. Macquarrie & E. Robinson, Trans.). San Francisco: Harper Collings Publishers.

Holly, C. M. (1993). The ethical quandaries of acute care nursing practice. *Journal of Professional Nursing, 9*(2), 110-115.

Holmes, S., Pope, S., & Lamond, D. (1997). Research and development. General nurses' perceptions of palliative care. *International Journal of Palliative Nursing, 3*(2), 92-99.

Iba, N., & Kawagoe, H. (2000). WAGA KUNI NO TERMINAL CARE NI KANSURU KENKYU NO DOUKOU TO KONGO NO KADAI (Research in terminal care in Japan and suggestions). *The Japanese Journal of Nursing Research (KANGO KENKYU), 33*(4), 261-271.

Iwasaki, E. (2001). IPPAN BYOUTOU DE SHUMATSUKI NO SEISINTEKI CARE GA DOKOMADEDEKIRUKA (How much end of life spiritual care could be provided in the general unit). *The Japanese Journal of Clinical Research on Death and Dying, 24*(2), 136.

Izumi, S. (1997). *KANGOFU GA TOUTSU KANWA WO MUZUKASHII TO KANJIRU RIYU TO TOUTSU KANWA WO MUZUKASHIKU SHITEIRU JOKYO (The Reasons and Context That Make Pain Control Difficult).* Paper presented at the The 12th Annual Congress of the Japanese Society of Cancer Nursing:, Sapporo, Japan.

Jameton, A. (1984). *Nursing practice: The ethical issues*. Englewood Cliffs: Prentice-Hall, Inc.

Jameton, A. (1993). Dilemmas of moral distress: Moral responsibility and nursing practice. *AWHONN's Clinical Issues Perinatal and Women's Health Nursing, 4*(4), 542-551.

Jameton, A., & Fowler, M. D. M. (1989). Ethical inquiry and the concept of research. *Advances in Nursing Science, 11*(3), 11-24.

Japanese Nursing Association. (1993). *Nursing in Japan*. Tokyo: Japanese Nursing Association.

Japanese Nursing Association (2002). *Nursing White Paper [KANGO HAKUSHO].* Japanese Nursing Association Publishing Co.: Tokyo.

Jenny, J., & Logan, J. (1992). Knowing the patient: one aspect of clinical knowledge. *Image the Journal of Nursing Scholarship, 24*(4), 254-258.

Kai, I., Ohi, G., Yano, E., Kobayashi, Y., Miyama, T., Niino, N., and Naka, K. (1993). Communication between patients physicians about terminal care: A survey in Japan. *Social Science in Medicine*, 36(9), 1151-1159.

Katada, N. (2002). 21 SEIKI NI TOU KANGO NO RINRI [Nursing ethics in 21st century]. *Journal of Japan Academy of Nursing Science*, 22(2), 54-64.

Kiba, S. (1993). *GANKOKUCHI IKOU (After the cancer truth telling).* Iwanami shinsho: Tokyo.

Kiba, S., Iino, K., Ishgaki, Y., Ishihara, K., Komatsu, H., & Okusaka, K. (1998). NIHON GAN KANGO GAKKAI NI OKERU KAKO 10 NENKAN NO GANKANGO KENKYU NO DOUKOU (Overview of cancer nursing research in last ten years). *Journal of Japanese Society of Cancer Nursing, 12*(1), 41-49.

Kitamura, K. (1998). SHUUMATSUKINI OKONAWARETA GAN KOKUCHI IGO NO KANGO (Nursing care after disclosure of cancer diagnosis in terminal stage). *Advances in Nursing Art & Science (RINSHOU KANGO KENKYU NO SHINPO), 10*, 136-145.

Kohlberg, L. (1981). *The philosophy of moral development* (Vol. 1). San Francisco: Harper & Row, Publishers.

Kojima, M. (1987). Nursing education in Japan and its future trends. *International Nusing Review, 34*(4), 94-101.

Kojima, M. (1997). *KANGO DILEMMA TAIOU MANUAL [Strategy manual for nursing dilemma]*. Igaku shoin: Tokyo.

Konishi, E. (1998). Nurses' attitudes towards developing a do not resuscitate policy in Japan. *Nursing Ethics, 5*(3), 218-227.

Konishi, E. (2000-a). *The right to die and the duty to die: Perceptions in Japan and the West*

(10672217). Nagano: Report of research funded by Ministry of Education.

Konishi, E. (2000-b). *End of life care for the elderly people and the family* (10672217). Nagano: Report of research funded y Ministry of Education.

Konishi, E. (2000-c). *Nursing ethical issues at the patients' end of life in Japan* (10672217). Nagano: Report of research funded by ministry of Education.

Konishi, E. (2000-d). KOUREISHA NO TERMINAL CARE NI TAISURU KOSEDAI NO ISHIKI (Small town families perceive end-of-life care for their elderly members). *The Japanese Journal of Hospice and Palliative Care, 10*(4), 314-318.

Konishi, E., & Davis, A. J. (1999). Japanese nurses' perceptions about disclosure of information at the patients' end of life. *Nursing & Health Sciences, 1*, 179-187.

Krishnasamy, M. (1999). Nursing, morality, and emotions: phase I and phase II clinical trials and patients with cancer. *Cancer Nursing, 22*(4), 251-259.

Lather, P. (1986). Research as praxis. *Harvard Education Review, 56*(3), 257-277.

Lebra, T. (1976). *Japanese patterns of behavior*. Honolulu: University of Hawaii Press.

Lebra, T. S. (1974). Intergenerational continuity and discontinuity in moral values among Japanese. In T. S. Lebra & W. P. Lebra (Eds.), *Japanese Culture and Behavior* (pp. 90-116). Hawaii: The University Press of Hawaii.

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept to person. In P. Benner (Ed.), *Interpretive Phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 43-64). Thousand Oaks: SAGE Publications.

Liaschenko, J. (1993). Feminist ethics and cultural ethos: Revisiting a nursing debate. *Advances in Nursing Science, 15*(4), 71-81.

Liaschenko, J. (1995a). Artificial personhood: nursing ethics in a medical world. *Nursing Ethics: an International Journal for Health Care Professionals, 2*(3), 185-196.

Liaschenko, J. (1995b). Ethics in the work of acting for patients. *Advances in Nursing Science, 18*(2), 1-12.

Liaschenko, J. (1997). Knowing the patient? In S. E. Thorne & V. E. Hayes (Eds.), *Nursing praxis: knowledge and action* (pp. 23-38). Thousand Oaks, CA: SAGE publications.

Liaschenko, J. (1999). Can justice coexist with the supremacy of personal values in nursing practice? *Western Journal of Nursing Research, 21*(1), 35-50.

Lincoln, Y., & Guba, E. (1985). Establishing Trustworthiness. In Y. Lincoln & E. Guba (Eds.), *Naturalistic inquiry* (pp. 289-331). Thousands Oaks: SAGE publication.

Lock, M. (1995). Contesting the natural in Japan: Moral dilemmas and technologies of dying. *Culture, Medicine, & Psychiatry, 19*(1), 1-38.

Long, S. O. and Long, B. D. (1982). Curable cancers and fatal ulcers: Attitudes toward cancer in Japan. *Social Science in Medicine,* 16, 2101-2108.

MacIntyre, A. (1984). *After Virtue* (2nd ed.). Notre Dame: University of Notre Dame Press.

Matsubara, Y., Katou, T., & Takehisa, H. (2001). SHI NI CHOKUMENN SHI IRYOUSHA WO KYOHI SHITA KANJAHENO KAKAWARI NI TUITE (Intervention to the patient who refused health care providers in facing her death). *The Japanese Journal of Clinical Research on Death and Dying, 24*(2), 131.

McDonald-Scott, P., Machizawa, S., and Sato, H. (1992). Diagnostic disclosure: A tale in two cultures. *Psychological Medicine,* 22, 147-157.

McGrath, P., Yates, P., Clinton, M., & Hart, G. (1999). "What should I say?": qualitative findings on dilemmas in palliative care nursing. *Hospice Journal Physical, Psychosocial, & Pastoral Care of the Dying, 14*(2), 17-33.

Merleau-Ponty, M. (1962). *Phenomenology of perception* (C. Smith, Trans.). London: Routredge & Kegan Paul.

Millette, B. E. (1993). Client advocacy and the moral orientation of nurses. *Western Journal of Nursing Research, 15*(5), 607-618.

Millette, B. E. (1994). Using Gilligan's framework to analyze nurses' stories of moral choices. *Western Journal of Nursing Research, 16*(6), 660-674.

Minami, H. (1985). East meets west: Some ethical considerations. *International Journal of Nursing Studies, 4*(22), 311-318.

Minegaki, A., Kameoka, Y., Aka, K., Uematsu, Y., Nishimura, H., Goto, Y., Takashima, S., Muramatsu, T., Isumura, S., Uchinuno, A., Toyota, K., Iioka, Y., Ohara, M., Izumi, S., Kawano, A., Chikazawa, N., Underwood, P., & Minami, H. (1997). *GAN KOKUCHI WO UKETA KANJA HENO KANGO SHIEN NO KENTOU: JIREI WO TOUSITE MIETA KANGOFU NO JOUKYOU (Nursing support to the patients who were told their cancer diagnosis: Nurses' situation)* (College of Nursing Art and Science, Hyogo Collaborative Research Fund). Akashi: College of Nursing Art and Science, Hyogo.

Ministry of Health Labour and Welfare (1996). *KOUSEI HAKUSHO (Health and Welfare White Paper)*, Ministry of Health, Labour, and Welfare: Tokyo.

Ministry of Health Labour and Welfare (2002). *KOUSEI HAKUSHO (Health and Welfare White Paper)*, Ministry of Health, Labour, and Welfare: Tokyo.

Mito, T., Konishi, E., & Davis, A. J. (1999). NIHON NO KANGO NI KAKAWARU RINRI

MONDAI (Ethical issues in nursing in Japan). *Nursing, 51*(13), 124127.

Mizuno, H. (1990). *INFO-MUDO KONSENTO: IRYO GENBA NI OKERU SETSUMEI TO DOUI (Informed consent : explanation and agreement in parctice).* Chu-kou shinsho: Tokyo.

Najita, T. (1989). On culture and technology in postmodern Japan. In M. Miyoshi & H. D. Harootunian (Eds.), *Postmodernism and Japan* (pp. 3-20). Durham: Duke University Press.

Nakajima, K., Kikuchi, Y., Takase, M., & Maeshima, M. (1999). SHUMATSUKI KANJA NO ISHI KETTEI WO SASAERU KAKAWARI. *The Japanese Journal of Clinical Research on Death and Dying, 22*(2), 175.

Nakajima, S., & Kakuta, N. (2000). KANWA KEA NI TAZUSAWARU KANGOFU NO STRESS (Stress of nurses in palliative care). *Japanese Journal of Palliative Medicine, 2*(2), 225-229.

Nakamura, Y. (1992). *RINSHO NO CHI TOHA NANIKA [What is knowledge of clinical].* Tokyo: Iwanami Shinsho.

Nakayama, Y. (1998). *An Interpretive Study of Everyday Practices and Clinical Judgments by Experienced Psychiatric Nurses.* Unpublished doctoral dissertation, Oregon

Health Sciences University, Portland, Oregon

Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley: University of California Press.

Oakley, J. (1992). *Morality and the emotions*. London: Routledge.

Ohi, G. (1997). Ethos and its changes: A commentary on 'facing death the Japanese way - customs and Ethos'. In K. Hoshino (Ed.), *Japanese and Western Bioethics* (pp.155-159). Netherland: Kluwer Academic Publishers.

Ohnuki-Tierney, E. (1984). *Illness and culture in contemporary Japan*. Cambridge: Cambridge University Press.

Okuno, S., Tagaya, A., Tamura, M., and Davis, Anne J. (1999). Elderly Japanese people living in small towns reflect on end-of-life issues. *Nursing Ethics: an International Journal for Health Care Professionals*, 6(4), 308-315.

Omery, A. (1995). Care: the basis for a nursing ethic? *Journal of Cardiovascular Nursing, 9*(3), 1-10.

Oosawa, K., Kasiwadani, Y., Ooshima, E., Sato, N., Mawatari, N., & Isozaki, C. (2000). JIKO KETTEI DEKINAI KANJA TO SONO KAZOKU NO CARE WO TOOSHITE (Care for the patient who could not make decision and her family). *The*

Japanese Journal of Clinical Research on Death and Dying, 23(2), 185.

Packer, M., & Addison, R. (1989). Evaluating an interpretive account. In M. Packer & R. Addison (Eds.), *Entering the circle: hermeneutic investigation in psychology* (pp. 275-292). New York: State University of New York Press.

Packer, M. J. and Richardson, E. (1991). Analytic hermeneutics and the study of morality in action. In W. M. Kurtines and J. L. Gewirtz (eds.), *Handbook of moral behavior and development.*(pp. 335-372). Hillsdale: Lawrence Erlbaum Associates, Publishers.

Parker, R. S. (1990a). Measuring nurses' moral judgements. *Image: Journal of Nursing Scholarship, 22*(4), 213-218.

Parker, R. S. (1990b). Nurses' stories: The search for a relational ethic of care. *Advances in Nursing Science, 13*(1), 31-40.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd Ed. ed.). Newburry Park: SAGE publications.

Pellegrino, E. (1985). The caring ethic: The relation of physician to patient. In A. H. Bishop & J. R. Scudder (Eds.), *Caring, curing, coping: Nurse, physician, patient relationship* (pp. 8-30). University AL: University of Alabama Press.

Pellegrino, E. D. (1993). The metamorphosis of medical ethics: A thirty year retrospective.

Journal of the American Medical Association, 269, 1158-1162.

Radwin, L. E. (1995). Knowing the patient: a process model for individualized interventions. *Nursing Research, 44*(6), 364-370.

Radwin, L. E. (1996). "Knowing the patient": a review of research on an emerging concept. *Journal of Advanced Nursing, 23*(6), 1142-1146.

Redman, B. K., & Fry, S. T. (2000). Nurses' ethical conflicts: what is really known about them? *Nursing Ethics: an International Journal for Health Care Professionals, 7*(4), 360-366.

Rubin, J. (1996). Impediments to the development of clinical knowledge and ethical judgment. In P. Benner, C. Tanner and C. Chesla *(eds.) Expertise in Nursing Practice*. (pp. 170-192). New York: Springer Publishing Company.

Sawada, Y., Takamiya, Y., Kuroko, K., Shiratsuchi, T., Hashiguchi, S., Saitou, M., Ono, J., Chou, S., & Kimura, R. (2000). DAIGAKU BYOUIN NI HATARAKU KANGOSHA NO KANWA CARE NI MUKERU IRYOUSHA NO KOKORO NI KANSURU CHOUSA (Survey about nurses' mind for palliative care in university hospital). *The Japanese Journal of Clinical Research on Death and Dying, 23*(2), 227.

Schon, D. A. (1982). *The reflective practice: How professionals think in action*: Basic Books, Inc.

Sherwin, S. (1992). *No longer patient: Feminist ethics and health care*. Philadelphia: Temple University Press.

Shibata, F. (1970). HASHIMOTO "KANGO RINRI" HIHAN [Critique of "Nursing ethics" by Hashimoto], *GENDAI KANGORON SHU* (Vol. 8, pp. 145-175). Tokyo: Medical Friend Co.

Shimizu, T. (2000). SHUMATSUKI KANJA NO KISHINENRYO WO DOU TORAERUKA (How to apprehend desire for death in terminally ill patients). *The Japanese Journal of Hospice and Palliative Care, 10*(3), 165-169.

Shimoyama, N. (2002). ATARASII OPIOIDS SEIZAI [New Opioids]. *Japanese Journal of Palliative Medicine*, 4(2), 97-98.

Shirahama, M. (2001). NIHON NI OKERU RINSHO RINRI NO TEKIOU [Application of clinical ethics in Japan]. *International Nursing Review, 24*(3), 78-85.

Smith, K. V. (1996). Ethical decision-making by staff nurses. *Nursing Ethics: an International Journal for Health Care Professionals, 3*(1), 17-25.

The Society for the Study of Issues in Nursing (2001). *KANGO KANKEI TOUKEI*

SHIRYO-SHU. Tokyo: Japanese Nursing Assicaiton Publishing Co.

Soyano, A., Konishi, E., Davis, A., Suzuki, M., & Ota, K. (1999). *Ethical issues at the patient's end-of-life: International and Japanese nurse's perceptions* (Kagaku Kenkyu Kiban Kenkyu C-2 09672413). Nagano: College of Nursing, Nagano.

Stein, L., Watts, D., and Howell, T. (1990). The doctor-nurse game revisited. *The New England Journal of Medicine,* 322(8), 546-549.

Storch, J. L., & Dossetor, J. (1998). Public attitudes towards end-of-life treatment decisions: implications for nurse clinicians and nursing administrators. *Canadian Journal of Nursing Administration, 11*(4), 8-33.

Tahata, M., & Nakamura, R. (2000). SHUMATSUKI KANJA HENO SEDATION SHIKOUJI NI IDAKU KANGOFU NO DILEMMA NI KANSURU CHOUSA (Survey about nurses' dilemma related to sedation for terminally ill patients). *The Japanese Journal of Clinical Research on Death and Dying, 23*(2), 226.

Takamiya, Y., & Minagawa, T. (1999). Nurses' role in team approach for terminall ill patients in university hopsitals [DAIGAKU BYOUIN NIOKERU MAKKI KANJA HENO TEAM APPROACH NO NAKADENO KANGOFU NO YAKUWARI]. *The Japanese Journal of Clinical Research on Death and Dying, 22*(1), 40-41.

Tamura, K. (1997). Meaning of ethical dilemma in terminal care. *The Japanese Journal of Hospice and Palliative Care, 7*(3), 200-203.

Tamura, K. (2000). Spiritual care for dying patient. *The Japanese Journal of Hospice and Palliative Care, 10*(2), 103-107.

Tanida, N. (1994). Japanese attitudes towards truth disclosure in cancer. *Scandinavian Journal of Social Medicine*, **22**(1), 50-7.

Tanida, N. (1998). Do we always need to tell patients the truth? *The Lancet,* 352(9142), 1787-1788.

Tanner, C., Benner, P., Chesla, C., & Gordon, D. (1993). The phenomenology of knowing the patient. *Image: Journal of Nursing Scholarship, 25*(4), 273-280.

Tarzian, A. J. (2001). Ethical issues encountered in nursing practice. *International Nursing Review, 24*(3 special issue), 103-108.

Taylor, C. (1985). *Human agency and language: Philosophical papers* (Vol. 1). Cambridge: Cambridge University Press.

Taylor, C. (1991). *The ethics of authenticity.* Cambridge: Harvard University Press.

Taylor, C. R. (1997). Everyday nursing concerns: Unique? Trivial? Or essential to healthcare ethics? *Hastings Center Report, 9*(1), 68-84.

Teshima, M. (1998). NIHONJIN NO RINRI TEKI HANDAN NI EIKYOU SURU YOUIN [Factors affect on Japanese ethical judgment]. *International Nursing Review*, 21(5), 31-34.

Tielney, P., Minarik, P.A., and Tierney, L. M. (1994). Ethics in Japanese health care: A perspective for clinical nurse specialist. *Clinical Nurse Specialist* 8(5), 235-240.

Tilden, V. P. (2000). Nursing care at end-of-life. *Journal of Gerontological Nursing, 26*(9), 5.

Tong, R. (1996). Feminist approaches to bioethics. In S. M. Wolf (Ed.), *Feminism & bioethics: Beyond reproduction* (pp. 67-94). New York: Oxford University Press.

Twomey, J. G., Jr. (1989). Analysis of the claim to distinct nursing ethics: normative and nonnormative approaches. *Advances in Nursing Science, 11*(3), 25-32.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario: Althouse Press.

Wilkinson, J. M. (1988). Moral distress in nursing practice: Experience and effect. *Nursing Forum, 23*(1), 16-29.

Wilkinson, J. M. (1989). Moral distress: A labor and delivery nurse's experience. *JOGGN, 18*(6), 513-519.

Wilkinson, S. (1999). Focus groups: A feminist method. *Psychology of Women Quarterly,* *23*, 221-244.

World Health Organization (1996). *Relief from cancer pain.* Tokyo: Kanahara Shuppan.

Wros, P. (1993). *Behind the curtain: Nursing care of dying patients in critical care.* Unpublished Doctoral dissertation, Oregon Health Sciences University, Portland.

Wros, P. (1994). The ethical context of the nursing care of dying patients in critical care. In P. Benner (Ed.), *Interpretative phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 255-277). Thousand Oaks: Sage.

Yarling, R. R., & McElmurry, B. J. (1986). The moral foundation of nursing. *Advances in Nursing Science, 8*(2), 63-73.

Yasui, Y., Miura, M., & Iwakiri, K. (2001). T-SHI FUSAI HA NANIWO MOTOMETE ITANOKA? (What Mr. and Mrs. T looked for?). *The Japanese Journal of Clinical Research on Death and Dying, 24*(2), 130.

Yeo, M. (1989). Integration of nursing theory and nursing ethics. *Advances in Nursing Science, 11*(3), 33-42.

Yokoo, K., Katada, N., Ibe, T., Shijiki, Y., Sato, Y., Tokai, T., Nakanishi, M., Fujieda, T., Mito, T., & Minami, H. (1993). NIHON NO KANGOFU GA CHOKUMEN SURU RINRITEKI KADAI TO SONO HANNOUEthical (Concersn for Japanese Nurses and Their Responses). *Journal of Japan Academy of Nursing Science, 13*(1), 32-37.

Appendix A

Letter of Invitation to Participate in Study of "Nursing Ethics in End-of-Life Care in Japan"

Dear nurse colleague,

My name is Shigeko Izumi, a doctoral student at Oregon Health & Science University School of Nursing in Oregon, the U.S. This is an invitation letter to ask your participation in my doctoral dissertation research titled "Nursing Ethics in End of life Care in Japan". The purpose of this study is to explore and understand the ethical practice and concerns of nurses in their everyday care of dying patients. I am going to interview nurses who are engaged in end of life care in Japan, and will ask participants to tell their stories of caring for dying patients. From these narratives, I will explicate nurses' ethical concerns and practice.

You received this letter because you have more than one year of experience caring for dying patients. If you agree to participate in this study, I will contact you to schedule an individual interview. The interview will take approximately one hour, and you will be asked to tell stories of your experiences caring for dying patients. The interview will be tape-recorded and transcribed later for analysis. Your name and any other identifiable information will be replaced with random initial code and will not be used in the project; therefore, no one can identify you from the study except me. In addition to the primary interview, you may be contacted by the researcher within six months of the interview for clarification of stories you told or for validation of the researcher's interpretations. I will not report who does and who does not participate my study to anybody, including nurse managers in your unit and the nurse director in your hospitals. Thus, your decision whether to participate in this study will not affect your employment or working conditions.

If you agree to participate this study, please check "YES" on the second page of this letter, fill in the requested contact information, and send it back to me in the enclosed self-addressed envelop. If you have any questions regarding this study, please contact me (CP: 090-xxxx-xxxx).

Thank you very much.

Sincerely,

Shigeko Izumi, RN, MSN

Please check "YES" box below, and mail this sheet back to Shigeko Izumi with enclosed self-addressed envelope, if you are willing to participate in this study. Please fill up the following information about your preference how to be contacted by the researcher to schedule the individual interview.

[ ] YES, I would like to participate this study.

If you send this sheet back, Shigeko Izumi will contact you to schedule an individual interview. Please indicate what method you would prefer to be contacted by her.

Your name:

Method of contact: _ Call me to my unit when I am working

(Work phone number:)

Best time to call ______________________

_ Call me at my home

(Home phone number:)

Best time to call ______________________

_ Visit me at my unit when I am working

(Unit location:)

Best time to visit ______________________

_ Other method:

(How? ______________________________)

Please mail this sheet back to Shigeko Izumi in the enclosed self-addressed envelope, if you are interested in to participate in this study.

Thank you very much.

Appendix B

Informed Consent Form

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
CONSENT FORM APPROVAL DATE:
NOV - 6 2002
APPROVED BY
PHONE NUMBER (503) 494-7887

IRB# 7231

Approved:________________

オレゴン健康科学大学

インフォームドコンセント

研究題: 日本のターミナルケアにおける看護倫理

研究者: 和泉成子　オレゴン健康科学大学看護学部博士課程
電話番号：+1-503-246-3646　(米国).

研究指導者:
Christine A. Tanner, RN, PhD. オレゴン健康科学大学看護学部　教授
電話番号：+1-503-494-3742　(米国).

研究助成機関: 山路ふみ子専門看護教育研究助成基金

目的: 日本で１年以上のターミナルケアの経験を有する看護師の方々に本研究への参加をお願いしております。本研究の目的は、ターミナル期にある患者の看護における看護師の倫理的な実践と倫理的な配慮を明らかにし理解することです。本研究への参加は、これから約１〜６ヶ月の間に１回の個人インタビューとインタビュー内容の追加説明あるいは解釈の確認のために行われるフォローアップに参加することを意味します。本研究ではインタビューで得られる情報の質と量に応じて１５〜５０人の看護師にインタビューを行うことを計画しています。

方法: 本研究への参加を承諾された場合、下記の要綱に沿って研究は行われます。

１.研究者による１度の個人インタビューが行われ、そのインタビューは研究者によりカセットテープに録音されます。インタビューは約１時間で、あなた自身の日々の看護実践とターミナル期にある患者のケアについての質問がな

されます。録音されたインタビュー内容は、個人を特定する情報をコードに置き換えた後、日本語のテキストへと変換されます。テキスト化された日本語のインタビューは、アメリカ人指導教員から分析の指導を受けるため、研究者によって英語へと翻訳されます。インタビュー後６ヶ月以内に、あなたが話した内容の確認あるいは追加の質問のために研究者から連絡があるかもしれません。

2. インタビュー後６ヶ月以内に、フォローアップのための面接を依頼されることがあるかも知れません。フォローアップの面接では、研究者の解釈が妥当で意味のあるものであるかどうか、またその解釈があなたの実践を忠実に表しているかどうかについて質問されます。

予測されるリスクと負担: ターミナル期にある患者へのケアの体験を語ることによって心理的な不快感あるいは負担を感じることがあるかもしれません。そのような時やあなたが話したくないことを質問された時は、答える必要はありません。また、いつでも研究への参加を中止することができます。あなたが関与したあるいは目撃した不法行為あるいは疑わしい行為についてインタビューの中で言及してしまう可能性が考えられます。インタビューの中で話したことによってあなたに何らかの不利なことが起こらないように、そのような体験について話すときは、それにまつわる特定の名前や地名を話の中にださないようにお願いします。

利点: あなた個人が本研究に参加することによって直接的な利益を得ることは少ないと思われますが、研究に参加することによって、将来の看護および患者にとって有益な情報を提供することに貢献することができると考えられます。

選択肢: 本研究に参加しないことを選択することも可能です。

守秘義務: あなたの名前も個人を特定する情報のいずれもが出版物としてあるいは公共の場で発表されることはありません。研究者はあなたの名前とその他の人物を特定する情報を、インタビューテープや日本語でテープおこしされた逐語テキスト、英文のテキストとは分別して、施錠されたキャビネットに保管します。テキストの中のあなたの名前は匿名に置き換えられ、その他の個人を特定できる情報もランダムコードに置き換えられます。あなたがインタビューの中で話す内容は匿名であり、テキストは研究者とその研究指導教員のみが見ることができます。研究に関する記録は、オレゴン健康科学大学の研究参加者の保護を目的とした組織内審査諮問委員会（IRB）によって閲覧あるいは複写されることがあるかもしれません。研究が行われている期間施錠されたキャビネ

ットの中に保管されている、参加者個人を特定できる情報、研究に関するテープ、逐語テキスト、コンピューターディスクは研究が終了したときには破壊処分されます。

費用：本研究への参加に費用はかかりません。

法的責任: オレゴン健康科学大学はオレゴン損害賠償条例（the Oregon Tort Claims Act (ORS 30.260 through 30.300)）の対象となっています。本研究に参加することによってオレゴン健康科学大学あるいは大学の雇用者から何らかの不利益を受けた場合、それを回復するために大学に対して法的な対処を取ることができます。この書類にサインをしても、上記の権利を放棄することは意味しません。これに関して質問がある場合はオレゴン健康科学大学リサーチサポートオフィスにご連絡ください(米国 503-494-7887)。

参加: 本研究の内容に関して質問がある場合は、和泉成子にご連絡ください(電話番号 090-9712-9425; 電子メール izumis@easystreet.com)。研究参加者としてあなたの権利について質問がある場合はオレゴン健康科学大学のリサーチサポートオフィスにご連絡ください(503-494-7887)。あなたが本研究への参加を拒否あるいは研究の最中に参加を中止しても、それがあなたと研究者、研究者が所属する大学、およびあなたの職場との関係に影響を及ぼすことはありません。あなたが研究の対象外であることが判明した場合は、研究の終了以前に参加の中断をお願いすることがあるかもしれません。また、いつの時点であっても、あなたが本研究への参加を中断すると決めた場合は、研究者にその旨をご連絡ください。本用紙のコピーを承諾書の控えとしてお持ちください。

署名: 上記の説明を読んだ上で本研究への参加を承諾される場合は、下記の欄にご署名をお願いいたします。

参加者: ________________________________ 日付: __________

研究者: ________________________________ 日付: __________

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
CONSENT FORM APPROVAL DATE:
NOV - 6 [illegible]
APPROVED BY
PHONE NUMBER (503) 494-7887

IC change in inclusion criteria
10/08/02

IRB# 7231

Approved:________________

OREGON HEALTH & SCIENCE UNIVERSITY

Informed Consent Form

TITLE: Nursing Ethics in End of Life Care in Japan

PRINCIPAL INVESTIGATORS:
Shigeko Izumi, RN, MSN. Oregon Health & Science University, School of Nursing. (503) 246-3646.

CO-INVESTIGATORS:
Christine A. Tanner, RN, PhD. Oregon Health & Science University, School of Nursing. (503) 494-3742.

SPONSOR: Yamaji Fumiko Foundation for Nursing Education and Research

PURPOSE: You have been invited to participate in this study because you have more than 1 year of experience engaging end of life care as a nurse in Japan. The purpose of this study is to explore and understand ethical practice and concerns of nurses in their everyday care for dying patients. Your participation in this study will last for 1-6 months. Approximately 15-50 nurses like you will participate in this study.

PROCEDURES: If you agree to participate in this study, your participation will include:
1. Attending at least one individual interview session with the principal investigator and

which will be tape-recorded. The interview will last approximately one hour and will involve question about your everyday practice and experience caring for dying patients. After your identifications are removed from the tape, the tape recorded interview will be transcribed in Japanese verbatim and the transcripts may be translated into English. You may be called upon after the interview for additional information or to provide clarification.

2. You may be asked to participate in a follow-up session(s) during which you will be asked if the descriptions the researcher provide in the session make sense to you and if they agree with your practice.

RISKS AND DISCOMFORTS: Psychological discomfort could potentially occur as a result of talking about your experiences of caring for dying patients. You are free to decline to discuss any topics or answer any questions that you do not wish to answer. There are potential risks for you to disclose disadvantageous information (e.g. your experiences involving illegal or questionable activities etc.) during the interview. The researcher will not ask you to identify specific names or locations in such incidents to minimize the threat to which you may be exposed.

BENEFITS: You may or may not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information which may benefit nurses and patients in the future.

ALTERNATIVES: You may choose not to participate in this study.

CONFIDENTIALITY: Neither your name nor your identity will be used for publication or publicity purposes. The principal investigator will keep your name and other identities separate from the recorded interviews, all transcripts, and observation notes, and they will be kept in locked cabinet. Your name will be replaced with coded identifier and any other identifiable information will be removed or replaced with unidentifiable initial codes on audiotapes and transcripts. The information you provide will be anonymous and will be reviewed only by the principal investigator and her dissertation committee. Any record of your identities will be destroyed at the completion of the study. Audio tapes, transcripts and computer disks of this study will be stored in a locked cabinet during the course of study, then they will be destroyed permanently. Research records may be reviewed and/or copied by the OHSU Institutional Review Board.

COSTS: There will be no costs to you for your participation in this study.

LIABILITY: The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers, or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Support Office at (503) 494-7887.

PARTICIPATION: Shigeko Izumi (090)9712-9425 (e-mail in Japanese: izumis@easystreet.com) has offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Support Office at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with the researcher, the institution the researcher belongs to, or your employment. You may be removed from the study prior to study conclusion, if you do not meet the inclusion criteria for this study. If you choose to withdraw from this study, you need to notify the principal investigator your withdrawal. You will receive the copy of this form.

SIGNATURE: Your signature below indicates that you have read the foregoing and agree to participate in this study.

Participant: ______________________________ Date: __________

Principal Investigator: ______________________ Date: __________

Appendix C

Pre-Interview Instruction

and

Interview Guide

Pre-Interview Instruction

"I would like you to tell me stories of your care with particular dying patients. Tell me stories of your practice in which you felt good/bad or right/wrong, or that were memorable. Please tell stories as if you are talking about the care you did today to your peers in the resting room. Use everyday language."

"I may ask you some questions to clarify and understand your stories. You are free to decline to discuss any topics or answer any questions that may be uncomfortable for you. Now, our conversation is tape recorded. When you want me to stop recording or want to take a break, let me know. If you are going to talk about some stories which, you may think, involve illegal or questionable activities, please do not identify specific names or location related to the incidence."

Individual Interview Guide

Purpose: To solicit narratives depicting nurses' concerns and ethical comportment in caring for dying patients in Japan accompanied with situations and context which give understanding about the background meaning.

1. Please describe your clinical experience briefly since you started working as a nursing staff member.
    (a) How long have you worked in units where you provide end of life care to adult dying patients?
    (b) Did you choose to work in this unit? If so, why?
2. Please describe typical dying patients you care for.
    (a) Can you tell me a little bit about them? What was their diagnosis?
    (b) What are common concerns in care for them?
    (c) How are you working with them?
3. When you look over your history as a clinical nurse, is there any episode or story that stands out in your mind?

(a) Would you tell me episodes in past dying patients' care which is strongly memorable for you?

- How were you involved in the situation?
- Why do you recall them?

(b) Would you tell me an example of care for dying patient that you felt good or right about?

- What was the situation?
- How were you involved in the situation?
- What made you think/feel good or right?

(c) Would you tell me an example of care for dying patient that you felt bad or wrong about?

- What was the situation?
- How were you involved in the situation?
- What made you think/feel bad or wrong?

(d) Would you tell me an example of care for dying patient that made you think the care for dying patient is difficult?

- What was the situation?
- How were you involved in the situation?
- What was difficult for you?

Is there anything else important about your experience and practice of caring dying patient you would like to tell