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FAMILY AUTONOMY: A JAPANESE PERSPECTIVE AND A THEORETICAL FRAMEWORK

By

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ABSTRACT

FAMILY AUTONOMY: A JAPANESE PERSPECTIVE AND A THEORETICAL FRAMEWORK

By

Michael Derwin Fetters

The family's role in medical decision making has become a subject of spirited debate in bioethics. Using tools of anthropology and philosophy, I argue for the existence of a medical decision model in Japan best described as family autonomy, and develop a theoretical framework for its implementation. In Chapter One, I examine the family's role in medical decision making in Japan based on religio-philosophical, social, and cultural considerations. I present a framework for clinicians to accommodate family decision making in the North American context. In Chapter Two, I examine the question of whether family autonomy is a morally viable paradigm that has utility for modern bioethics. I propose seven precepts for implementing and limiting family autonomy. While further inquiry about the moral relevance and the family's role in medical decision making is needed, I contend that acknowledgment and utilization of family autonomy can improve the quality of medical decision making.

DEDICATION

This work is dedicated to my wife Sayoko Eileen Ann Moroi-Fetters and my sons Kori Michael Fetters, Tomoyuki David Fetters, and Kazuhisa Bruce Fetters. Without their patience and support this work could not have been completed.

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LIST OF JAPANESE TERMS

ai - love - a formal term of love

amae - dependence (see Takeo Doi reference)

en - relatedness

gisei ni suru - to make a sacrifice

ie - household, generational family

kanjinshugi - collectivism

makaseru - entrust decision making to others

shini me ni au - meet the eyes of death"; come to the patient's bedside at the time of death

shokku wo ukeru - be "shocked" mentally [by bad information]

yasurakani - the notion that the patient should be allowed to die a peaceful death

INTRODUCTION

THE FAMILY, JAPAN AND BIOETHICS

The notions of patient self-determination and patient autonomy are central to the modern bioethics movement. In one of the most widely read texts on bioethics, patient autonomy is one of four competing principles, the other three being beneficence, non-maleficence, and justice. Of these four, patient autonomy is usually given the greatest weight. The standard interpretation of ethics prior to the modern era is that it was driven by the model of paternalism. Physicians paternalistically made medical decisions for their patients. The moral basis for a greater role of patient participation is two-fold. First, because the patient is the one affected by illness, the patient will likely be more affected by the outcome of the medical decision than any other party. Second, the notion of bodily integrity argues that the threat of invasive procedures, makes respect for the patient of great importance. Thus, the patient should be given greatest moral weight in medical decision making. Under paternalism, the doctor made the decisions. Under the paradigm of patient autonomy, medical decisions are primarily the moral province of the patient.

To the family physician, this tidy rendition is problematic. Patients often explicitly want family members to be participants in medical decision making, and furthermore family members often have competing, compelling interests that should be given great moral weight. The role of the family in medical decision making has become the hot subject of debate in the bioethics literature. This literature largely examines how the family can take an auxiliary role in patient medical decision making, rather than the family taking the primary role in medical decision making.

In this paper, I argue that modern bioethics has mistakenly functioned on the premise that the only models of medical decision making for competent patients are paternalism and patient autonomy. I will use the tools of anthropology and philosophy to argue for the existence of a medical decision model in Japan best described as family autonomy, and then to develop a theoretical framework for implementing family autonomy. I have chosen this strategy because I believe that modern bioethics needs to first recognize the existence of this alternative model of decision making and then account for its moral legitimacy.

In many places I have used the words Japan, the U.S., the Japanese, North Americans, etc. Such generalizations inevitably risk oversimplification, and inadequate description of the diversity that characterizes these vibrant cultures. To the extent feasible given flow and space considerations, I have attempted to qualify overgeneralizations as regularly throughout the text. I have no intention of distorting the rich cultural features of any culture or society.

To contextualize this discussion, I begin Chapter One by examining the role of the family in medical decision making in Japan based on religio-philosophical, social, and cultural considerations. I then present a framework for accommodating family decision making in the North American context. In Chapter Two, I examine the question of whether family autonomy is a paradigm like paternalism that pales in comparison to patient autonomy, or whether it is truly a morally legitimate alternative paradigm to the prima facie emphasis on patient autonomy.

If modern bioethics is to have meaning for all members of society, it cannot serve strictly as a venue for mainstream North American values. Moreover, modern bioethics has a profound influence on the development of interpretations of moral rights and wrongs in many other parts of the world. North American bioethics should take leadership in the development of robust models for assessing moral rights and wrongs.

SELF-REFLECTIONS ON THIS RESEARCH

In anthropology there is a trend for researchers to undergo a process of reflexivity, that is, for the scholar to conduct an accounting of one's own roots, interests, and world views. Consequently, it is appropriate to begin with such an examination. I was born the second son of a middle class family in the eastern part of the Midwest. I have an older sister and a younger sister. Like many other families growing up in the sixties, my family initially relied completely on my father's income. When I was about four years old, my mother began a job for reasons which I suspect were primarily economic. Both of my parents were children of farming families and I believe that this gave all of the children in my family a strong work ethic. The school system I attended was part of the public school system. We lived in a small suburb outside of Columbus, Ohio. At the time, this suburb was perceived as being in the "boonies," though as a consequence of economic growth in the area, it is now considered a highly desirable place to live. A series of exciting events occurred that changed my rather unremarkable life.

My sister became a summer exchange student to Belgium. After her return, her host-father visited our home. Based on my sister's stories and those of her Belgian host-father, I realized the world was much bigger than the little corner of the earth I had grown up in. Later, my family hosted an exchange student, Jean-Philipe Ecoffey from Switzerland. Jean was a very dynamic and popular person. As part of the year long program there were several weekends where the local exchange students got together to discuss their feelings about their experiences in the United States and to share their own experiences, values, and beliefs as relevant to their own countries. Sometime during the course of hosting Jean-Philipe, I decided that I should apply to be an exchange student. Because I had studied Spanish for five years I had hoped to go to Spain, but thought that I would probably go to a South American Spanish speaking country. Under the American Field Service program the student applying to become an exchange student could not dictate one's destination, and as it turned out, I went to Japan.

This one year experience in Japan left an indelible mark on my perception of the world. It became clear that notions about "right and wrong," about "good and bad," "more delicious or less delicious" were largely determined by cultural norms. This experience in Japan, a country that has such a different historical, social, and linguistic background, strongly influenced my current position as a relativist. That is, I became convinced that notions about rights and wrongs could only be interpreted within a particular cultural context.

My own training is very diverse. As an undergraduate I majored in Japanese studies but because of all the premedical curriculum requirements, I was only two classes short of a second major in anatomy. This diversity which began as an undergraduate, set the stage for my life long professional development. I have maintained both interests in the sciences and the humanities. During medical school, the courses I found most stimulating were those relating to the behavioral sciences. This preference certainly was a major influence upon my decision to become a family physician. Not surprisingly, family medicine has its own particular flavor. In many ways it is the anti-science specialty of the medical world. The discipline of Family Medicine has a counter-culture history that could be characterized as anti-technological and anti-reductionist.

During my residency training in Family Medicine, I realized I wanted to acquire advanced skills for understanding the scientific basis of clinical medicine, as well as skills for conducting research. I was accepted into a research fellowship, the Robert Wood Johnson Clinical Scholars Program, and utilized the funding for a M.P.H. in Epidemiology at the University of North Carolina. With no stretch of the imagination, Epidemiology is primarily a quantitative, reductionist discipline. In the spirit of my relativist background, I used my elective time to take courses in qualitative research methodology and medical anthropology.

My professional interests were undoubtedly influenced by my experiences in Japan and other cross-cultural settings. I have spent nearly three years living in Japan over a course of nine trips. During the first trip, I was a high school exchange student for a year. The second trip I was a college exchange student. The third trip I was a pavilion guide and interpreter at the world exposition on science in 1985. My next major experience was as a family practice resident when I investigated the discipline of family medicine in Japan, and I also conducted a survey on family practice residents attitudes about training in Japan and the United States. This experience was followed by a three month research investigation as a Fulbright Scholar during which time I conducted a project examining Japanese physicians' attitudes about end of life medical decision making. My subsequent research has focused largely on the ethics of cancer disclosure in Japan.

Other important cross cultural experiences have included six weeks as a medical student working in the Kuskokwim Delta Region in southern Alaska for six weeks, and two months as a medical student observing traditional Chinese medicine in the People's Republic of China. Currently, I provide care for Chinese patients one to two times per week. Moreover, I am a constant participant observer of Japanese culture since 70-80% of my patient visits are with Japanese expatriates in the United States. In this way the Japanese language and culture has become part of me and my multicultural practice.

To date, my publications and ongoing research interests largely reflect the interdisciplinary nature of my background. I have published on the following topic areas: pragmatic aspects of conducting research in Japan; effectiveness of vaginal smears after hysterectomy for benign disease; family practice training attitudes in Japan and the United States; religious leaders perspectives on the human genome project; home care in Japan; traditional Chinese medicine and implications of the theory for western practitioners of medicine; the influence of medical culture on maternity care; and the epidemiology of bioethics.

I frequently am called upon to teach a variety of medical students, residents, and practicing physicians about topics in bioethics, clinical medicine, preventive medicine, research methods, and culture and medicine. In my academic career, I have used both qualitative and quantitative research methods and I recognize there are strengths and limitations for both types of research. The strengths of anthropology and philosophy for examining transcultural bioethics prompted me to enter the Michigan State University Interdisciplinary Program in Health and Humanities. My long-term goal is to apply the tools and knowledge I have acquired in medicine, epidemiology, anthropology, and philosophy for my clinical, educational, and research endeavors in bioethics. As a starting point, I hope that population, cultural, and philosophical perspectives will enhance modern bioethic's understanding of the role of the family in medical decision making.

Thus, my choice of Japan for this discourse reflects my own long-standing interest and relationship with Japanese language and culture that spans over 20 years and includes experiences as a high school student, a college student, a medical researcher, and a family physician for Japanese expatriates living in the U.S. My arguments and observations are based on both existing scholarly work, my living experiences in Japan, and my research experience in Japan in which I have formally interviewed over 50 Japanese physicians and

30 patients, and informally discussed these issues with many more of both, even on a near daily basis with the latter which accounts for 70% of my patient population. I have surveyed many more physicians, and mentored a medical student who interviewed and surveyed Japanese physicians. I have lived, worked and collaborated with many other Japanese physicians and health professionals. My immersion in Japanese culture has been a catalyst for my desire to develop an enhanced understanding of the role of the family in medical decision making in Japan, and the implications for the moral relevance of the family in bioethics.

CHAPTER 1

THE FAMILY IN MEDICAL DECISION MAKING: JAPANESE PERSPECTIVES

There has been a recent flurry of discussion about the role of the family in medical decision making (Hardwig 1990; Doukas 1991; Nelson 1992; Blustein 1993; Lindemann Nelson and Lindemann Nelson 1995; Kuczewski 1996; Reust and Mattingly 1996). The purpose of this paper is to extend this discussion by examining how culture can influence notions about the morally correct role of the family in medical decision making. Specifically, I offer a Japanese perspective on the role of family in medical decision making as one example of how cultural differences have relevance for assessing the ethically desired role of the family in medical decision making. I will show that in Japan there is a model of family autonomy in which the family is deemed the legitimate locus of decision making authority for both competent and incompetent patients. I offer a framework for guiding U.S. clinicians who are treating Japanese patients or patients from other collectivist cultures for whom respect for patient autonomy may not be a predominant paradigm. Clinicians who feel pressure to operate in accordance with a family autonomy framework that conflicts with the physician's customary paradigm of respect for patient autonomy should find this discussion helpful.

To achieve these ends, I examine the sources of bioethics in Japan, the family as the primary social unit, and descriptive and empirical literature about the family in Japan. These sources underscore why family interests are paramount in Japan and illustrate that within the Japanese context, medical decision making can have more of an impact on the family than on the patient. This circumstance challenges the notion of unconditional respect for the patient's wishes at the expense of the family. In contrast, it supports the legitimacy of family autonomy in cultures which value collectivism (or the tendency to emphasize group goals over individual goals when these goals are conflicting) to a greater extent than the more individualist-oriented North American tradition does (Nakane 1970; Befu 1980; Kim, Triandis et al. 1994; Yamaguchi 1994). I do not claim that there is an exclusive emphasis on individualism in North American culture. Nor do I presume that Japanese culture is static and homogeneous with an exclusive emphasis on collective thinking. I openly acknowledge the increasing emphasis on individualism in Japan, but make the claim that family autonomy functions and exists there. Family autonomy probably predominates in many circumstances in Japan, particularly for socially stigmatized medical conditions such as cancer, Alzheimer's disease, and schizophrenia. There is a need to look at Japan with a macroscopic lens if we are to understand the role of family in decision making. To contextualize the discussion, I begin with a brief overview of the sources of medical ethics in Japan, and the social importance of the family unit.

SOURCES OF ETHICS

Bioethics is a newly developing academic discipline in Japan, and there are a diversity of interpretations as to what values are respected by Japanese physicians. Examination of the rich philosophical, religious, and cultural traditions of Japan offers the prospect of formulating an ethical framework for guiding medical decision making influenced by diverse East Asian values. Whereas Christianity and Judaism have been the predominant religious influences on Western ethics, Shinto, along with the predominant religio-philosophical tradition of Buddhism, and the philosophical heritage of Confucianism, have been the outstanding influences in Japan as illustrated in the significant code of *bushido* (Way of the warrior). The ethical basis for decision making in Japan has been attributed to the philosophical traditions of Confucianism, Buddhism, and cultural values of harmony, consensus, and deference to authority. While individualism has flourished in the West, the philosophical traditions of Shinto and Buddhism have not nurtured the development of individualism in Japan. Scheper-Hughes and Lock attribute the low emphasis on the individual to the animism of Shinto, a religion that fosters a sense of immersion in nature (Scheper-Hughes and Lock 1987). In regard to Buddhism, they argue that "...the techniques of Buddhist contemplation encourage detachment from earthly desires and gross passions, experienced in the attainment of *mu*, or nothingness." Buddhism suppresses the egotistic self.

In his book *The Pulse of Wisdom,* Michael Brannigan systematically examines the philosophical traditions of Japan, and his analysis provides a philosophical foundation and feasible starting point for a Japanese bioethics (Brannigan 1995). He argues that the philosophical underpinnings of Japanese Buddhism and Neo-Confucianism as illustrated in *bushido* stress duties, obligations, loyalty, faith, and compassion. These traditions have undoubtedly influenced the Japanese sense of morality. The Buddhist construct of destiny (*inga*) links past, present, and future lives and instills a sense of *mono no aware*, an awareness of the fleeting nature of this world. One's lot in life is pre-determined and not self-determined. The influence of Confucianism in Japan is evidenced by the emphasis on relationships, benevolence (*jin*), and righteousness (*gi*) as extolled in the Neo-Confucian Shushi (or Chinese Chu Hsi) school. One's actions should be driven by these relationships and the duties of *jin* and *gi* rather than one's own preferences or will. The teachings of *bushido* emphasize a constant preparedness for death, unending service (*giri*), and purity of heart. The warrior should exhibit self-less devotion to his master. Thus, Shinto, Buddhism, and Confucianism all de-emphasize the importance of the individual. Against the backdrop of this overview of philosophical influences, I will now review some values articulated by various scholars as being relevant to Japanese bioethics.

Kimura argues that the Confucian concept of *jin* or "loving kindness" fostered paternalism in Japanese medicine (Kimura 1987). Kimura argues that medicine was perceived as an art of *jin*, an expression of loving kindness by the physician, and cites survey research by Nakano to support the belief that patients still abide by the notion of *jin* as the basis for receiving medical services. He argues that Japanese people have come to accept authoritarian and paternalistic patterns in the doctor-patient relationship as a result of *jin*. Second, Kimura theorizes that *kanpo* (traditional Chinese medicine) may foster a holistic approach by emphasizing the patient rather than the disease. He argues that the notion of bioethics itself has been interpreted with a totally new holistic approach to life, death, and virtually all health issues. Third, Kimura argues that *en* or "relatedness" has lessons for modern bioethics. He cites the work of Fujiyoshi and Tamaki, and deduces that the Buddhist teachings on *en* illustrate humans' relatedness with each other and with nature (Kimura 1987). Kimura emphasizes the role relatedness can play for helping Japanese people develop mechanisms for sharing information, developing trust, and determining treatment by both medical professionals and patients. He posits that a more delicate sense of relatedness is essential for recovering one's true humanity within nature. This interpretation of *en* is supported by Watsuji's interpretation of *aidagara* or "in-betweenness." The self is determined by the relationships within one's various groupings such as marriage, family, community, society, culture, world, and universe (Brannigan 1994). *En* and *aidagara* illustrate the fundamental relationality of our existence as part of others and not as an independent self.

Eric Feldman concludes that medical ethics are influenced strongly by two aspects of Japanese culture (Feldman 1985). First, the Japanese emphasize group harmony and consensus. He argues that the Japanese make every effort to maintain a calm, balanced compatibility in interpersonal relations, professional gatherings and governmental operations in order to avoid conflicts. In general, Japanese people prefer to avoid conflicts as this will inevitably result in loss of face for at least one party, an outcome that is bad for both parties. He observes that the appearance of compatibility may be true agreement, conformity, or acquiescence. There is a specific term in Japanese, *nemawashi*, that describes the art and intentional process of obtaining consensus in decision making (Fetters 1995). Coming to a decision requires input of the appropriate parties in the appropriate order, and is a much more complex than the open dialogue that is often expected in the U.S.

Second, Feldman observes that Japanese physicians have a tremendous amount of power (Feldman 1985). He attributes the status and power of Japanese physicians to the cultural norm of deference to people with a high level of education. This again reflects the influence of Confucian thought, and the respect for knowledge and status that it accords. By virtue of their intensive years of training and scholarly inquiry, it is natural for physicians to be given high social status and influence in decision making. Nonetheless, recent increasing pressures to emphasize patient autonomy and informed consent are illustrated by the burgeoning patients' rights movement, recent legal cases, and newly issued guidelines on informed consent from both the Japan Medical Association and the Ministry of Health and Welfare.

Kimura has argued the need for culturally relevant ethical principles and believe patient autonomy alone does not suffice as an ethical approach in Japan (Kimura 1986, 1987). Beyond attempts to integrate these Japanese values is a need for new paradigms that better fit the reality of decision making in Japan. In the following section, I present a cultural basis for the centrality of family in medical decision making.

THE FAMILY AS THE SOCIAL UNIT IN JAPAN

In Japan the family was purposely cultivated as a fundamental social unit at least since the Meiji restoration in the 19th century, and Confucian teachings on the importance of respect for family structures are even much older. This respect for family authority, and family relationships as a model for other relationships in society contrasts with that created in the U.S. under the influence of the pioneer spirit and individualism (Payer 1996). Further, it illustrates how the context impacts discussions and notions about the role of the family in medical decision making in the two countries. In the past century, Japanese society has strongly emphasized group and societal rights over individual rights (though there is certainly a growing sense of individualism, especially in metropolitan areas). Similarly, there has been a strong emphasis on family decision making. In contrast, American law and customs are largely based on the rights and interests of the individual. Since philosophical arguments are neither conceived nor debated in a vacuum, the individualism of American culture and the group-orientation of Japanese culture inevitably impact interpretations of moral rights and wrongs.

A detailed discussion of the history of the family in Japan is beyond the purposes of this paper, but a brief review of several historical events is necessary for understanding the current context of the family in Japan. The restoration of the Meiji Emperor in 1868 followed a feudal period of 400 years, during which time the family system of the warrior class had developed in conjunction with the evolution of the feudal order. The regulations and laws of the *bakufu* (feudal government) and feudal domains affected the family system by making the trusting relationships in the family paradigmatic for most human relations. Under the overarching authority of the head of the family, each member had a designated place, according to sex and age. Every member was expected to live each day in such a way as to guarantee the continued existence of the family. In this system, the head of the household held absolute authority over every single member, in much the same formalized way that a feudal lord governed his domain. Predominance over other members by the head of the family was symbolized by the authority of the father, husband, and eldest son. The wife, other sons, and all daughters were to obey the family head, such obedience constituting the highest moral code for their lives (Takeo 1973).

In the interval since that time, Japanese society has been developing economically, politically, and militarily, though many other elements of the feudal system have persisted. While the formal feudal system was destroyed with the restoration of the Meiji Emperor, personal and social hierarchical relationships prevailed extensively. Legally, the family structure remained rigidly patriarchal. After the educational Rescript of 1890, children were taught ultimate loyalty to the emperor. Society was merely the family writ at large, with the emperor at its head (Livingston

1973). In its desire to maintain social stability, the Meiji government sought to impose an idealized samurai family structure organized according to Confucian principles (Ike 1973). In 1873, the Dajokan decreed that commoners should follow the system of primogeniture that prevailed among the nobility. Five sections of the Civil law from 1896 and 1898 standardized the family system to traditional feudal values. In essence, lineage relationships were reinstated; family ties were stressed as the basic structure in Japanese society; and centrality of the household was affirmed for bearing the ancestral spirit of the family. The right of the eldest sons to inherit all family properties, and duties, was reinstated; furthermore, the revised civil law strengthened the authority of the family head. Specifically, his will determined the residential location of all family members (Takeo 1973).

This historical material serves as a prelude to contemporary Japan. Japanese scholars emphasize the family as the most important social and political unit in Japan. Until the World War II, the Japanese constitution and civil code gave the legal household head virtual autocratic and absolute authority over persons quartered with him, and even over members of the legal household unit who lived elsewhere (Beardsley 1965; Scheper-Hughes 1987). Scheper-Hughes and Lock argue that rather than the individual, it is the family that is the most natural and fundamental unit of society. They further argue that for four centuries, the greatest tension in Japan has between the individual's obligations to the state and to the family (Scheper-Hughes 1987). In addition to this importance of "family structure" at the macro level in politics, business, and medicine, the traditional extended family continues as an important functional unit at the citizen level as well. As of 1989, 14.2% of Japanese households contained three generations. The family is the foremost group to which an individual owes allegiance, and Powell and Anesaki, for example, emphasize continued importance of traditional family ties and responsibilities (Powell and Anesaki 1990).

The responsibilities are hardly uni-directional. The Japanese family in no small way is judged to be responsible for the behavior of its members, and there is no clear delineation of the responsibility for minors and adults. For example, the family's sense of responsibility for a deviant individuals' behaviors is often used in Japan to pressure the deviants to improve their behavior (Vogel 1979). Taro Takemi, former president of the Japan Medical Association, emphasizes the importance of *ie* in Japan (Takemi 1981). Translation of the word *ie* defies description by a single word, but it basically refers to the home, family, and family heritage. He states, "Each *ie* has its own pride in its ancestry, heritage and dignity of its own and also confidence in the health of its members. The responsibility for ancestor worship is passed on generation by generation. All these are shared by its relatives, and therefore, they do not crumble easily merely because one's *ie* abandons them."

The hierarchical structure of the family has a parallel in the doctor-patient relationship. Unlike Western culture, the doctor-patient relationship is not characterized by a contract between patient and physician which encourages patients to directly participate in medical decision making. Traditionally, doctors have a power relationship to the patient which could be considered parent-like. In the context of an analogous parent-child relationship, Kai argues that the patient can be interpreted as expressing *amae* to the doctor (Kai, Ohi et al. 1993). The psychiatrist Takeo Doi critically analyzed the meaning of *amae,* which has been translated into English as "dependence" on others (Doi 1971; Taketomo 1986). *Amae* is described as a feeling and behavior of trust and dependence toward one expected to look out for the best interests of the person who is in a dependent position. It may even be a "regression" to an infantile dependence on others that is regarded either as a positive or at least neutral indulgence in Japan, but would be construed negatively in Western thought. When *amae* unfolds in the doctor-patient relationship, a physician is expected to infer the patient's preferences and intentions without the patient making explicit requests or asking favors, which are both considered too direct and rude. While more passive, *amae* or dependence appears to underlie the concept of deference to authority as elaborated by Feldman. Kai et al. argue that *amae* in the doctor-patient relationship supports the ethical principle of non-maleficence and prohibits disclosure of harmful truth to terminally ill patients. They postulate that the reluctance of Japanese physicians to give candid information about terminal illness may be explained in part on this basis. Particularly in the case of malignant disease, the patient is isolated from accurate knowledge about his or her disease by physicians and the family. The exclusion of the patient shifts the decision making responsibility to the family.

In addition to a psychological importance of the family in Japan, there is a sociological importance as well, particularly for elderly people. The family care paradigm has been a fundamental traditional value in Japan. To some extent, this tradition may have roots in the primogeniture system which was only abolished after the end of World War II. While the oldest son held claim to his father's estate, he also had an obligation to provide care for his parents in life, and after death, including the duty of conducting daily rituals to honor the family ancestors (Scheper-Hughes 1987). The continued importance of family care without the backing of the legal system speaks even more strongly of the importance of family (Lock, 1993). Christie Kiefer reports that the rate of long-term institutionalization in Japan is 1.6% of those over 65 (versus 5% in the United States), and concludes that there are Japanese norms and social conditions mandating, "Thou shalt care for they dependent elderly relatives" (Kiefer 1987).

THE FAMILY IN MEDICAL DECISION MAKING IN JAPAN

In contrast to the growing number of papers that examine the role of the family in medical decision making in the United States, I have been unable to find a single paper dedicated in entirety to the role of the family in medical decision making in Japan from the English or Japanese literature. Of the scholarly work that only superficially touches upon the topic, the role of the family is typically discussed in relation to cases of terminal illness. Given this restriction, I will focus in the following discussion on the process of surrogate or substitute decision making by the family. In contrast to the typical usage of these words in Western bioethics, surrogate or substitute decision making in Japan does not necessarily imply patient incompetence.

In the classic paper, "Curable cancer and fatal ulcers: attitudes toward cancer in Japan," Susan and Bruce Long specifically discuss the role of the family in medical decision making for the terminally ill cancer patient in Japan (Long and Long 1982). The investigators interviewed over 150 individuals including 48 physicians during a stay in Japan. They report the following paradigm for dealing with medically proven diagnosis of cancer: "If it is curable, it is cancer, if it is terminal it is something else. Family members, more often than the patient himself, are told the true diagnosis." Still, as described by Long and Long, as well as others, the diagnosis is commonly revealed to patients that have surgically curable illness, obstructive symptoms which require surgery, or breast cancer which can be disfiguring. When the cancer is terminal, however, at least one family member is always told the diagnosis. Family members sometimes become substitute decision-makers for competent patients. Long and Long describe this as an uncomfortable role, since the family becomes an intermediary between the medical world and the patient's personal world, and feels responsibility to make sure the best decision is made.

A more recent article by Japanese authors further delineates the concept of substitute decision making. Hattori et al. elaborate on the role of family as the accepted, legitimate substitute decision maker in the paper "The patient's right to information in Japan—legal rules and doctor's opinions" (Hattori, Salzberg et al. 1991). The authors surveyed a convenience sample of physicians and medical students in Yamaguchi Prefecture. The 654 respondents answered 19 questions about controversial topics, including medical malpractice suits, brain death, and artificial fertilization. When the participants were asked what they would do if indispensable life-saving treatments were rejected by the patient, about 37% of the respondents said they would abide by the patient's decision, whereas about 40% said they would override the patient's wishes and proceed with treatment based on consent obtained from the patient's family. In the discussion the authors explain that Japanese people often prefer an indirect approach in which the family is told the diagnosis, but the patient is told that the problem is benign.

Hattori et al. cite three reasons for the use of substitute consent in Japan: 1) the relations of individuals to others within the family as embodied by the traditional Japanese concept of the family, *ie,* in which all the family members were dependent on each other; 2) the tendency to depend upon and trust others as embodied by the concept of *amae* as previously discussed; and 3) the belief by Japanese that a patient threatened with death should be allowed to die in peace (*yasurakani*). The anthropologist Emiko Ohnuki-Tierney's elaboration of the first and third points may facilitate better understanding of the role of the family. She describes a different notion of self in Japanese society. In contrast to being an independent, elemental person, she argues that in Japanese society, a person is structurally defined in relation to others (Ohnuki-Tierney 1984). This collectivist behavior in Japan is referred to as *kanjinshugi,* characterized by interdependence, mutual reliance, and respect for person-to-person relationships irrespective of costs and benefits (Yamaguchi 1994). In this way, the family takes responsibility for the patient.

Many authors attribute the practice of non-disclosure to a general fear that the conditions of patients will immediately deteriorate if they are told the diagnosis. Others fear cancer patients will be emotionally shocked (*shokku wo ukeru*), becoming depressed or even suicidal. The latter is of particular concern to a family seeking to prolong a patient's life since Japanese culture sanctions and even extols suicide (Long and Long 1982; Ohnuki-Tierney 1984; Kimura 1988; Hattori, Salzberg et al. 1991; Morioka 1991). Hence, there is cultural support for the concept of *yasurakani,* letting a family member or friend who is stricken with severe illness die in peace without direct or explicit knowledge of the illness. The patient should be spared burden of anxiety associated with the knowledge of the cancer diagnosis (Ohnuki-Tierney 1984). Cumulatively, these diverse sources illustrate that an understanding of substitute decision making, i.e., family autonomy, in Japan is crucial for medical ethics in Japan. Family members can legitimately give consent on behalf of a competent patient in such decision making processes as disclosure of risk, the diagnosis of cancer, and in cases where treatment is rejected by the patient.

Doctors are not unique in their judgment that families hold legitimate decision making power in Japan—a substantial proportion of the general population also appears to sanction substitute decision making for competent cancer patients. For example, Morioka assembled data collected from 1981 to 1985 in an annual Mainichi Newspaper survey on truth telling administered to the general public (Morioka 1991). Only 10 to 12% of respondents thought a family member should be told the diagnosis, whereas over 50% of the respondents consistently stated that they would prefer to be informed of the cancer diagnosis if afflicted themselves. In regard to this low level of assent for informing family members Morioka concludes, "It is difficult to inform the patient when the family is opposed to the idea. In most cases in our country (Japan) the will of the family prevails."

Despite the overwhelming assertion in the literature that Japanese medical culture is paternalistic, the discussion to this point illustrates this is an oversimplification of decision making reality due to the powerful role often taken by the family.

JAPAN - A CASE FOR FAMILY AUTONOMY FOR COMPETENT PATIENTS

For at least a century, the family has been a legitimate locus of decision making authority in Japan. Among the decision making patterns that developed is a paradigm that can best be described as family autonomy. The essence of this principle is that a common, socially sanctioned pattern of decision making is for the family, or a family member entrusted as a spokesman for the family, to make decisions for other members of the family, regardless of the individual family members' competency. Individual family members defer to the advice and collective wisdom of other members, or to that of a single key decision maker in the family. In many cases, the individual will presume that decisions will be made on his or her behalf by someone else in the family.

The very notion of family autonomy has received little examination. The particular phrase "family autonomy" can be traced at least as far back as *A Theory of Medical Ethics*, in which Veatch discusses the importance of including a theory about moral communities deemed important to the patient such as clubs, churches, and professional organizations, and other ascribed communities (Veatch 1981). However, Veatch only addresses states of patient incompetence or non-competence. Specifically, he covers: 1) patients who were previously competent and indicated in some way their preferences for treatment while still competent; 2) patients who were never competent; and 3) patients who were previously competent and did not indicate their preferences for treatment. Veatch does not address family autonomy for competent patients, a model of decision making that clearly operates in Japan.

It would be misleading to claim that respect for family autonomy is the only model of decision making in Japan. Family autonomy co-exists with physician paternalism and patient autonomy. The model that predominates depends on the particular circumstances. This model holds when all of the family members mutually agree to act in accordance with this model of decision making but is less likely to be the model if the decision making authority in the family resides with the person for whom the decision is to be made—in such a case that individual frequently retains final decision making authority. Family autonomy reflects an acceptance by the individual and the family that decision making authority is vested in one or more family members in place of, but with consideration for, the affected individual.

Recent innovative work by Fan on an East Asian principle of autonomy provides a philosophical basis for family decision making. The East Asian principle of autonomy stated in the positive asserts, "Every agent should be able to make his or her decisions and actions harmoniously in cooperation with other relevant persons," and stated in the negative asserts, "No harmoniously made decisions and actions should be subjected to controlling constraints by others" (Fan 1997). Fan bases this principle in three precepts: 1) family self-determination; 2) an objective construction of the good; and 3) harmonious dependence. While Fan finds roots for this paradigm in East Asia, I believe the underlying structures of family self-determination, an objective construction of the good, and harmonious dependence are not uniquely East Asian. Rather, these assertions have equal relevance for much of the world. Just as patient autonomy functions in many parts of East Asia, family autonomy functions in North America and the West. The comparison of the Western and the East Asian approaches are valuable for illuminating the most predominant patterns of decision making, but such narrow descriptions fail to capture the spectrum of approaches in these regions of the world. Since family-determination is central to Fan's thesis, and because its relevance extends beyond East Asia, I propose the term *family autonomy* as the preferred terminology. Fan's analysis provides a compelling starting point in the development of a philosophical basis for autonomy, though a detailed analysis is beyond the immediate purposes of this chapter. It is often stated that the "ethics are in the details." Hence, my task now is to elucidate the details of the Japanese context to illuminate the moral importance and role in decision making of the family.

THE FAMILY IN DECISIONS ABOUT CANCER DISCLOSURE

Japanese physicians have been harshly criticized for not disclosing the truth about cancer to their patients. While it is has been argued that medical decision making in Japan is driven by physician paternalism, there are at least some contexts in which physician paternalism appears to be superseded by family autonomy. In interviews with me, Japanese physicians have argued that there is 100% informed consent for cancer patients because the family is always informed of the diagnosis. While physicians may be able to influence the family when deciding whether to inform the patient, it is clear that Japanese physicians are extremely reluctant to override explicit family preferences for disclosure or non-disclosure. When the family opposes disclosure, even if the physician feels it is in the best interest of the patient to know the diagnosis, the most common pattern is to follow the wishes of the family and not disclose the diagnosis to the patient. Physicians seek family input due in great part to their belief that the family knows the patient's personality, values, and preferences much better than the physician, and is more qualified to make such an important determination about the degree to involve the patient as a family member in decision making.

These claims are made based upon our previous empirical research. Elwyn et al. describe Japanese physicians' experiences with family opposition to disclosure to the patient (Elwyn, Fetters et al. 1997). While 73% of Japanese physicians surveyed stated they would be more likely to disclose the cancer diagnosis if the patient indicated a preference to know, only 35% of them said they would be more likely to disclose a cancer diagnosis if the family opposed, even if the patient indicated a preference to know. Only 7% of the physicians reported experiences overriding family opposition to disclosure when the patient indicated a preference to be told. In summary, the power to decide whether the patient is told often resides with the family. In these circumstances, the decision about whether and to what extent the patient is involved is primarily a family decision.

THE FAMILY IS MORE AFFECTED BY END OF LIFE DECISIONS THAN THE PATIENT

A central argument that places patient autonomy supreme in ethical decision making is the claim that the patient is affected more profoundly by medical decisions than anyone else. Experience in Japan has forced me to critically evaluate this assumption. One contextual difference relates to time. Western bioethics focuses largely on the patient's life from the time of conception (or birth) up until the patient's death and the immediate period thereafter. By the Judeo-Christian tradition, an individual has one opportunity to achieve everlasting life; that is, how you live your life this one time determines whether you spend eternity in heaven or hell. By the

Buddhist tradition, an individual's life is a transient event in a much longer course of time. Through rebirth, the individual will return to the world in a series of future reincarnations until one attains nirvana through the process of enlightenment. Through ancestor worship, one has obligations to those who came before and to those who will come after (Smith 1974). In this context, individual interests seem much more selfish and egocentric. Selfishness runs counter to traditional Japanese values of self-sacrifice (*gisei ni suru*) and entrusting others to make decisions (*makaseru*).

A second perspective provides another contextual difference. Contemporary family members continue to live after the patient's death. Regardless of the religious context, once the patient is dead, the impact of medical decision making for that individual is over. The family, however, must continue to live with *how* the patient died and the impact of the dying process after the patient is dead. In Japan, the deceased continues to exert considerable influence on the family even after death (Smith 1974). There is a series of mortuary rituals after death, all of which the family must perform to satisfy family pressures and social pressures (Ohnuki-Tierney 1994).

Traditional expectations about death highlight the impact of how the patient dies on the family. It is commonly considered dishonorable for the family if an individual patient dies without a family member in attendance at the time of the patient's death (*shini me ni au*). While most Japanese people would prefer to die in their own home, most now die in hospitals. Transplanting the location of death to the hospital has created problems for family members who feel an obligation to be at their family member's bedside at the time the patient's heart stops beating. Unfortunately, the general lack of private rooms in Japanese hospitals inhibits family members from staying in the hospital. Consequently, patients often have cardiopulmonary resuscitation (CPR) with the sole purpose of "keeping the patient alive" so that a family member can be called and come to the hospital to be at the patient's bedside at the time of death. Even when there is no hope of survival, sometimes CPR is conducted for an hour or more to allow family members time to arrive. Once the family arrives, the respiratory support is removed and chest compressions stopped so that the patient can die in the company of family. In short, CPR is conducted for the family to provide the family time both to process the threat that their loved one is about to die, and to prevent a lifelong sense of guilt for not being at the bedside since *shini me ni au* is the cultural expectation.

Finally, the three-generation household has important financial implications. Unlike the common Western expectation that adult children will establish nuclear families financially independent of their parents, a common Japanese tradition is to maintain intergenerational financial ties throughout life. This is by no means novel, and certainly even in the West many adults support or are supported by their parents, but the Japanese situation is significant in both the extent of the family's financial obligations to an individual family member, as well as the potentially serious financial implications of the patient's care for the family. Though there is no longer a legal basis for primogeniture, patterns of inheritance and responsibility often follow the spirit of the tradition of primogeniture. For example, it is still common (though not the only pattern) for the eldest son to inherit the family home and family business. On the basis of filial piety (*oya koko*), the eldest son and his wife are expected to provide care for his parents until their death. When the eldest son marries, his new bride comes into his family's *ie* to become a new family member. This melding of fortunes, with the eldest son bearing the financial costs of his parents' support yet also reaping the financial benefit of their accumulated wealth, is much different than in the West where individuals are more expected to become financially independent. In this sense, the family fortune belongs to the *ie* or the generational family. The head of the household is a steward of the long-term family wealth and has an obligation to his ancestors and future generations to maintain financial solvency. Within this context, expensive end of life medical care has very different implications than in the West where it is expected that the resources an individual garners during his lifetime are appropriately spent back on him during his time of medical need. In Japan, sacrifice by the patient in the interest of preserving the family wealth is both expected and considered venerable.

THE CANCER DISCLOSURE PARADOX

The cancer disclosure paradox describes a phenomenon found in opinion surveys in which the majority of Japanese respondents state that if affected by cancer themselves, they would prefer to be told the truth, but that if a family member were afflicted with cancer, they would not want the family member to be told. In 1981, 53% of respondents stated they would prefer to be told if they developed cancer, while in 1994, this number climbed to 64% of respondents. In regard to the situation in which a family member was afflicted with cancer, in both the 1981 and 1994 surveys, 58% responded that they would prefer that the family member not be told (Morioka 1991; Tokyo Yomiuri Chokan 1993; Tokyo Yomiuri Chokan 1994). The percentage of the population opposed to disclosure to a cancer-afflicted family member has had minor fluctuations in the intervening 13 years, though there are two trends. First, the number of people who wish to be told the truth about the cancer diagnosis is gradually increasing, and second, the number who believe that the diagnosis of cancer should be withheld from a family member afflicted with cancer is staying about the same. In my interpretation, the former trend reflects an increasing prevalence of the belief that patients have a right to know their own diagnosis, or ethically speaking, that physicians should respect patient autonomy. The second trend reflects the notion that individual family members have the authority to make a decision on behalf of a family member, or ethically speaking, that it is morally legitimate to respect family autonomy over individual patient autonomy. Finally, in the most recent polls, over 30% of participants did not express a preference to be told the truth if cancer was diagnosed. In effect, this suggests a substantial minority of patients are saying, "I want someone besides myself to bear the decision making responsibility if I have cancer."

The logic behind the cancer disclosure paradox is not intuitively clear. However, our recent research may suggest differing interpretations about a family member's age as a plausible explanation. From the data of Elwyn et al. it is clear physicians are most likely to tell a middle-aged person; with decreasing age or with increasing age, physicians are decreasingly likely to disclose a cancer diagnosis (Elwyn, Fetters et al. 1997). Japanese expatriates who were mostly in their thirties and forties, and who mostly indicated preferences for cancer disclosure if affected themselves, also thought that a cancer diagnosis should be withheld from an older family member (Fetters 1997). Thus, the cancer disclosure paradox probably reflects respondents answering the question, "If your family member had cancer, would you tell?" with variable interpretations by respondents with regard to the age of the family member afflicted with cancer.

These trends illustrate the evolving tension between individualism and the traditional collectivism of the past. The decline of the traditional family structure, as evidenced by the increasing number of divorces and single parent families; the decreasing number of three-generation households; as well as increasing individual prosperity and financial independence in Japan illuminate the growing influence of individualism. The idea of withholding cancer from a family member represents the persistent influence of traditional values emphasizing family autonomy. With the approach of the twenty-first century, a major challenge for bioethics in Japan is to determine how to balance these two forces.

CLINICAL BIOETHICS: FAMILY AUTONOMY VERSUS PATIENT AUTONOMY

The recent work of Blackhall and Carrese is among the most prominent literature reminding North American ethics of the need to be more tolerant of other cultures found within the continent's own borders (Blackhall, Murphy et al. 1995; Carrese and Rhodes 1995). From an epidemiological perspective that utilizes the world's population as the denominator, patient autonomy is probably not the most prevalent decision making paradigm. We should occasionally remind ourselves that the North American emphasis on patient autonomy and individualism is the exception to the rule from a global perspective.

So what should a Western clinician do when confronted with a situation in which she feels a conflict between, on the one hand, her professional mores and training that emphasizes respect for patient autonomy, and on the other hand a pressure to respect family autonomy? There are a number of factors the clinician should consider. First, the clinician should accept that the patient and family may prefer to function under an alternative model of decision making such as family autonomy. Second, she should realize that an approach which says, "This person and this family are in the United States (for example), and therefore have to abide by its rules," is not only a culturally insensitive approach, but is also arguably a particularly paternalistic approach as it reflects the physician's imposition of her values about what is right and wrong onto the patient. Third, the clinician must resist the assumption that a patient will anticipate a model of family autonomy or paternalism simply because the patient's associated culture is generally known not to exercise respect for patient autonomy. For example, a young Japanese woman afflicted with cancer known to me chose to stay in the United States as she felt uncomfortable with the approach to cancer management in Japan. To assume she did not want to make decisions for herself would be as bad as assuming that she wanted someone else to make the decisions for her. Fourth, clinicians in the U.S. need to assess the degree that the patient wishes to adhere to the traditional norms of decision making characteristically associated with the patient's cultural background. Fifth, in the event that the clinician is uncomfortable with the decision making model preferred by the patient and family, she should be willing to refer the patient to a physician who can accommodate their preferences; she should not have to violate her own professional integrity. Sixth, physician intervention to allow (or force) the patient to exercise autonomy should be restricted to circumstances in which the clinician feels a tension between the patient and family preferences.

Two clinical approaches have been articulated that are relevant for accommodating patients who may choose to operate under a family autonomy paradigm. The first, the family covenant, provides a preventive ethics approach (Forrow 1993) and acts as an agreement in which the primary care clinician is entrusted with the family's health care with their consent (Doukas 1991). Patient autonomy and family beneficence claims start with equal weight. The clinician is called upon to weigh both ethical claims where there is conflict between patient autonomy and family beneficence claims on a case-by-case basis. In the course of a trusting relationship, it will be possible for the physician to better learn the patient's values and preferences, and to serve them in accordance with the family covenant.

Unfortunately, it is not always possible to take such prophylactic measures because patients will invariably present with acute illnesses that may preclude a preventive ethics approach. In this circumstance, the clinician may wish to offer the patient truth (Freedman 1993). With this approach, the clinician ascertains how much information the patient wants to know. The patient is given the opportunity to learn the truth at the level of detail that the patient desires, and the patient may autonomously defer decision making to the family or the clinician.

DISCUSSION

In this paper, I have argued that historical, religio-philosophical, social, and cultural factors have resulted in a family autonomy model in Japan in which the family is the legitimate locus of decision making authority. This illustrates one example of how notions about what is morally right and wrong are determined by cultural values. In Japan, a lower emphasis on patient rights and individualism support the legitimate role of the family in medical decision making even for competent patients. Ultimately, in Japan and the United States, medical decision making rests with those empowered to make decisions, and there can be no mistake about the traditional power of the family as a social unit in Japanese culture. While there is a general perception that physician paternalism has driven the doctor-patient relationship in Japan, to at least a limited extent, the family has also been a legitimate locus of decision making authority and illustrates a functioning paradigm of family autonomy.

There are at least two caveats about family autonomy in Japan. First, in individual circumstances it may be dysfunctional and individual rights may be placed secondary to family or group interests. However, there may likewise be circumstances when patient autonomy can be dysfunctional. In both cases, the details and circumstances must be examined on a case-by-case basis, and must yield to the most morally compelling claim. Second, to the extent that Japanese society is patrilineal, a feminist critique of the family autonomy model might suggest that a family autonomy decision making model in Japan comes at the expense of not only individual rights, but differentially of women's rights. There are certainly cases in which a woman serves as the primary substitute decision maker for incompetent and competent patients alike. Further examination of the role of gender in medical decision making in a variety of cultures is necessary. For example, what is the role of family autonomy in matrilineal societies?

Recent social trends suggest that many people in Japanese society are unwilling to maintain the status quo. Advances in medical technology and grassroots movements are pushing physicians and ethicists to change the traditional decision making models. Does a model that shifts power further away from physicians to the family meet the needs of the cultural context, or is there a need to shift power from physicians *and* families to patients? In light of the recent social changes in Japan, will a family-centered decision making model survive? Is family autonomy an antiquated model destined for extinction as enlightened generations become older? Given the traditional importance of the family, it is unlikely that, at least for the immediate future, respect for patient autonomy as conceptualized in North American bioethics will be the only model. Will or should different decision making models vary by disease or health condition? Further, does the approach to decision making vary by age or gender?

Perhaps Japanese society will be more tolerant of multiple models which include patient autonomy and family autonomy, or even less exclusionary, currently undescribed patient-family autonomy hybrid models. For example, Akabayashi et al. describe the case of an elderly patient who expressed a preference to her family not to be told a cancer diagnosis if she ever developed cancer (Akabayashi, Fetters et al. Under Review). After seeking the family's opinion about disclosure of cancer to the patient, namely, family consent for disclosure, the physician explored the patient's preference to participate in decision making through a process of ambiguous disclosure. The attending physician alluded to the plausibility of cancer, but never overtly presented it to the patient. The patient never expressly indicated a preference for more detailed information, and non-verbal cues suggested to the attending no interest in further elaboration of the issue. Examination of mechanisms such as ambiguous disclosure might help Western bioethics become more pluralistic and better accommodate decision making models more tolerant of family interests. Nelson asks "...whether structures can be developed that more appropriately accommodate the values of affected intimates while at the same time preserving to acceptable degree the values promoted by patient-centeredness" (Nelson 1992). The question in Japan is, "Can structures be developed that more appropriately accommodate the values of the affected patient while at the same time preserving to an acceptable degree the values promoted by family-centeredness?"

In the quest to answer questions about the morally legitimate role of the family in medical decision making, ongoing cross-cultural bioethical inquiry may help delineate alternate decision making models that adequately account for both patient and family interests, as well as their cultural values. This line of inquiry will also help prepare U.S. clinicians for the increasingly common and real-life episodes of providing care for patients who prefer to operate under other decision making paradigms. Further, it will provide Japanese clinicians, and clinicians in other cultures where exclusive emphasis on a model of patient autonomy is not feasible, ethical justification and legitimization of practices not accounted for in current bioethics paradigms.

CHAPTER 2

A THEORETICAL FRAMEWORK FOR FAMILY AUTONOMY

Much of the world cannot wholeheartedly embrace the North American approach to bioethics because it fails to incorporate and adequately address the role of family in medical decision making. Exclusive emphasis on a model of either paternalism or patient autonomy fails to address a third important model, family autonomy. The social structures in most of the world do not support individualism and self-determination to the extent evident in North American culture. There is a much greater role for the family in medical decision making than is accounted for by modern bioethics in which the family's role is an auxiliary support for the competent patient, or a surrogate for the incompetent patient. In Chapter 1 and previously, I have argued that a combination of historical, religio-philosophical, social, and cultural circumstances created a decision making milieu in Japan in which family autonomy functions as a legitimate model of decision making (Fetters 1995). Family autonomy is acceptable in Japan because of the value structures within Japanese culture. My purpose now is to move beyond the level of existence and moral relativism. It is necessary now to develop a theoretical framework for family autonomy.

While patient autonomy is a steadfast model, it is not the only morally relevant model of decision making, particularly in collectivist countries where family-determination is pervasive. In many other cultures, patient self-determination is not valued to the same extent that it is in North American culture. The exclusive emphasis on patient autonomy does not effectively address the family in medical decision making. In this way, the current North American bioethics paradigm is incomplete. It is imperative for bioethics to account for all the models of decision making, to explicate the moral basis for their application, and to articulate the rationale for executing one model over another (Brody 1990). Before the accounting is complete, conclusions about the morally preferred approach are premature.

Mainstream bioethics is incomplete for global, ethical, medical decision making needs as it is not sufficiently pluralistic. From a global perspective, there is a fundamental need for an ethical alternative to the model of patient autonomy. Outside of North America, patient autonomy is perceived as a minority view model. There is an urgent need to address the family in medical decision making, a need in my opinion to explicate a framework for implementing family autonomy. I further hold that while patient autonomy clearly is a majority view model in North America, there is a need to understand family autonomy, as it has great relevance for both North Americans who hold deeply their values about family-determination while living in an environment focused on self-determination, and non-North Americans who look to North America for its leadership role in medical ethics. Examination of family autonomy thus offers a fresh perspective and an opportunity to re-examine the central features of modern bioethics and foster the growth of a more robust discipline. In these ways, a theoretical framework of family autonomy can meet the global need for an ethical basis of the family in medical decision making, as well as the need in North America to understand the moral fabric of family determination.

Thus, my purpose is to analyze family autonomy at a theoretical level. I will begin with a historical perspective on the family and a review of the bioethics literature on the role of the family in medical decision making. I propose a definition of family autonomy, and examine the moral basis for family autonomy. I illustrate that patient autonomy and family autonomy can both manifest as patient decision making or family decision making. Subsequently, I offer seven precepts that can serve as a theoretical framework for implementing family autonomy. I proactively anticipate criticisms of the model and respond to them. Finally, I close with a discussion of family autonomy's role in modern bioethics.

HISTORICAL PERSPECTIVES

Modern bioethics asserts that the model of decision making until the mid-twentieth century was driven by physician paternalism. This physician-centric view implies that physicians made the medical decisions. Modern bioethics also asserts that social changes, advances in medical technology, and legal precedents in the 1960s gave birth to a second model of decision making, that of patient autonomy (Rothman 1991; Pellegrino 1993). The main thrust of modern bioethical inquiry toward how to resolve dilemmas when there are discordant views between these two moral agents, the physician and the patient. Modern bioethics also articulates the morally preferred surrogate decision making mechanisms for incompetent or incapacitated patients (Buchanan and Brock 1990).

I believe it most appropriate to begin our discussion by taking a more macroscopic view of decision making about health. It is important to remember that there are two types of decision making related to health: medical decision making and decision making about illness. Medical decision making implies the participation of a physician, whereas decision making about illness does not require a physician's participation. Modern bioethics asserts that medical decision making was historically driven by paternalism. While there is truth to this assertion, it does not hold that decision making about illness was also driven by paternalism. Patients, families, and other non-physician healers have been making health and illness decisions long before there was ever even the concept of a physician. Until the past several hundred years or less, most ill individuals never even had access to a physician. In the face of illness individuals used treatments from family, friends, and neighbors. When these failed, they sought care from lay healers in their community who were often self-taught or trained through an apprenticeship (typically, the same way that physicians learned their skills). Given the universal nature of human suffering and the absolute paucity of physicians until the modern era, the assertion that paternalism drove medical decision making is technically correct, though it is also misleading. Patients, families, and non-physician healers have a long history of making decisions about illness that modern bioethics ignores.

Even in the modern medical era, the vast majority of illness consultations are not with physicians (White 1961). Rather, most ill individuals self-treat, or seek consultation with a family healer or lay healer prior to seeking the services of a physician. This epidemiological perspective illustrates that although the major thrust of the modern bioethics inquiry has been focused on illness encounters only with physicians, such interactions account for only an absolute minority of health-related decisions (Fetters and Brody 1998). If this critique is correct, we must accept that patients and families in consultation with each other and with friends and lay, non-physician healers have been making health decisions much longer and more broadly than physicians. These points further underscore bioethics's need to understand and accommodate the role of family in decision making.

To the extent that family is participating in illness decision making up until the time the patient seeks consultation with a physician, it is quite unnatural to believe that after such consultation the family will either drop out of the picture altogether, or at best play only a supporting role in patient decision making. Unfortunately, allowing a greater role of the family in medical decision making complicates things to a much greater degree than when the decision making agents are limited to the doctor and patient. In the latter case, there are essentially only two possibilities: either the physician decides, or the patient in consultation with the physician decides. Within these interactions, the patient and physician either agree on the intervention, or disagree. A dilemma arises when there is disagreement between the physician and patient about the best course of action. This conflict between patient autonomy and physician paternalism based on the physician's interest in benefiting the patient has been extensively explored, and will not be examined further.

Unfortunately, the elegant simplicity of examining only these two moral agents limits its relevance for clinical decision making. Clinical decision making is much messier and is frequently not distillable to these fundamental units. On the contrary, as the difficulty of the decision increases, the likelihood of more complex paradigms increases. In this way, bioethics has been largely limited to a simple addition model. The addition of the family as a third moral unit to the discussion introduces the potential for exponential expansion of the set of circumstances. This expanded set of circumstances is untidy and messy because a greater number of human interactions must be accounted for. In this way, greater scrutiny of the family is helpful and necessary as it is a closer representation of the real context in which clinical decision making proceeds (Reust 1996). The recent surge in discussions of the family reflects a recognition of the need to move beyond a dichotomous moral agents model and to account for the family as highly relevant moral agents with more than just a role in supporting the patient's decision (Hardwig 1990; Nelson 1992; Blustein 1993; Lindemann Nelson and Lindemann Nelson 1995; Kuczewski 1996; Reust 1996).

BIOETHICS PERSPECTIVES ON THE FAMILY

In 1990, John Hardwig focused modern bioethics attention on the family and the need to better account for the role of family members in decision making for *competent* patients (Hardwig 1990). This initial work was followed by Nelson's examination of the special moral value of intimacy (Nelson 1992). The intrinsic value of the family, not just its instrumental, practical value, is examined in greater depth in the subsequent book by Hilde and James Lindemann Nelson, *The Patient in the Family—An Ethics of Medicine and Families* (Lindemann Nelson and Lindemann Nelson 1995). The Lindemann Nelsons identify seven guiding principles, so called "stars to steer by:" 1) family members aren't replaceable by similarly (or better) qualified people; 2) family members are stuck with each other; 3) the need for intimacy produces responsibilities; 4) causing someone to exist produces responsibilities; 5) virtues are learned at our mother's (and father's) knees; 6) families are ongoing stories; and 7) in families, motives matter a lot (p. 74). This pioneering work offers a framework for accommodating the family's perspectives into patient care and medical decision making.

However, it may not provide a complete framework for recognizing the decision making roles of families in non-individualistic societies. For example, love is not necessarily a component of family in all cultures. In contrast to the very casual use of the word *love* in the United States, the most comparable word in Japanese, *ai*, is used infrequently and in much more rigid circumstances in Japan. Similarly, while motives may be important, symbolic actions taken regardless of the motives by family members in Japan on behalf of others may be seen as equally or more important than motives. In this way, recent philosophical inquiry informs bioethics of the need to involve the family to a greater extent, though exploration to date remains incomplete. A comprehensive framework for guiding the family's role in decision making is lacking. The conceptualization of family autonomy is needed to extend bioethics's understanding of the family in medical decision making.

DEFINITION OF FAMILY AUTONOMY

Family autonomy describes a decision making paradigm in which all decision making authority must derive from the family, the fundamental moral unit. Individual family members in this paradigm exist, but are incomplete moral entities since they are defined by their relationships to others. It explicitly states that individual preferences are subject to interpretation and deliberation by the family. The family is self-identifiable. In some cases it may be strictly defined as blood relatives, while in other circumstances, family may be characterized by the nature of having a close personal, family-like relationship to the individual. For example, the patient who states, "My cousin Rick is like a brother," illustrates the extent that Rick qualifies as "family." While bioethics continues to struggle with defining the family, when the family is called, the family shows up (Lindemann Nelson and Lindemann Nelson 1995).

Fan offers a philosophical basis for family-determination which he terms an "East Asian principle of autonomy" (Fan 1997). He proposes both its positive formulation, "Every agent should be able to make his or her decisions and actions harmoniously in cooperation with other relevant persons," as well as its negative formulation, "No harmoniously made decisions and actions should be subjected to controlling constraints by others." I think this is a superb rendition of the underlying principle, though I am troubled by Fan's lexicon. Fan defines "other relevant persons" as family members (usually the spouse, parents, and adult children) and the physician. For me this definition is problematic as it goes too far in lumping together moral agents, namely, the physician and the family, who have distinctly different perspectives on health, values, and medical treatments. Given physicians' paternalistic track records, there are morally compelling reasons for treating them in a separate category. It is somewhat curious that Fan proceeds to state that the family has the final authority to make clinical decisions, while choosing to call this principle the "East Asian principle of autonomy." The phrase "family autonomy" better describes the decision making authority described by Fan.

As I indicated previously in Chapter 1, Fan finds roots for this paradigm in East Asia. The underlying structures of family self-determination, an objective construction of the good, and harmonious dependence are not solely East Asian. Fan's assertions are relevant beyond East Asia. Since family-determination is central to Fan's thesis, and because its relevance extends beyond East Asia, I propose the term *family autonomy* as the preferred terminology. These considerations aside, I will now examine the Fan's assertions as a moral basis of family autonomy.

FAN AND THE MORAL BASIS OF FAMILY AUTONOMY

Ruiping Fan claims that a morally compelling argument for family autonomy can be found through examination of Western and

East Asian constructions of autonomy (Table 1) (Fan 1997). Fan begins this argument by examining Beauchamp's distinction between morality in the narrow sense and morality in the broad sense (Beauchamp 1996). Fan's interpretation of Beauchamp is the following: morality in the narrow sense refers to the universal philosophical precepts usually categorized as principles, rules, and rights (Fan 1997). Fan summarizes Beauchamp as saying, "These precepts (a) 'are vague, general, and indeterminate precepts' having only 'abstract content'; (b) 'constitute the morality wherever it is found' and thus are 'universally binding'; and (c) offer 'a basic orientation for addressing specific moral problems' and 'provide an objective basis for moral judgment and international law.' Morality in the broad sense refers to the divergent philosophical, religious, and cultural commitments that have varying weight in different situations. Fan interprets Beauchamp as saying that the universal moral precepts in the narrow sense receive further interpretation, and that they are not absolute; that there are exceptions to them; and that there is no single ranking of them, since in different situations, people may assign different rankings. Fan argues that East Asian morality in the narrow sense is based on an East Asian construction of autonomy fundamentally different from the Western construction. Western autonomy is characterized by: 1) patient self-determination; 2) a subjective conception of the good; and 3) individual independence. Fan's "East Asian autonomy" is characterized by: 1) family self-determination; 2) an objective conception of the good; and 3) harmonious dependence. Systematic examination of each of these is beyond my purposes, but the second comparison between the West's subjective view of the good and the East's objective view is of crucial relevance.

In regards to the question, What is the basis on which to decide?, Fan states it is determined by the second feature, namely, an objective conception of the good. With a clear definition of the good, the question of best interests, balancing different values within the family, becomes moot because physicians have a clear understanding of how to judge and critique a family's decision. Fan first illustrates the basis of the subjective notion of the good as having its roots in the Enlightenment, and shows how this subjective nature of the good becomes articulated in bioethics. In their discussion of medical decisions made for children in relation to the children's good he illustrates that Buchanan and Brock assert "...that the goal [of socialization in the West] is to prepare a child with opportunities and capacities for exercising self-determination as an adult in choosing and pursuing his/her own view of values, rather than foster a child to lead a life in accordance with a certain conception of the good life objectively understood" (Fan 1997). He counters that in East Asia, there continues to be a homogeneous conception of the good, and values generally espoused by various communities, families, and individuals serve as an impersonal, objective formulation of the good. He argues that Confucian, Buddhist, Taoist, and Shinto precepts have overlapped in Asia and formed overlapping values. Parents raise their children to accept life in accordance with the objective conception of the good the parents hold. Family autonomy discounts patients' preferences for treatment if they do not fit into the objective conception of the good (Fan 1997).

In Fan's formulation, the moral basis of family-determination depends upon an objective conception of the good. As such, this point merits scrutiny to determine if indeed an objective conception of the good withstands critical analysis. For discussion purposes, assume that there is an objective good. Faced with a medical decision about a family member, the family must choose the objective good, otherwise, family autonomy is morally suspect. For example, suppose the patient is diagnosed with appendicitis. Without surgery the appendicitis will perforate and the patient will become very sick or even die. A course of surgery as an objective good recognized by the doctor, family and patient in the family must be followed, or family autonomy becomes morally suspect. That is, pursuit of the objective good, i.e., the morally right course, leaves no room for autonomous decision making. Even if the objective conception of the good is obvious only to the family and the patient, a family's choice of anything other than the objective good results in an immoral decision. In short, while there may or may not be an objective conception of the good, it is clear that an objective conception of the good alone cannot suffice as the moral basis of family autonomy. Still, as I show below, an objective conception of the good is not a necessary condition to illustrate the importance of family autonomy. Another look at the role of individualism and how it impacts the assessment of morality is needed.

THE MORAL BASIS FOR PATIENT AUTONOMY AND FAMILY AUTONOMY: THE INFLUENCE OF INDIVIDUALISM AND COLLECTIVISM

As patient autonomy is a robust model, scrutiny of its moral pillars can serve as a starting point to establish the moral foundation of family autonomy. There are at least two relevant considerations: 1) Who are the moral agents most affected by the decision?; and 2) What are the issues of bodily integrity? The first moral pillar of the patient autonomy paradigm is the interpretation that the patient is most profoundly affected by medical decision making since it is the patient who is ill and may live or die based upon the decision that is made (Katz 1984). Clearly, the patient is profoundly affected by medical decisions. Using Japan as an example in the previous chapter, I have argued that the family may be profoundly affected as well. Rather than repeat in full each argument, I will summarize them here. First, there are financial considerations particularly in three generation households where there is a melding of fortunes between the generations, and obligations to ancestors to maintain the solvency of the household (*ie*). Second, the way the patient dies has profound implications for the family. Family members who fail "to meet the eyes of death" (*shini me ni au*) have not filled their filial obligation. Third, the deceased continues to exert pressure on the living through post-mortem ceremonies. In comparison to the patient's risk of dying, losing a limb, or living with a complication of treatment such as paralysis, do these family considerations pale in comparison?

A second moral pillar of autonomy is based on the notion of bodily integrity. Patients should be able to maintain wholeness of mind and body. There is no need to dispute this, though a Japanese interpretation might also ponder the importance of bodily integrity of the family. Undeniably, a patient's illness has a profound impact on the bodily integrity of the family, both in regards to illness among individuals, and overall ill effects on the integrity of the family. For example, decision making for competent adults by the family in Japan occurs just as surrogate decision making by parents for children who do not meet criteria for competency occurs in the U.S. The child is an incomplete moral agent as the child lacks the intellectual capacity for rational judgment. Under a model of family autonomy, it is not the intellectual capacity for rational judgment that is lacking, but a social construction of individualism, and right to decision making authority. In a sense, the patient is but an integral organ of the more complete whole body of the family. Under this model of self, illness by the patient is an assault on the physical integrity of the family body. Given this notion of the family body, respect for family autonomy thus draws from the notion that the patient's illness is a threat to the integrity of the whole. The importance of bodily integrity of the patient and the bodily integrity of the family both have moral relevance. Still, does family integrity seem trivial in comparison to patient integrity?

While other arguments to support patient autonomy have been made, these two central issues are sufficient for my purposes here. The answer to these questions about which has greater importance is a matter of interpretation. In each case, two determinations must be made. First, who is affected the most, and second, which is most important? These determinations can be made only when there is agreement about how they are being evaluated. I maintain that these assessments are not (and can not be) value-neutral. Either interpretation is based on a particular moral perspective. The assessment of moral superiority will depend if the cultural framework of evaluation is more individualist as in mainstream U.S. society, or more collectivist as in the case of Japan.

Since the word individualism has been used in so many ways, I will diverge briefly to clarify the meaning of individualism I am referring to. Steven Lukes has identified 11 basic ideas of individualism (Lukes 1973). The U.S. individualism to which I refer includes four of Lukes's ideas of individualism, namely, respect for human dignity, autonomy, privacy, and self-development. These four facets of individualism are fundamental elements in the ideas of equality and liberty, which are in turn cornerstones of U.S. political philosophy. According to Lukes, the idea of human dignity or respect for persons supports the idea of equality, while autonomy, privacy, and self-development represent three facets of liberty or freedom. While further examination of these four facets of individualism is beyond my purposes, suffice it to say that autonomy of the individual is one of the defining features of individualist U.S. society. With autonomy as one of the defining values of U.S. society, clearly it will be difficult for modern bioethics who's heart resides in the U.S., to value higher any paradigm other than one that upholds these self-defining, core values.

At the risk of stating the obvious, not all cultures of the world emphasize the U.S. version of individualism (Kagitcibasi 1994). Recently, cross-cultural social scientists have begun utilizing the terms individualism and collectivism to illustrate the varying emphasis on individualism and collectivism in a variety of cultures (Kim et al. 1994). Cigdem Kagitcibasi cites four kinds of empirical evidence that have brought interest in individualism and collectivism: 1) there are systematic differences among societies, and it is possible to rank societies on these variables; 2) subjects from individualist cultures tend to have individualist values and behaviors, and subjects from collectivist cultures tend to have collectivist values and behaviors; 3) these differences are found in other psychological processes as well; and 4) there is cultural variability at the individual level illustrating the natural diversity one would expect within a culture (Kagitcibasi 1994). Additionally, any given individual may be more individualist or more collectivist depending on the circumstance (Triandis 1994).

These data and others illustrate that there are very different cultural constructions of the self in other cultures (Geertz 1966). My purpose in presenting these data about individualism and collectivism is to illustrate it will be difficult if not impossible to "prove" that family autonomy is a morally superior model to patient autonomy as long as the balance for measuring is viewed through individualist lenses. The difficulty is in removing them, and trying on a pair of collectivist lenses. Given that there are individualist and collectivist societies; there are individualist and collectivist individuals in all of these societies; and there are individualist and collectivist tendencies even for an individual, modern bioethics must try these different collectivist spectacles if it is to meet the multicultural needs domestically and internationally.

This impasse about cultural relativism aside, there are at least two compelling constructs that Western clinicians ought seriously to consider before disregarding the moral importance of the model of family autonomy, namely, relatedness, and dependence. The Japanese equivalent to relatedness is *en* as I illustrated in Chapter 1. The argument goes that there is a relatedness of all things in the world, and that one must resist the temptation to reduce complex social phenomenon such as decision making about illness to over-simplified fundamental questions. Relatedness finds support from a variety of sources. Yin and yang, from Chinese philosophy illustrate the inter-relatedness of all things. Feminist critiques have recently advocated the need for examining patients "in-relation" (Candib 1995). Perhaps the best example of the relevance of relations is illustrated by Schwartz who examines how in the individualism/ collectivism continuum, autonomy/relatedness are considered one of its bipolar dimensions (Schwartz 1994). He explains,

> In cultures at one pole on this dimension [individualism/ collectivism], the person is viewed as an autonomous entity endowed with independent rights and desires who relates to others in terms of self-interest and negotiated agreements. This view is expressed in values favoring autonomy or individual thought, feeling and action (e.g., curiosity, creativity, varied life). At the opposite pole, the person is viewed as a part of the social fabric whose significance derives from his or

> her participation in and identification with the group in carrying on its shared way of life. This view finds expression in values favoring propriety and harmony in interpersonal and person-to-group relations (e.g., moderate, social order, security, reciprocation of favors).

In short, consideration of the individualist formulation of autonomy in isolation without consideration of the fact that autonomy as a concept sits on a continuum with relatedness ignores the evidence social scientists have found.

A second consideration involves the human element of dependence that has been treated most comprehensively by Doi (Doi 1971). As illustrated in Chapter One, the word *amae* in Japanese has been termed dependence. Doi illustrates that there are a number of facets of dependence which include both a passive tendency to depend upon others. Simultaneously, it may also be valued positively as an indulgence. Doi describes among even adults the unconscious desire when threatened with external factors (such as illness) to be nurtured compassionately as a mother would a child. It can be argued that Western autonomy under values this fundamental aspect of human nature, while it is considered natural and a matter of course in Japanese culture. Autonomists might argue that patient autonomy clearly provides the patient the option of autonomously deferring decision making authority to others. While this gives the appearance of an all encompassing, all accommodating moral model, the fact remains that it does require the patient to actively participate as a decision maker, perhaps not in the details of medical decisions, but certainly in the delegation of decision making responsibility for the patient. Katz for one, implies that individuals who do not want to take this responsibility should be pushed to decide for themselves, an approach that has the appearance of paternalistically forcing a model of patient autonomy (Katz 1984).

To summarize, the fundamental nature of being human includes relatedness to others, and other things in the environment, and perhaps, an unconscious desire for dependence on others particularly when there is an external threat (such as illness) to one's well being. If respect for patient autonomy is the only paradigm for guiding our interactions with patients, we have arguably deprived them of fundamental aspects of their very existences.

In these previous sections, my goal has been to illustrate a moral foundation for family autonomy, and if nothing less, to provide sufficient evidence to raise doubts about the adequacy of patient autonomy alone to be the exclusive prima facie moral guide for medical decision making. My purpose now is to delve into some of the practical issues of bridging the theoretical with pragmatic needs of clinical decision making. A necessary starting point is further clarification of the multiple relationships between patient and family decision making, and patient and family autonomy.

PATIENT AUTONOMY AND FAMILY AUTONOMY: HOW THEY RELATE TO PATIENT AND FAMILY DECISION MAKING

The model of patient autonomy is a very robust paradigm as it can account for independent patient decision making without input from the family; patient driven decision making in consultation with the family; and patient deferral of decision making to the family or other decision maker. Given this broad capacity, what then does family autonomy add to understanding about the family in medical decision making? How does decision making under the model of family autonomy differ from the family making medical decisions as outlined in the third model above?

Three factors will clarify our understanding of the difference. These factors are: 1) the moral model of decision making, namely, patient autonomy or family autonomy; 2) the primary source of decision making authority under that model; and 3) the moral agent—patient or family—making the decisions (Table 2). The first factor, the moral model of decision making, refers to the specific model of consideration, namely, patient autonomy or family autonomy. The second factor refers to the source of the decision making authority under the model. The third factor asks if the moral agent making the decision is the patient or the family. Using this analytic framework, there are a total of four patterns, namely, two patterns of patient autonomy and two patterns of family autonomy.

Pattern 1-patient autonomy in the first sense. In the first pattern, the moral basis for decision making is respect for patient autonomy. In this model, the patient is the primary source of decision making authority. The patient also serves as the actual agent making medical decisions. This represents the model of patient autonomy as it is widely understood and practiced in clinical medicine. Respect for patient autonomy draws from notions of the patient's right to self-determination and preservation of bodily integrity.

Pattern 2-patient autonomy in the second sense. In the second pattern, the moral basis for decision making again is respect for patient autonomy. However, the patient is not the moral agent actually making the decisions. Rather, the family serves as the moral agent making decisions, even though the primary source of decision making authority is still the patient. Under this pattern, the patient autonomously defers decision making to the family. This mechanism for accommodating family decision making is very appealing to the North American model of bioethics because it seems not to violate our moral sense of the importance of respect for patient autonomy. Freedman has articulated an ethical approach for incorporating a patient's preferences for autonomously deferring decision making authority to family when the patient is afflicted with a terminal illness such as cancer (Freedman 1993).

Pattern 3-family autonomy in the first sense. In the third pattern, the moral basis for decision making is respect for family autonomy. In this model, the family also serves as the moral, decision making agent, and is the primary source of decision making authority. I will cover more about the process of decision making below. As articulated by Fan, the moral basis of this model has its roots in three domains, family sovereignty, objective conception of the good and harmonious dependence (Fan 1997). Its moral basis also is supported by the natural laws of relatedness and dependence or need for nurturance.

Pattern 4-family autonomy in the second sense. In the fourth pattern, the moral basis for decision making again is family autonomy, but the patient becomes the decision making moral agent. The family autonomously defers decision making authority to the patient. The fourth model's moral roots come from the same domains as the third model, even though a superficial examination might lead one to believe that this simply reflects patient autonomy because the patient makes the decision. At first glance, one might wonder if this model even exists. I believe it does and that no one has ever sufficiently scrutinized cases to identify it because there is an assumption that if the patient decides, there is an underlying model of patient autonomy.

Systematic elaboration of these four patterns illustrates that family decision making may draw its moral legitimacy from either a patient autonomy/family decision making model (second model), or a family autonomy/family decision making model (third model). It also illustrates that patient decision making may draw moral legitimacy from either a patient autonomy/patient decision making model (first model), or a family autonomy/patient decision making model (fourth model). The primary difference between patient autonomy and family autonomy is that in patient autonomy, patient participation in delegating decision making authority is prerequisite, and family participation in decision making is optional at the patient's discretion. In family autonomy, family participation in delegating decision making authority is prerequisite, and patient participation in this decision is optional pending the family's judgment.

Thus, patient decision making does not necessarily equal patient autonomy, nor does family decision making equal family autonomy. Clinically, it may be difficult to distinguish whether patient decision making has its moral basis in respect for patient autonomy or respect for family autonomy. In the clinical setting it is assumed that patient decision making equals patient autonomy. Without using this framework to scrutinize the actual dynamics of decision making, family autonomy functioning according to the fourth model goes unrecognized. For example, a minor making treatment decisions for herself appears to reflect a model of patient autonomy, even though the family is autonomously deferring decision making to the patient in accordance with a model of family autonomy. Similarly, without close scrutiny, it will be difficult to distinguish whether family decision making has its moral basis in respect for family autonomy or patient autonomy. As long as medical decision making proceeds without conflict in preferences, the currently functioning model may be not readily discernible or even perceived as relevant. Only when there is conflict between the patient's preferences and the family's preferences does the resulting tension between the paradigms render the model noticeable and problematic for mainstream bioethics.

I have shown that there is moral support for the principle of family autonomy as a model of medical decision making. As patient autonomy must account for both the first and second patterns of decision making, so must a theory of family autonomy account for the third and fourth patterns of decision making. I now propose a series of precepts that taken together provide a framework for implementing and limiting exercise of family autonomy.

GUIDING PRECEPTS OF FAMILY AUTONOMY

Family autonomy describes a decision making paradigm in which all decision making authority derives from the family, the fundamental moral unit. Individual family members in this paradigm exist, but are incomplete moral entities. It explicitly states that individual preferences are subject to interpretation and deliberation by the family. In the following, I propose a series of precepts that taken together can be a starting point for implementing family autonomy (Table 3). These precepts are intended to serve as a framework for ethical implementation of family autonomy. After all, even in individualist U.S. society, it is widely agreed that there must be checks and balances on patient autonomy. Likewise, there are ought to be checks and balances for family autonomy as there is no absolute moral good. After presenting these precepts, I anticipate and respond to criticisms.

The first precept states that the family in exercising its decision making authority will place the patient's best interests first to the extent possible within the constraints of sometimes conflicting but typically congruent family interests. Even though the patient is a morally incomplete entity it is still completely possible for the patient to have interests that are separate from the family. The difference is that the balance is weighted toward the family's interests rather than the patients interests. In the event that there is detectable discordance, the physician is obliged to determine to the extent possible the source of the conflict, and to encourage the family to resolve the discordance. It may be appropriate for the physician to make an assessment as to whether there are morally compelling reasons to override the family in favor of the patient's preference (see precept 4 below).

The second precept of family autonomy states that the patient's preferences should, as a general rule, receive more weight than another individual family member's preferences. Family autonomy does not imply that the patient's interests in or preferences for decision making will be ignored. Rather, in most circumstances, the patient's opinion will likely be the most influential of all family members. The patient's opinion may be either explicit or implicit. An explicit preference in North American mainstream culture is almost always preferable, but not prerequisite. North Americans generally assume that the best communication is explicit, that is, there is an underlying assumption that explicitness is better than implicitness. This epistemology is not universally valid. In Japan for example, implicitness is frequently asserted to be superior to explicitness. This is because being implicit allows for ambiguity.

The third precept is that the family's autonomy should override physician preferences when discordance arises from the physician having a different preference than the family and the patient. The moral grounds for a physician to override patient preferences under a patient autonomy model will have equal relevance for overriding family and patient preferences under a family autonomy model, and will therefore not be further justified here.

The fourth precept is that unconditional respect for family autonomy is not an absolute moral good. Just as there are circumstances when patient or physician preferences for decision making cannot be respected, there will be circumstances under which family preferences will be overridden. Justification for overriding family preferences requires a preponderance of evidence illustrating that exercise of family autonomy is morally unacceptable. A corollary of this precept is that evidence for a strong patient preference is the highest challenge to prioritization of a family autonomy model over a patient autonomy model. However, because the patient is not a complete moral agent in this paradigm, a strong patient preference does not trump necessarily the decision making authority of the family. Deliberation about what to do when these precepts are in conflict should proceed in the same way that moral judgments proceed when principles of beneficence and justice, or autonomy and beneficence are in conflict. All ethics is situational; just as patient autonomy is not an absolute moral good, so too, family autonomy is not an absolute moral good.

The fifth family autonomy precept states that the level of the patient's involvement needs to be determined by the family. Absent compelling judgment by the family that the patient will be harmed by participation, the patient has a moral right to participate in the implementation of family autonomy by virtue both of being the family member primarily affected by illness, as well as being a constituent member of the family.

The sixth precept of family autonomy states that the family is responsible for articulating the family position. While the clinician has an obligation to provide the family with accurate information about the circumstances of the patient's medical condition, the burden of resolving the conflict within the family rests on the shoulders of the family itself. Since articulation of the family decision may take time, clinicians need to be patient for the family decision making process to occur. Occasionally, life-threatening decisions need to be made very quickly, but in general, most truly important decisions can be made over time if the clinician is willing to temper his or her own preference to take immediate action.

It cannot be assumed that the individuals who constitute the family necessarily have an equal voice in decision making. In fact, given varying degrees of intimacy and moral claims, the weight of individuals' preferences in formulating the family position should be variable. Their voices should typically be tempered depending upon the prevailing model of decision making within the family. Thus, the decision making process by the family could follow one of several models including: 1) the decision is made by the head (male or female) of the household; 2) the decision is made by consensus opinion; 3) the decision is made by a family member either self-selected or appointed by the family; 4) the decision is made by the individual with the highest degree of intimacy with the afflicted patient. Other models are also possible. Regardless, it is the family's obligation to determine whose voice will convey the family opinion.

The seventh precept of family autonomy states that discordance within the family is not itself a sufficient condition for rejection of the family autonomy model in favor of a patient autonomy or paternalistic model of decision making. Discordance can take two forms, resolvable discordance and irreconcilable discordance. Resolvable discordance may be a healthy form of discordance as it suggests there has been a broad examination of the potentially relevant and when applicable, ambiguous considerations. It indicates that the parties agree there may be alternate interpretations about what is best for the patient, and through group process (see precept 6) differences can be reconciled, and a decision reached. Irreconcilable discordance can result in two outcomes, peaceful disagreement or hostile disagreement. In the former, the family peacefully concludes they cannot agree upon a single preferred course of action. In the latter, the process of trying to come to a decision results in irreconcilable hostility among the family and paralysis of family decision making. Unfortunately, if the family is unable to agree about the best course of action, the physician must resort to direct examination of the patient's preferred approach, even if the family's prevailing approach is to not involve the patient directly and despite any indications the patient may have given of a preference not to be involved in decision making. Facing a need for resolution, a physician threat to resort to direct discussion with the patient may be a sufficient and appropriate use of physician power.

CRITICISMS AND RESPONSES TO CRITICISMS

Critics will quickly point out that the family will sometimes not have the patient's best interests at heart and will substantiate the claim with a series of cases of families who tried to take advantage of the patient. The argument states that since there are circumstances in which the family will try to take advantage of the patient's debilitated status for its own benefit, the riskiness inherent in the model of family autonomy renders it fatally flawed. While I am the first to agree that there are ill-intentioned families, this criticism completely ignores the fact that in the vast preponderance of circumstances, family decision making works very well. Because there is no conflict, there is no appeal to an ethics committee and there is no appeal to the legal system. Unfortunately, these vastly more common experiences with excellent outcomes typically go unnoticed (Fetters and Brody 1998-projected). From an epidemiological perspective, the occurrence of cases of families with devious, ill-intentioned motives appear to be the exception to the rule. Bioethics should discard the presumption of the ill-intentioned family and start with a presumption that the family has the patient's best interests at heart. Families should be given the benefit of the doubt unless there are indications to the contrary.

Critics might then respond that the harm from even the occasional ill-intentioned families will be so great as to invalidate the model of family autonomy. However, under all but the most unusual circumstances, it will be obvious when there are conflicts between family decision making and the patient's best interests. When there is conflict, the clinician should resort to the usual mechanisms of resolving conflicts. Invariably, there will be cases in which the family may violate the patient's best interests. Furthermore, families with the best of intentions may occasionally violate the patient's best interests unwittingly and without open conflict with the patient. They may not know the patient's interests sufficiently or they make a decision based on medical information that is subsequently proven wrong.

While in circumstances such as these, occasionally there will be bad outcomes. Clinicians I believe will be comfortable with this as they are familiar with clinical practice in the course of which unexpected complications occasionally occur despite all efforts to the contrary. This is no less than the reality of clinical medicine, which can never be perfect. Bad outcomes don't invalidate the model if it is followed in an ethically correct way. Stated in a different way, this counter argument appeals to the sense that one shouldn't throw out the baby with the bath water. It accepts that there will occasionally be a moral wrong, but that a much greater level of moral good will follow from reliance on a model of family autonomy in accordance with the preferences of patients and families. As a utilitarian argument, it will be vulnerable to criticisms generally lodged against utilitarian thinking. Still, medical decision making in clinical practice is primarily utilitarian in nature. In this sense, I appeal to the fact that we are dealing with clinical ethics.

Moreover, it is widely argued that the patient autonomy model of decision making is not without flaws. There are clearly shortcomings to medical decision making being driven strictly by patient preferences, particularly when patients begin demanding treatments that may be injurious, ineffective, or of such economic expense as to be unacceptable on the grounds of depriving others of more vital medical interventions. There are pitfalls in patient autonomy, but we need not completely discard the model simply because it fails to meet our idealistic notions. Respect for patient autonomy has dramatically improved the quality of medical decision making. It is my contention that acknowledgment and utilization of family autonomy can improve the quality of medical decision making.

Another potential criticism is that accepting a three-party model (patient, family, and doctor) of medical decision making will be so messy as to prevent it from being a practical clinical or moral endeavor. The potential circumstances for concordance and discordance among the three parties superficially appears to be so overwhelming that negotiations between the three groups would exceed the capacities of clinical practice. In reality, however, it is less complicated than it might appear at first glance if the options are examined systematically.

For purposes of our discussion, I will examine systematically the plausible combinations of treatment preferences given the choice of whether to treat prostate cancer with surgery (Table 4). There are eight combinations of agreement/disagreement for the moral agents of the doctor, patient, and family. These combinations result in possible group discordance and possible family-patient discordance. These eight combinations can be combined into one concordant pair and three discordant pairs according to whether or not there is group discordance and patient-family discordance.

Among the concordant pairs, there is a concordant triad in favor of prostate surgery (No. 1), and a concordant triad opposing prostate surgery (No. 2). When there is concordance, adjudication about which of the three moral models, patient autonomy, beneficence, or family autonomy, has the highest moral claim becomes primarily a theoretical enterprise with virtually no clinical implications. If all agree to prostate surgery, or all are opposed to prostate surgery, there is no conflict and no ethical dilemma for any of the parties concerned.

The first pair of discordant triads occurs when the physician's preference differs from the preference of the family and the patient. That is, the physician prefers surgical removal of the prostate, but the patient and family are opposed (No. 3), or the physician is opposed to prostate surgery, but the patient and family are in favor (No. 4). The previously elaborated third precept of family autonomy serves as a guide that the decision should follow the patient and family preferences.

The second pair of discordant triads occurs when the family's preference is discordant with the doctor's and patient's preferences (Nos. 5, 6). These triads are interesting because they represent the clash between paternalism and patient autonomy on one hand, and family autonomy on the other hand. In one triad, the patient and physician are opposed to prostate surgery, but the family prefers surgery. In the opposite circumstance, the patient and physician prefer surgery but the family is opposed. To the extent that prostate surgery against the patient's will is a considerable violation of the physical being of the patient and carries inherent and immediate life-threatening implications for the patient, I believe an appeal to the fourth precept of family autonomy may be justified. That is, there are substantial and compelling moral grounds for overriding the family's preferences in favor of patient autonomy. When the patient and the doctor prefer surgery, but the family is opposed, a careful examination of all the relevant circumstances and interests is needed. If the patient is at imminent risk of death due to obstruction, and the family simply wishes the patient to die, then the fourth precept would provide sufficient grounds for rejecting family autonomy. In contrast, if the patient has unrealistic expectations, and the physician admits doing surgery rather than providing medical treatment is simply a professional preference that is not supported by empirical research, the weight of evidence would favor respecting the family's rejection of surgery.

The third and final pair of discordant triads occurs when the patient's preference is discordant with the physician's and family's preferences (Nos. 7, 8). Under these circumstances, the physician has an obligation to examine her own values in order to understand her own preferences and should also expend diligent efforts to look for evidence of ulterior motives on the part of the family who voices an opinion that differs from the patient's preference. If the physician has sufficient grounds to believe that the family is placing their self-interests over the patient's in a substantive way, the physician would have a moral obligation to override both her own and the family's preferences and act in accordance with the patient's preferences.

Thus, this systematic examination of treatment preferences reveals the possible combinations of concordance and discordance, as well as mechanisms for resolution when the latter occurs. To the extent that patients, family, and physician are all morally relevant all agents and decision making patterns must be accounted for and not left neglected because doing so is ethically inconvenient.

Critics might also argue that what happens and exists in other cultures has little relevance for U.S. medicine, and that individuals who come to seek care in the United States should have to function by our rules. In short, these critics present a "When in Rome, do as the Romans do" argument that foreign patients should be expected to follow the model of patient autonomy because it is the overwhelmingly predominant paradigm. In examining such an attack on family autonomy, it is relevant to ask what the motivations for available relevance. The afflicted individual is indeed vulnerable. The patient is the one who is sick and frequently dependent on others. Given the patient's vulnerability, it can be argued that bioethics has a special obligation to advocate for vulnerable populations, and to the degree possible, make decision making a fair and just enterprise for them. Such a circumstance raises the need to reconcile the Western physician's perceived obligation to respect a patient autonomy model, and hence protect the vulnerable patient, and the pressure from the family to exercise a family autonomy model.

Critics may charge that decisions often change over time, and the patient who initially accepted family autonomy, may subsequently wish to exercise patient autonomy. Thus, it is necessary to recognize that the decisions are not static. As such, the family and/or patient position may well change with time, so physicians need to maintain a willingness to reassess decisions already made and decision making needs. Further, critics may charge that the analysis above fails to accommodate circumstances when there is dissent among physicians as to the most recommended choice. Under such circumstances, family decision making may have the most value due to the family's moral investment in the patient. In many ways, families will have greater clout in negotiating a resolution in such conflicts. It is widely recognized that family members' assessments of a patient's preferences in decision making often are no more informative than a coin toss. In response it must be remembered the family has the ultimate decision making authority. The family should responsibly try to determine if there has been a change in the patient's preferences, although accurate assessment is not an absolute necessity: the essential point is that the family participates in the process. The emphasis on process here argues that the morally appropriate choice is not necessarily the choice that may have been preferred by the individual.

It might further be argued that while the theoretical examination of family autonomy is an interesting exercise, it has no relevance to North American bioethics. U.S. society in particular is very individualistic. How could such a model have any relevance? Aren't U.S. families too disjointed and transient for such a model to function? Given the faltering family, can Americans be persuaded to allow the family to make medical decisions for the patient? These criticisms largely ignore the multicultural nature of North America and the world. That is, it ignores the varying preferences for individualism or collectivism in differing societies, among different people in the same society, and even for an individual given the known tendency for behaviors to change with varying circumstances. The model of family autonomy may have infrequent practical utility in North America; moreover there may not even be an opportunity to exercise family autonomy (Fetters Under Review). However, the opposite seems true as well. Just as the family autonomy model does not fit with mainstream individualist American values, the patient autonomy model likewise does not fit with the collectivist values esteemed in many other parts of the world. This work precisely argues the need for bioethics to be more pluralistic. Only in this way can it have adequate moral relevance for individuals and family members living in North America that do not share mainstream North American values. Similarly, for modern bioethics to be relevant internationally, the need to be more pluralistic is clear.

Another consideration is the concern that adoption of a family autonomy model may result in physicians feeling pressured to act in accordance with a model of family autonomy that violates the physician's own moral sense of right and wrong. The virtuous physician cannot be compelled to provide treatment that is counter to the physician's own sense of what is morally right and wrong (Pellegrino and Thomasma 1993). On the other hand, the risk of forcing one's own views onto others risks physician paternalism. Which then becomes the morally inferior approach: paternalism overriding family autonomy, or family autonomy overriding physician paternalism? The family autonomy precepts favor the later.

A final criticism might be that conflicts between the patient's preferences and the family's preferences will paralyze decision making. The theoretical framework articulated above does provide guiding principles for resolving issues. The conflicts between patient and family preferences need to be resolved just as conflicts between patient and physician preferences must be resolved. There is no one principle (nor should there be) with absolute trumping power. Rather, their implementation must be situational.

DISCUSSION

Anthropology informs us that there are both "universal truths" and "culturally relative truths." It is in bioethics's best interest to develop a greater understanding of what truths are universal and what truths are just culturally relevant. Pellegrino has argued that respect for patient autonomy is a universal human good, though this assertion is made in a cultural context closely tied to individualism where a high value is given to patient self-determination (Pellegrino 1993). It is difficult to envision family autonomy as a model which will predominate in mainstream North American medical practice. However, the model should not be ignored simply because it isn't mainstream. Medicine frequently requires clinicians to pick unusual therapeutic regimens for treating an individual patient. For example, treatments that are expensive or have other kinds of costs associated with them, such as a less desirable side effect profile or frequent dosing interval, may inhibit patient compliance. For unusual problems, clinicians must be comfortable utilizing medications or treatment regimens which they do not routinely use in “usual” circumstances. Given the widespread predominance of individualism and self-determination in the health care environment, the need to respect the family autonomy paradigm may in fact be an unusual circumstance. Still, physicians have a moral obligation to utilize the decision making paradigm most appropriate to the case, be it unusual or not.

Is family autonomy a transcultural model, or is its applicability limited to cultures where collectivism predominates? It can only be a transcultural model if those with power such as patients, families, physicians, other health professionals, and bioethicists, socially sanction and accept it in non-collectivist societies. As illustrated in Chapter 1, there is compelling evidence that family autonomy is indeed functioning and commonly applied in Japan. Since Japan ranked as one of the least collective societies in Hofstede’s research on individualism and collectivism in 53 countries, it is logical to believe that family autonomy is commonly functioning in many other societies as well (Hofstede 1980). I believe family autonomy will be evaluated as a morally compelling, and perhaps superior model to patient autonomy in societies that exhibit an even greater tendency towards collectivism.

The question for North American bioethics thus becomes “Is family autonomy destined to be recognized as a morally inferior but justifiable model under the rubric of moral relativism, or is it a transcultural model that has a legitimate place in North American bioethics?" In this chapter, I have argued that there is a morally legitimate basis for family autonomy, and presented a framework for implementing family autonomy that can be applied to bioethical dilemmas. It remains to be seen whether clinicians will use this framework to guide clinical decision making. The barriers to its acceptance, particularly in individualist, mainstream U.S. society are significant indeed.

In many respects, this work raises more questions that are ripe for further inquiry. First, a more detailed analysis of the differences in patient autonomy and family autonomy is needed. Second, further clarification of the term "family" is needed. For example, family can be defined by such factors as kinship, residence, intimacy, socioeconomic factors, and perhaps others. Which of these family types have greatest moral claim when there are discordant preferences, e.g., the gay partner of a comatose male prefers different interventions from the patient's parents? Third, are all family decision making processes morally equivalent? In the sixth precept in Chapter Two, a variety of decision making processes were described. It is unclear if all of these family decision making processes are morally equal. For example, is family decision making by consensus superior to patriarchal decision making? Fourth, what are the historical, religio-philosophical, and social features of the family in the U.S., and how do they compare to Japan? Finally, what are the competing interests that patients, family members, physicians and other health care providers bring into the health care setting, and how do they impact family decision making?

To summarize, I have aspired in this thesis to define family autonomy, to establish its moral legitimacy, and to lay out a theoretical framework for implementing it. There is much more to be said and debated before the value and moral relevance of family autonomy for modern bioethics can be judged. It is my hope that in this work I have provided sound arguments for furthering the dialogue about the family and the role of the family in medical decision making.

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TABLE 1. FAN'S COMPARISON OF WESTERN AUTONOMY AND EAST ASIAN AUTONOMY

	WESTERN AUTONOMY	EAST ASIAN AUTONOMY
1. Who has the final authority to decide in accordance with the principle?	Self-determination	Family-determination
2. What is the basis on which to decide?	Subjective conception of the good	Objective conception of the good
3. What is the major value that the principle upholds?	Individual independence	Harmonious dependence

TABLE 2. FOUR PATTERNS OF PATIENT AND FAMILY DECISION MAKING

	Moral Model of Decision Making	Primary Source of Decision Making Authority	Moral Agent Making Medical Decisions
1	Patient autonomy in first sense	Patient	Patient
2	Patient autonomy in second sense	Patient	Family
3	Family autonomy in first sense	Family	Family
4	Family autonomy in second sense	Family	Patient

TABLE 3. PRECEPTS OF FAMILY AUTONOMY

1. The family in exercising its decision making authority will place the patient's best interests first to the extent possible within the constraints of sometimes conflicting but typically congruent family interests.
2. The patient's preferences should, as a general rule, receive more weight than another individual family member's preferences.
3. The family's autonomy should override physician preferences when discordance arises from the physician having a different preference than the family and the patient.
4. Unconditional respect for family autonomy is not an absolute moral good.
5. The level of the patient's involvement needs to be determined by the family.
6. The family is responsible for articulating the family position.
7. Discordance within the family is not itself a sufficient condition for rejection of the family autonomy model in favor of a patient autonomy or paternalistic model of decision making.

TABLE 4. PATTERNS OF MORAL AGENTS IN DECISION MAKING, GROUP DISCORDANCE AND CHALLENGE TO FAMILY AUTONOMY

	Moral Agents			Group Discordance?	Family/ Patient Discordance?	Circumstance to Challenge Family Autonomy
	Family	Patient	Doctor			
1	yes	yes	yes	no	no	no
2	no	no	no	no	no	no
3	no	no	yes	yes	no	no
4	yes	yes	no	yes	no	no
5	yes	no	no	yes	yes	yes
6	no	yes	yes	yes	yes	yes
7	yes	no	yes	yes	yes	yes
8	no	yes	no	yes	yes	yes