Chapter 1
Informed Consent: Why Family-Oriented?

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1.1 Introduction

This volume introduces an East Asian Confucian ethical perspective on the place of the family for informed consent regarding clinical treatment and biomedical research. It offers a unique perspective on an approach to informed consent salient in East Asia but generally unexplored in English-language literature. By drawing on bioethics scholars from Hong Kong, mainland China, South Korea, and Taiwan, this volume offers a cluster of viewpoints that play a major role in law and health-care policy in East Asia, although they are nearly unknown in Western bioethical reflection. Contributions from four American scholars are also offered in order to place the East Asian Confucian perspective in a broader context. Even in the West, there has been a move to address issues of dependency, family care, and shared decision-making that have many similarities with the concerns addressed by East Asian scholars. The themes of the five sections designed for this volume range from theoretical reflections on such concepts as autonomy, individualism, rationality, dependence, independence, and interdependence to the practical explorations of issues like end-of-life decisions, organ donation, research participation, truth telling, and the arrangement of advance directives. The focus of the whole volume is on the role that the family ought to play in the proper exercise of informed consent in biomedical practices.

Regarding the concept of "family," there are roughly two different meanings adopted throughout the chapters of the volume. On the one hand, "family" is used in a loose sense, referring to any well-functioning unit of people connected either by blood or marriage or by alternative bonds, where there is mutual concern among

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the various members. This sense of "family" is invoked by some authors in addressing biomedical decision-making issues in contemporary Western countries. On the other hand, most chapters in the volume appeal to the concept of the traditional family—a husband with his wife and their biological children (and the husband's and the wife's parents as well, as they, at least in East Asian regions, are usually involved in medical decision making for the husband and the wife respectively)—to formulate their views and develop their arguments for the appropriate engagement of family members in the process of biomedical decision making in a Confucian cultural context. Indeed, in East Asian regions such as mainland China, a three-generation stem family remains the normal model of the family. This stem family is taken for granted as essential to any informed consent practice for any significant biomedical issues of their family members. This is the case even when the grandparents, in most situations, no longer live under the same roof with their adult child's nuclear family (cf. Deng 2014, pp. 203–218).

This introductory essay does not intend to outline the views and arguments of every chapter one after another. Instead, based on the major concerns of all the chapters, I attempt to defend the merits of the family-oriented model of informed consent in East Asian health care contexts. First, I summarize the major problems faced by individual-directed informed consent. Next I reconstruct the useful ideas of justification conveyed by the authors for the family-oriented model. In the following section I address the critiques and challenges faced by the engagement of family members in the informed consent practice and explore suitable ways to deal with these challenges. In the final section I give some concluding remarks about the importance of the traditional family in contemporary society.

1.2 The Problems of Individual-Directed Informed Consent

The dominant model of informed consent in contemporary Western biomedical practice is individual-directed rather than family-oriented. As H.T. Engelhardt describes this practice: "Those who regard autonomous individualism as the presumptively appropriate relation among persons would require any deviations to be established by explicit statement and agreement. For example, patients would be presumptively treated as autonomous individuals willing and committed to choosing on their own, unless they explicitly demanded to be regarded and treated within a traditional family structure" (Engelhardt 2002, pp. 24–25). Evidently, securing such an autonomous individualist vision has required a progressive political view that recognizes itself as having an adversarial relationship with traditional family structures and forms of familial authority. Indeed, as Mark Cherry points out, liberal individualist advocates often appreciate the family as a major impediment to social implementation of their preferred conceptions of equality and social justice, in which they intend to see the family as no more than a social construct, created through the particular agreements of its participants, with no independent reality of its own (Cherry 2014, pp. 43–62). It is for this reason that the liberal individualist notion of personal autonomy is highlighted as integral to human good and human flourishing in the established American account of bioethics (Beauchamp and Childress 2009).

As a result, the practice of informed consent under this individualistic model is at least family-unfriendly in multiple ways, even if it is not family-hostile in nature. First, the individual is appreciated as possessing sole or exclusive decisional authority in biomedical matters independently of his family. While patients usually do not make truly single or solitary decisions, there is the sense in which the modern Western medical establishment and the social apparatus of decision making expect solitary decisions from patients. They are approached individually in the decision making process as if they were not members of functioning families, even if they wish to be treated as members of functioning families. Family members have no right to participate in the process, unless such participation has been explicitly authorized by the patients through a formal or quasi-formal procedure (Faden and Beauchamp 1986; Wear 1993). In this way, the exclusive authority of the individual in making medical decisions independently of the engagement of the family is secured, implemented and promoted.

Indeed, there is a series of institutional barriers to family involvement in informed consent. As Jeffrey Bishop demonstrates, "the structures and practices of medicine, including informed consent and decisions about removing life support in the critically ill, organize decisions such that the family is structurally marginalized. Individualized informed consent—as well as living wills, durable powers of attorney, privacy laws (such as HIPAA), and even the case-law itself—is set up to support the myth of an isolated individual alone in the world making his own decisions by himself and for himself" (Bishop 2014, pp. 27–42). Such barriers have already been exported to East Asian regions through the design of an individualist informed consent mechanism for biomedical research. As Rui Deng indicates, when families are eager to participate in the decision-making process to protect their family members from the likely risk of biomedical research, they find that they have no role to play in the "standard" implementation of informed consent (Deng 2014, pp. 203–218). Worse yet, contemporary bioethics, healthcare systems, and laws increasingly assume that a family is not in a state of integrity and is not helpful in biomedical practice. As Ryan Nash indicates, this mistrust of family has become a presupposition or at least a practiced assumption in Western society. The family is treated as something to be wary of, a problem to prevent, or even a disease to attempt to cure. The current system of informed consent reinforces the overly simplistic individualist view that decision making is merely between the individual and the medical establishment. Accordingly, as Nash sees it, the current system encourages a practice of familial and cultural shunning (Nash 2014, pp. 219–230).[1]

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[1] This is not to deny that many patients in the West regularly include families in their health care decision making. However, this volume is making the point that the policies set up in light of the dominant individualist model form barriers to including families in health care decision making

In addition to its family-unfriendly features, the individual-directed model of informed consent suffers serious conceptual and practical problems. In the first place, the exclusive decisional authority possessed by the patient independently of her family members is not beneficial to the practical reasoning required to make biomedical decisions, as such practical reasoning is inevitably engaged in accord with her moral identity, established character, and/or her long-standing life plan. Under the individual-directed model, informed consent is defined as an individual's *autonomous* authorization of a medical intervention or of participation in research. Since a patient may hold altruistic intentions or otherwise reasonably unselfish values in making her medical decisions, her autonomous choices may not necessarily be in her best medical interest. Thus it need not be the case that an individual's autonomous decision will always be in her best medical interest. Instead, in contemporary bioethics it is generally assumed that "[t]o respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs" (Beauchamp and Childress 2009, p. 103) This is to say, leaving the best-interest-consideration aside, a patient's "personal values and beliefs" must be taken seriously in order to respect her as an autonomous agent as well as her right to the fostering of autonomous decisions. Now a question arises: is it the case that as long as an agent is psychiatrically judged not incompetent and is independent from any controlling influences by others, then any of her biomedical decisions, whatever they are, should be taken as having been made in accord with her "personal values and beliefs," so as to be definitely autonomous? If the answer is yes, then our notion of autonomy would be overly shallow and trivial. It would be analogous to the notion of "capricious freedom" in the sense that one is free insofar as one has a power of acting without a motive (cf. Sidgwick 1888). I don't think any serious bioethicist should accept this notion of autonomy. If it is discovered that a patient's individual medical decision is egregiously in discord with the essential features of her moral identity, cultivated integrity, or a well-standing life plan that she has long cherished, then it is nonsensical to hold that her decision has been made based on her "personal values and beliefs" and so autonomous.

Indeed, one's "personal values and beliefs" are typically integrated into the features of one's moral identity or character in the exercise of practical reasoning through one's life experience. The genuine way of formulating decisions based on one's "personal values and beliefs" is inevitably an exercise of practical reasoning that one performs in the company of others on whom one depends, and "there is no point then in our development towards and in our exercise of practical reasoning at which we cease altogether to be dependent on particular others" (MacIntyre 1999, p. 97). In the predicament of serious illness, as Jue Wang argues, the essential relevance of dependence on family members to making autonomous choices becomes even more explicit and dominant. To see this point clearly, readers can look

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in the West. As Nash points out, "Beauchamp and Childress (2009, pp. 106–107) suggest that the practical way to deal with those requesting family-oriented consent is to ask the individual if this is his preference. This, of course, is the application of an individualistic system and already does violence to any family-oriented consent" (Nash 2014, pp. 219–230).

at an illuminating case that Wang discusses in her chapter (Wang 2014, pp. 65–82). Contrary to the individualist myth that one's moods, beliefs, and intentions are only transparent to oneself and largely opaque to others, the patient's own voice can often sound frustrated, broken, and ambiguous, far from being an indisputable standard for judgment. Instead, the very exercise of practical rationality presupposes a caring network through interdependence and attachment—the paradigm of which is the family—as its foundation that makes practical reasoning in accord with one's convictions and values possible. Accordingly, individualistic informed consent undermines the patient's chance of making autonomous decisions in accord with her values, beliefs and life aspirations, because this model assumes a single decisional authority possessed by the patient alone and regards the effective exertion of the authority as isolated from the patient's significant relations with her family (Wang 2014, pp. 65–82).

Following this line of thought, Lawrence Yung contends, self-interpretation and interpretation of the self by others are interrelated. As Charles Taylor puts it, "we define our identity always in dialogue with, sometimes in struggle against, the things our significant others want to see in us" (Taylor 1994, p. 28). As an individual's self-interpretation is important to his capacity for autonomy, this is all the more important for a patient, since his decisional capacity may be undermined by his internal weaknesses or psychological impediments, such as irrational preferences, false consciousness, a belief in oppressive norms, or deformed desires (Yung 2014, pp. 109–124). From Jue Wang's observation, while the patient himself may be confused due to suffering from illness, the family is in a position to judge whether a certain medical decision is consistent with the patient's life plan. This is because a meaningful medical decision has to be assessed according to a coherent narrative of one's life, and it is through such a narrative that the patient brings unity to his life, by orienting all his decisions and actions towards some core commitments that determine who he is as a person. Accordingly, the patient's personal identity in key part depends on how well he lives out that unity and brings it to completion (Wang 2014, pp. 65–82). As Alasdair MacIntyre powerfully argues, the self has to find its identity in and through its membership in communities such as the family, in the sense that my story is part of the story of other family members just as their story is part of mine (MacIntyre 2007, p. 221). Particularly, in the process of making a medical decision with his family, the patient gains the better understanding of his conditions, his options, and his genuine wishes (Yung 2014, pp. 109–124).

This is to say, a mistaken understanding of autonomy is implicit in the scope of the exclusive individual authority assumed by individual-directed informed consent. As Bishop argues, "despite the reigning myths of the American individual who enacts and rejects treatment at the end of life, in truth the family, who can bring the nuance of spiritual and moral values to the clinical scenarios, is in the best position to make decisions on behalf of an individual rendered dependent by his illness. Dependency necessitates a family to enact a community of care" (Bishop 2014, pp. 27–42). Similarly, Kysungsuk Choi contends that we have to revise the individualistic notion of autonomy so that it may reflect a desirable sense of moral agents as it is embedded in the Eastern way of life, in which the family is just as important as the individual in participating in the process of biomedical decision making. This revision avoids depriving patients of the company of their families—and it is only through and with their families that patients can maintain the integrity of their moral agency in the practice of informed consent (Choi 2014, pp. 83–92).[2]

Another problem of the individual-directed model of informed consent is the mistaken assumption that the patient can sovereignly and independently control his actions and determine his fate in today's high-tech medical contexts, such as the ICU. By drawing on the notion of "technological brinksmanship" coined by Daniel Callahan, Bishop shows why this assumption is illusory. By technological brinksmanship Callahan means the drive to seek more aggressive care, thinking that, at some point in the course of the illness, an individual will be able to know when he has crossed a threshold. In crossing that threshold, he will know it is time to say 'no' to more aggressive care (Callahan 2000, p. 41). In other words, the social apparatus of decision making in contemporary American medicine holds that the self is in a position to control one's body, life, and death, knowing when to say, 'enough is enough.' As Callahan suggests, "[t]he only evil greater than one's personal death is increasingly taken to be the loss of control of that death" by the individual decision-maker (Callahan 2000, p. 37). The social apparatus of the ICU, along with all the documents that an individual ought to have completed before going into the ICU—living will, durable power of attorney, and consent forms, has at its heart a sovereign and independent individual who sets in motion the aggressive technological features of medicine. This apparatus also assumes that the sovereign individual is capable of conquering the power of this technological environment and bringing his life and death issues under his own control (Bishop 2005, 2014, pp. 27–42).

However, because of the sheer power of the apparatus of the ICU, it is not at all clear that the individual will be in a position to know precisely when he has crossed over the brink so as to be able to give an explicit directive to withhold or withdraw aggressive technological treatment. Even if the individual knows that a time will come when the machines may no longer be to her benefit and has completed all the documents—such as a living will or advance directive—those machines might not be rightly turned off in terms of her genuine wishes. As Bishop indicates,

> For the most part, living wills and the consent that they imply, say something similar to this: "in the event that I am unable to participate in decision making, and if my attending physician thinks that aggressive treatment will not result in return of function, I authorize the doctor to stop" various aggressive treatments. However, anyone who has ever practiced medicine knows that the complicated physiological nature of seriously ill patients does not offer bright lines that are baldly apparent to anyone. Rather, there are nuances of clinical judgment and interpretation that are part of the decision-making process, and *having a*

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[2] Indeed, in this volume the Western reader finds for the first time in English a presentation of the grounds of East Asian approaches to individual autonomy and informed consent and their differences from what have generally prevailed in Western bioethics. Without such an understanding, East Asian practices would to the Western bioethicists appear puzzling at the very least.

> *family there who can help to make these decisions is so much more important than having a living will, or a document of informed consent that has been individually executed*. The truth is that, when we are at our most frail, for the vast majority of cases it is the family that knows its members best and the family that knows how best to reason with and to inform the doctors of what is best for the sick individual (Bishop 2014, pp. 27–42).

This is to say, though the general ethos of contemporary bioethics promotes the attitude of technological brinksmanship and individual-directed informed consent, the actual circumstances and practices of care at the end of life can never place the patient in a position to be capable sovereignly and independently of controlling her actions and determining her fate. The patient cannot *independently* know when it is the right time to say 'no.' Neither can a living will, set out in the general delimited circumstances of critical care, explicitly tell the doctor what the patient precisely wants. The engagement of family members is not only beneficial but also inevitable.

In addition, individual-directed informed consent does not fit the reality of East Asian cultural circumstances in general and their practices of biomedical decision making in particular. It will even be ethically inimical if this individualist model is forced on East Asian patients. For example, as Kysungsuk Choi reports, most elderly people in Korea feel a moral obligation to their offspring. When they say they do not want any life-sustaining treatments, they are probably concerned with sparing such treatments for saving money that can be used by their offspring for better lives (Choi 2014, pp. 83–92). Similarly, based on their research findings, Ho Mun Chan et al. find that a strong ethos of familism is still manifested in current Hong Kongese society. In this ethos, people are often willing to sacrifice their own interests, such as health, material interests or other self-centered interests, for the sake of promoting the interests of other family members. This means that interests of the self may include the interests of other family members. In other words, the interests of other family members are inseparable from one's own interests, and so one's own interests have to be sacrificed for the sake of promoting the interests of other family members. Accordingly, in the process of medical decision making, the patient should not be conceived as an independent or isolated being; rather, the patient must be appreciated as a person situated in a family network, and the patient's wishes should not be dictated solely by what he wants for himself but should sometimes be overridden by the family's decision for the patient's benefit (Chan et al. 2014, pp. 151–170).

In Taiwan, from Shui Chuen Lee's observations, family relations are still very intimate, and family involvement in all kinds of personal activities remains common practice. Medical decisions are no exception. Family members can provide the most needed help and trust when one is sick and vulnerable. Family members are also usually a reliable source of the patient's values and preferences, which provide the best guidance for treating the patient and ground the medical decisions for the health professionals. The medical law in Taiwan is even written in such a way that diagnoses and results can be disclosed either to the patient or to the family, and in some cases the diagnosis is not made known to the patient at all. In cases of terminal illness, the family's legitimate participation is critical because it is often the case that the wishes of an incompetent or comatose patient are unclear for health professionals trying to determine which alternatives to deploy. The family as a whole is usually competent to make such a decision. This may help health professionals avoid some of the hard moral dilemmas. On the other hand, family participation is also useful for preventing the abuse of weak and lonely patients by health professionals. In short, as Lee sees it, it would be a non-starter for Taiwan to change to the individual-directed model of informed consent (Lee 2014b, pp. 125–136).[3]

Finally, individual-directed informed consent is characteristic of a type of principlism that is not sensitive to the biomedical complexities and nuances that call for context-relative virtuous practices. The most popular contemporary bioethical principlism holds as a starting assumption that "no more basic moral content exists than the collection of rules and general moral judgments that are developed from the four clusters of principles": the principles of respect for autonomy, nonmaleficence, beneficence, and justice (Beauchamp and Childress 2009, p. 387). These four principles, from this principlist view, not only "function as an analytical framework intended to express general norms of the common morality that are a suitable starting point for biomedical ethics," but also "function as general guidelines for the formulation of the more specific rules" (Beauchamp and Childress 2009, p. 12). In contrast, there remains within East Asian culture a quite different Confucian approach to bioethical issues that does not take general principles as the starting point. Instead, this approach is rooted in Confucian understandings of a life of virtue (德) and is embedded in a way of life sustained by rituals or rites (禮) towards virtue. The focus is not on offering an exhaustive set of principles to formulate specific guiding rules for all cases, but on cultivating virtue through ritual exercise which is inevitably context-relative and practice-dependent. In short, Confucian thought appreciates that the moral and bioethical life is not just directed by general principles, but is learned and manifested in concrete manners in which specific ritual practices play a fundamental function in attending to the nuances and complexities of biomedical matters in the virtuous way.[4]

By analyzing a recent Chinese case in which a wife conceals the cancer diagnosis from her husband, Wenqing Zhao argues that the principlism implicit in individual-directed informed consent is bioethically misleading. From Zhao's view, the case of concealing illness from the patient partly reflects the Confucian way of

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[3] Here again puzzles regarding East Asian approaches to the bioethics of informed consent can be resolved. These approaches do not discount the individual, but rather appreciate the individual patient within the context of the dependency of illness and the thick social relations that many patients have within their family.

[4] Here one has a light shed from the East on the one-sided and incomplete appreciation of general principles as envisaged within some Western accounts of medical decision making within the practice of informed consent. To act freely is always to act in a thick social context. From a Confucian view, only in the *constitutive* ritual or quasi-ritual practices of the life world (as Confucius disclosed 2500 years ago), can general principles play their secondary *regulative* function (cf. Fan 2012).

making medical decisions, which is primarily not general principle- or rule-guided, but is ritual- and virtue-based and family-oriented. In this case, on the one hand, the wife treated her husband according to her knowledge of what was best for him, which shows a Confucian understanding of caring. Her shouldering of all of the fear, stress, and suffering arising from her husband's worsening condition is, according to Confucian norms, regarded as manifesting her virtue as a wife in treating her ill husband with great courage and love. From the Confucian point of view, a virtuous person need not obey the rule of truth telling regardless of the mental and physical condition of the patient. It is a much more complicated process of weighing the consequences of different decisions, carefully evaluating the patients' mental and physical condition, and most importantly listening to the will of the patient and other family members. In this story, the husband showed a strong will to live, and the wife was afraid that knowing the bad news would diminish her husband's courage to fight the cancer. Thus, one could hardly say that informing the husband of his condition would really be doing what was best for his care. There are no Confucian rules or requirements stating that the family must or must not conceal information from the patient. The right decision is highly contextual. From Zhao's view, taking such a Confucian approach is often much harder than simply following the principles of beneficence, justice, and, most importantly, respect for autonomy. If one always acts by deferring to some general principles or rules, such as that of telling the truth to the patient, one would have shied away from one's *virtuous* responsibilities to significant others in the complex bioethical context (Zhao 2014, pp. 231–244).[5]

1.3 The Justification of Family-Oriented Informed Consent

Family-oriented informed consent denies what the individual-directed model assumes: that the patient has exclusive decisional authority. From an East Asian Confucian perspective, the patient does not have an individual right to include or exclude family decision making. Instead, this perspective stresses the naturalness,

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[5] Some Western readers may not find Zhao's example compelling. They may contend that it is one thing to affirm that the wife was well-intended, but quite another to judge whether hiding the truth from the husband was actually in his "best interest": just because the wife thought it would be in his best interest, doesn't mean it was so. However, it should be noted that Zhao's main purpose of addressing this case is to indicate a fundamental cultural difference, which invites Western readers to consider how Chinese people view this situation. As Zhao observes, this case was met with general approval and admiration in mainland China. In addition, it is at least theoretically possible that it was in his best interest—in the same way that the Western physician sometimes invokes the "therapeutic privilege" condition for non-disclosure. Importantly, as Zhao points out, in order to judge best interest, we need to appeal to a particular conception of the good shared in a culture. While she does not offer a full-brown Confucian conception of the good, she emphasizes the Confucian experience that "to be able to rely on one's family members in the final stage of life is the good thing to do, and it makes the patient happy" (Zhao 2014, pp. 231–244).

usefulness and normalness of the engagement of family members in a patient's biomedical decision making, thus acknowledging a shared decisional authority enjoyed by both the patient and his family. In East Asian regions, such a family-oriented model requires the physician to recognize the family as a fundamental unit for making medical decisions for the patient. Can such a family-oriented (rather than individual-directed) model of informed consent be justified? The first consideration of justification would be to attend to relevant sociological facts and social customs existing in society. In this regard, Ana Iltis summarizes two main reasons in favor of family engagement in biomedical decision making even in the American context: family members may have a stake in each other's well-being, and may also be concerned with advancing and protecting each other's interests because they care about each other's well-being. She warns that clinicians and researchers should not assume that most patients and potential research participants exist outside of an intimate family whose participation in health-related decisions is unnecessary or even inappropriate. Rather, these two considerations give us important reasons to take families seriously in the health care setting. As Iltis remarks, these considerations are especially important when patients are faced with severe diagnoses or critical-care situations or individuals are asked to assume health risks primarily or exclusively for the benefit of others (Iltis 2014, pp. 171–186).

The practical benefits of the involvement of family members in medical decision making are significant and multi-dimensional. First, as Lawrence Yung points out in his chapter, a lamentable characteristic of modern medicine is that the physician-patient relationship has become highly formalized, regulated and constrained due to the application of ever-changing medical technologies and ever-increasing health care bureaucratization. Thus a huge gap has been formed between the patient and the physician, and this gap prevents them from forming a personal, communicative and intimate relationship. A family platform may provide the kind of caring and emotional support that a patient needs most during illness. It may also empower the patient when dealing with difficulties from a highly bureaucratized relationship with his physician, so as to mitigate the gap between them (Yung 2014, pp. 109–124). In other words, the involvement of family members is capable of creating and sustaining a space in which both patients and their family members find themselves commonly situated to pull together in face of crisis. Their shared life history, memories and commitments put them in the best position to inform and reason with the physician, so as to get the physician appropriately engaged in the treatment of the patient. In short, the involvement of family members creates a locus that helps bring the physician into a closer, more committed, and more "biographical based" relationship with the patient, against the background of highly specialized and bureaucratized medical practice (Wang 2014, pp. 65–82).

Moreover, as Bishop observes, the family seems to be best suited to take on this role of decision making for at least three specific practical factors. First, the family has a special role in caring for the material needs of its members. Second, the family is in the best position to appreciate and preserve the values of its members due to a common or shared life history. Finally, the family is able to carry out the methods of decision-making and methods of discernment utilized in the biomedical setting.

And these methods are much more likely to render decisions that are consistent with the moral and meaningful life-world of the family-member who has become ill. Not only are the family-members' values enacted, but both the family and the individual family member learn how to make these sorts of decisions in a family-oriented model of informed consent (Bishop 2014, pp. 27–42).

The turn to family-oriented informed consent could also contribute to the solution of certain thorny biomedical issues, such as cadaveric organ donation. In her chapter, Yu Cai proposes that the individual-directed legal model adopted in mainland China for cadaveric organ donations should be converted to a family-oriented model, where the express consent of the individual to cadaveric donation during her lifetime should be a decision jointly made with her close family members, and this requirement should be reflected on a consent document to be signed by both the donor and a representative of her family. Although the currently adopted individualist legal model in China only requires individual consent, it is simply impossible—culturally and socially—that the doctor could remove a donor's organs after his death without having to seek out the extra informed consent of his family members. From Cai's view, only by changing to a family-oriented policy as she proposes, can a Chinese citizen's right to dispose of his corpse and his family's right to the ownership of his body (as it is culturally appreciated) be both respected and fulfilled. In this way doctors could avoid the embarrassment of having to ask for the permission of family members and would not risk harvesting organs without the family's consent (Cai 2014, pp. 187–199).[6] Similarly, for biomedical experiments using human subjects in mainland China, Rui Deng proposes "a family-based binary decision model" to protect Chinese subjects. In this binary decision model, the family has a right to affirm or deny a family member's consent to being a research subject. The family, however, does not have the right to require that a family member participate in a trial. That is, for any trial, if a person decides not to participate, the family cannot require her to participate. However, for any significant experiment, if a person decides to participate, she still needs to get the consent of her family; if the family denies consent, the person should not be allowed to participate in the experiment. As Deng states, this right of the family's participation in the decision making is necessary to consider the risks of scientific research from more angles so as to protect the important interests of individual family members as subjects (Deng 2014, pp. 203–218).

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[6] What is the way of resolving disagreement if one family member thinks differently? This is certainly an inevitable question from Western readers. However, Western readers should be informed of a general Confucian cultural ethos in which people have formed a familist mentality and attitude: family members, since they are from one family, should reach agreement and make one decision about any important matters (such as donating organs after death) confronting any of their family members. This "one-decision" strategy for each family is understood as the basic way of manifesting the integrity and solidarity of the family in the process of protecting the morality and interest of each family member, and all family members, in their life experiences, have been cultivated by Confucian virtues (such as harmony (*he*) and relevant rituals (such as family meetings) to practice this "one-decision" strategy. Thus, agreement will usually be achieved through familial discussion. Those families that cannot reach agreement will be despised by others as wanting of necessary familial virtue and integrity (Fan 2011; Fan and Chen 2010).

In addition to being accepted as a normal social custom, the engagement of family members in biomedical decisions in East Asian contexts has also been supported by the Confucian moral virtues prevalent in the region. Indeed, from a Confucian virtue perspective, the family has a moral obligation to protect the interests of its members who are ill or interested in participating in biomedical research. The family cannot undertake this obligation without being actively involved in the decision-making process for its members. For example, as Ilhak Lee indicates, Confucian filial duty (孝) has served as the backbone of social relationships and guided children in the care of their parents in Korean society. The younger generation regards it as their moral duty to care for their elderly parents in return for the grace they received in the early days of their lives. Since this sense of moral responsibility and gratitude to one's parents and grandparents is taken as a given in South Korea, it is morally impossible for adult children not to be included as principal decision makers to protect their parents' and grandparents' interests (Lee 2014a, pp. 137–148).[7] From this Confucian moral perspective, as Yu Cai points out, the family stands as a morally united entity for mutual responsibility, and in this united entity every member's health care or life-sustaining treatment is no longer an individual matter, but is a common matter, for which every member is morally responsible (Cai 2014, pp. 187–199). Echoing this view, Rui Deng states that everyone's moral identity is formed and confirmed in the family. To make morally important and good decisions in the course of one's life, such as matters of education, employment, marriage, health, hospitalization, and medical treatment, one's family members are morally obliged to join in the deliberating and decision-making process (Deng 2014, pp. 203–218).

Finally, family participation in biomedical decision making gains support from the ontological-metaphysical account of the family that is still prevalent in East Asian contexts. In this account, as H.T. Engelhardt presents it in a recent essay (2013), the family is appreciated as a deep, normative social entity, and this appreciation has traditionally been endorsed by such religions as Confucianism and Christianity. Differing from the libertarian/liberal construal of the family that has been adopted by fashionable contemporary bioethical strategies in the West, the ontological-metaphysical account of the family recognizes the family as a normative reality that should be realized by particular families as far as possible. This account brings with it pre-existing roles for husbands and wives, fathers, mothers, and children. The family, in this account, tends to be multi-generational, looking back with respect and support to previous generations, while looking forward with love and concern to succeeding generations. From Engelhardt's view, because the social entity of the family embodies itself in a normative socio-biological unity, it supports the autonomy and integrity of the family, inevitably endorsing family-oriented biomedical decision making and policies of confidentiality in preference to individual-directed ones (Engelhardt 2010, 2013).

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[7] The East Asian appreciation of the virtue of filial piety allows one to take what otherwise would be a narrow, rule-based imposition of autonomy in informed consent and see it more amply in terms of a virtue ethics.

Based on this ontological-metaphysical understanding of the family, authors for this volume, such as Jeff Bishop and Jue Wang, further explore the rationale of family engagement in the informed consent practice for the possibility of human flourishing. As Bishop states it, since the individual is typically dependent on (rather than independent from) the family, the family is the first and fundamental unit of care when the contingencies of injury, disease, and other afflictions threaten one of the family-members. It is the family, not the individual nor the *polis*, that does the vast majority of care when injury or disease strikes the individual. In this regard, families are actually the sites where the virtues of acknowledged individual dependence are first and most fundamentally nurtured, and family members shape the specific forms of giving and receiving within families as they strive to meet and to attenuate the contingencies of injury, disease, and other afflictions upon any of the family members. It is for this very reason, Bishop contends, that the family is best situated to take on the role of participating in the decision-making process of its members (Bishop 2014, pp. 27–42). Children, spouses, parents, and grandparents are the context within which bodily dependency is attenuated, intellectual needs are met, and moral values are formed. It is within the context of the family that, as bodily and intellectual needs are met, the moral and existential meanings and purposes of the lives of its members are inculcated (Bishop 2014, pp. 27–42). Similarly, along these lines of consideration, Jue Wang adds that the embodied, vulnerable and dependent condition of the human individual prescribes a common way of human flourishing, that is, to be included and cared for in the family—a network of unconditional taking and giving that constitutes the common good for every individual. Accordingly, if due attention must be paid to the frailties and dependencies of human life in our practical reasoning in biomedical contexts, we will inevitably bear witness to the ontological necessity of the family as well as the moral necessity of family participation in the decision-making process, since human flourishing first and foremost occurs within the family (Wang 2014, pp. 65–82).

1.4 Challenges to Family-Oriented Informed Consent

There are numerous misunderstandings of and challenges to family-oriented informed consent in contemporary bioethics. This section will tackle a few of them that appear prominent. First, it is mistakenly thought that in urging family engagement in informed consent, one is pushed to take family interests over the interests of individual family members. This charge sounds all the more plausible when the word of "familism" is used in addressing biomedical issues as I frequently do in my Confucian bioethical work. As Kam Por Yu suspects in discussing the two examples constructed in his chapter, if one can provide better care to his family as a whole by letting his father die, then from the perspective of "familism," letting his father die may be the right thing to do. Similarly, if one's mother is regarded as a more important member in the family than one's 3-year-old son, it can be argued that killing the son to save the mother is to the greater interest of the family (Yu 2014, pp. 93–106). Does family-oriented informed consent really have such repugnant moral implications? If not, how should the probable tension and conflict between individual and family interests be resolved?

It seems to me that the real issue at stake is what standard should be adopted to guide biomedical decisions, regardless of whether they are made in family-oriented or individual-directed manners. As is well-known, in traditional Western medical ethics as characterized by the Hippocratic Oath, the best interest of the patient was invoked as the standard for the physician to make medical decisions. In the modern West, in contrast, the patient's own wishes, no matter whether they are in his best interest, take pride of place as long as they do not violate the physician's professional integrity. In Confucian culture, a proper medical decision is taken to follow the way of heaven (天道) as manifested in the requirements of the virtues, such as *ren* (loving humans), *yi* (being loyal to relatives), *xiao* (being filial to parents), and *he* (seeking harmony). Hence, although the Confucian ethical tradition has been robustly familistic rather than individualistic, it has never held a utilitarian principle of interest calculation or utility maximization. When the best interests of the patient and the family come to conflict with each other, the Confucian approach to medical decision making does not provide a guiding formula that requires either family interest or individual interest to trump the other. Rather, the Confucian standard is always following virtue by performing the rituals (禮) that have been affirmed in the tradition, such as mutual concern, family meeting, and deliberation. The result, accordingly, has to be contextual. The ideal is to integrate patient interest and family interest into a possibly harmonious system that is structured by the guidance of the virtues (Fan 2011).

It could be charged, on the other hand, that family-oriented informed consent advocates a kind of family-paternalism—family members may, in the name of pursuing the best interest of the patient, be allowed to impose their conception of the good upon the patient who actually holds very different values and preferences. Such medical family-paternalism is morally objectionable not only because it deprives the patient of her decisional authority, but also because it allows family members to substitute their judgments for those of the patient as if they knew better what was conducive to the interest and wellbeing of the patient (Yung 2014, pp. 109–124). This charge, which may be made against any form of family-oriented informed consent, is especially serious to the robust form of family-oriented informed consent embedded in the so-called Confucian bioethics exercised in East Asian regions. I don't have enough space here to address this challenge in detail, but it suffices to point out one crucial point to demonstrate that Confucian bioethics is not committed to family-paternalism in the general sense. While the robust form of Confucian family-oriented informed consent stresses "family sovereignty" or "family autonomy" rather than "individual sovereignty" or "individual autonomy," it by no means excludes the patient from sharing the authority of the family. In other words, though Confucian bioethics does not accept that the patient has a sole decisional authority for his biomedical matters, neither does it hold that his family members possess an exclusive power. What is actually stipulated is that both the patient and his family members share the "family" authority to make proper medical decisions for the patient. Of course a key issue is what should be done when the patient and his family members disagree. Confucian bioethics does not want to establish any “universal” principle to demand that either the patient’s preferences or his family members’ wishes be always followed. Rather, in such situations the physician is usually called for to exercise medical professionalism by favoring one side in order to protect the best medical interest of the patient according to his professional judgment. At the end of the day, unless the situation is urgent, the patient must be persuaded, rather than coerced, to accept a medical intervention. In short, because the family members are not taken to have unique authority to “force” the patient to accept medical treatment for the patient’s benefit, this type of family-oriented informed consent cannot reasonably be criticized as family-paternalism (Fan and Chen 2010).

When the patient becomes incompetent, how should surrogate decisions be made for the patient? Wouldn’t family-paternalism become prominent in such cases? Surely there are different standards that have been suggested in the literature regarding surrogate decision making. The best interest standard holds that a surrogate decision should be made by deciding what would be best for the patient. On the other hand, the proxy judgment standard holds that a proxy (who should be appointed by the patient before becoming incapacitated) should make surrogate decisions according to the patient’s expressed wishes or other knowledge of the patient’s values. Evidently, the proxy judgment standard has nowadays become dominant in Western bioethical accounts. In contrast, in East Asian regions, the best interest standard is still prevalent: family members are making decisions for their incompetent patients according to their judgment of the patient’s best interests. Sometimes they do appeal to their own judgment of the patient’s best interests to trump the patient’s previously expressed wishes, and this indeed is a kind of family-paternalism. In his chapter, Lawrence Yung attempts to defend this kind of family-paternalism by arguing that the patient could have been persuaded to accept the family members’ decision if he were competent and possessed the relevant information of his new condition (Yung 2014, pp. 109–124). Indeed, some American bioethicists have discovered that even most terminally ill patients in the United States prefer to have surrogate decisions be made by balancing the patient’s own wishes, the proxy’s judgments about the patient’s best interests, and the input of the physician, rather than demand that their wishes be absolutely followed (Sulmasy et al. 2007).

Of course, medical family-paternalism could be abused in practice, not to be executed to the genuine benefit of the patient. Let us consider East Asian Confucian cultural contexts, in which adults are morally obliged by filial duty to take care of their elderly parents, including making medical decisions to maintain or withdraw their life-sustaining treatment. In this connection Ilhak Lee uses the South Korean situation to address relevant issues. Generally children seem to feel that it is their duty to provide every possible means of curative care for a parent, regardless of the likelihood of recovery. Even in cases where parents explicitly refuse aggressive medical interventions, children still feel (or would be expected to feel) guilty if they cease to request every possible medical treatment for their parents. They will sacrifice their savings, jobs and houses to pay the hospital expenses allowing their parents to remain in the hospital longer. Indeed, filial duty requires a child to think from the perspective of the welfare and happiness of one's parent in order to make decisions. But Confucian ethics and bioethics have yet to provide updated, specific or "quantitative" criterion of filial duty that can be applied by adult children to make appropriate end-of-life decisions for their parents in contemporary high-tech medical contexts. Children do not want to risk being blamed or scrutinized for "killing" or "abandoning" their parents. Therefore, their decisions are usually made in a very cautious manner: e.g., the parent remains connected to a ventilator for as long as possible (Lee 2014a, pp. 137–148).

The abuse of elderly care can be generated by various factors and improper incentives. I heard some Chinese cases in which the patients in persistent vegetative state were kept ventilated for years in order for their relatives continuously to enjoy certain material privileges assigned to the patients by government policy as long as the patients were "alive." Such decisions were not made in the genuine interests of the patients. What we should be concerned with here is whether such abuse is necessarily caused by family-oriented informed consent and will be ruled out by changing to individual-directed informed consent. From my understanding, similar abuse can take place under the individualist model as well, because the patient may individually require keeping his life no matter what. Thus, it may not be that the family-oriented informed consent or the Confucian virtue of filial piety is necessarily to blame. Rather, as Ilhak Lee recognizes, people do not need to abandon their ethical tradition to be ethical. In the Korean case, what needs to be done, from his view, is for adult children to understand that aggressive life-sustaining treatment is not always useful but can be harmful to their parents; accordingly, suitable palliative care is not abandoning their parents and should not be seen as a failure of filial duty. At the same time, elderly patients should be encouraged to participate in the decision-making process to exchange their views expressively with their children and medical professionals so that appropriately shared medical decisions can be made for their care. In the Confucian tradition, this is a more active way of seeking the parent's wishes and letting them conform to the way of heaven, so that family-oriented informed consent can be maintained and perfected in South Korea in contemporary times (Lee 2014a, pp. 137–148).

Another challenge to family-oriented informed consent concerns the issue of truth-telling to the patient. The critic would contend that at least in East Asian medical practices, family-oriented informed consent has the effect of encouraging the family members (and subsequently the physician) to hide the truth from the patient so as to violate his right to know his own health condition and choose his own treatment. To meet this challenge, the case discussion and theoretical exploration offered by Wenqing Zhao in her chapter are illuminating (Zhao 2014, pp. 231–244). Briefly put, Confucian ethics and bioethics do not accept a robust liberal individualist conception of human rights. Instead, from a Confucian perspective, while it is helpful in contemporary society to set down Confucian rights as legal requirements to protect Confucian individuals' basic legitimate self-interests, Confucian rights as entitlements may be necessary only as a fallback apparatus. This is to say, rights are needed only when the virtues fail to obtain or people's personal relationships break down

(Chan 1999; Fan 2010, p. 58). Accordingly, in the Confucian-cultural context, the patient's right to medical truth serves only as a fallback right: when the doctor finds evidence that family members do not care for the best interest of the patient and/or that their decisions violate the best medical interest of the patient according to the doctor's professional judgment, the doctor is morally obliged to take the initiative to intervene and tell the truth to the patient (Fan and Li 2004, p. 179).

What if, after the patient becomes incompetent, family members cannot arrive at a consensus among themselves? They may have significant disagreements about what is best for the patient. Here, from Shui Chuen Lee's observation of Taiwanese experience, medical professionals can assist in conducting and moderating family meetings. As he remarks, medical advice is important for preventing family members' misunderstandings and unfounded worries about the patient's medical possibilities. Meanwhile, through open discussion with family members, medical professionals can learn about the differences expressed among family members, the family's structure, as well as the values and preferences of the patient and the family as a whole. With such understanding, medical professionals would be better able to protect the best interest of the patient in cases of deadlock among family members. In rare cases in which the patient is maliciously manipulated by his family members, medical professionals can serve as powerful regulators and protectors of the vulnerable patient (Lee 2014b, pp. 125–136).

Should an ethics committee be set up to check the family's decision and make the final decision for the incompetent patient in the case of, say, DNRs? Shui Chuen Lee, using Taiwan's Hospice Palliative Care Act as an example, answers the question in the negative. In a previous version of the Act, there was the requirement that an ethics committee examine and approve the family's decision before it could be implemented. This was required to prevent the possible abuse of family members and physicians to the detriment of the patient. However, it was subsequently discovered that the ethics committees refused reasonable decisions arrived at by the head physicians and the major family members for DNRs simply because the committee members worried about accusations by other opposing family members. Unlike the patient's major family members who are actually sharing in the suffering of the patient or the patient's medical professionals who are committed to the care of the patient, such committee members are detached and removed from the patient so that they tend to be conservative in their decisions in order to protect themselves from possible troubles, at least in the Taiwan context. In this way, the ethics committee became a mechanism that furthered the pain and suffering of both the family members and the health professionals. Thus, this provision in the Act was deleted from its most recent version in 2012, so that decisions made by major family members supported by the medical professionals have become final (Lee 2014b, pp. 125–136).

Finally, how should the family-oriented model of informed consent arrange for the patient to prepare an advance directive before she becomes incompetent to assess her future treatment? In addressing this issue, both Hon Chong Wong and Yaning Yang in their respective chapters agree that such documents are helpful for families to know better about their patient's wishes and preferences so as to facilitate their decisions after the patients become incompetent. From Wong's view, encouraging the patient to work out an advance directive individually and appoint one of her family members to be her formal proxy does not in any sense undermine the value of the family or the intimate relationships she has with her family members (Wong 2014, pp. 245–256). On the other hand, Yang argues that the process of appointing the durable power of one family member as one's attorney by the patient must have the involvement of all of the patient's major family members. The surrogate decision maker should be recognized not only by the patient herself but also by her other major family members. In fact, Yang thinks that all family members should participate in determining who should serve as the formal proxy on behalf of the entire family, and the living will document or the durable power of attorney form should be signed by both the patient and all major family members to empower its function. From Yang's view, this Confucian family-oriented model of advance directives has two advantages. First, it can encourage patients, especially elderly patients, to discuss their end-of-life care and decision making with their family members so that their family members can better understand their desires and wishes. Moreover, it can also help the patient and her family members engage in harmonious cooperative interactions to arrive at important medical decisions, so as to prevent possible conflicts between the surrogate decision maker and other family members after the patient becomes incompetent (Yang 2014, pp. 109–124).

1.5 Concluding Remarks

The force of the reflections in this volume is to bring bioethicists in East Asia to appreciate better the family as the central ground of their approach to consent for medical treatment. It also makes available in English a basis for appreciating less one-sidedly and incompletely informed consent within Western bioethics. The importance of this task is underscored by the American contributors to this volume. These reflections on the East Asian emphasis of family-located informed consent interestingly reflect the recent discovery that many Americans (especially native Americans) wish to have consent for their treatment embedded within a family context. It is hoped that, having made this discussion available in English, a rich and critical response will develop. Indeed, part of the response has been made by Lisa Rasmussen in her thoughtful Epilogue to this volume.

The traditional family has largely been broken in the West. In his chapter, Mark Cherry cites a series of statistics and figures to show the severity of this crisis. For example, in the United States, unmarried birth rates in 2011 tracking the race of the mother were as follows: Black—72.3 %; Hispanic—53.3 %; American Indian or Alaska Native—66.2 %; White—29.1 %; Asian or Pacific Islander—17.2 % (Cherry 2014, pp. 43–62). Such data ought to raise significant concern because children reared outside of the traditional family environment face real disadvantages (Cherry 2010). On the other hand, out-of-wedlock birth rates and single parent families in East Asian regions are fortunately still low: for example, in Hong

Kong, there were 81,705 single parents in 2011 (among a population of a bit over 7 million) and the average number of dependent children for single parents was 1.3 (Census and Statistics Department of HKSAR 2012); in South Korea, there were approximately 16,000 unwed mothers raising children in 2010 (D'Itri 2010); in Taiwan, the proportion of single-parent households has grown by 50 % over the last decade, numbering 560,000 and accounting for 7.6 % of the totally 7.41 million households of Taiwan in 2012 (Taiwan Insights 2012). Accordingly, while East Asian bioethicists still have a great deal to learn from the ethics and practice of the modern West, they should not find everything worthy to learn. Instead, they should be cautions and critical about the changes of modern Western families. Indeed, they should be warned of the lamentable damaging effects of dominant and fashionable modern ideologies on the traditional family as Michael Oakeshott remarks: "First, we do our best to destroy parental authority (because of its alleged abuse), then we sentimentally deplore the scarcity of 'good homes,' and we end by creating substitutes which complete the work of destruction" (Oakeshott 1991, p. 41).

Indeed, as Bishop observes, "the excesses of the West have been to spend too much time thinking about the *independence* of practical reasoners, that is to say too much time on the autonomous agent as an individual on the one hand, and too much time thinking about the political nature of human thriving on the other, and all to the neglect of the family" (Bishop 2014, pp. 27–42). By focusing on the debate between individual-directed vs. family-oriented informed consent in the biomedical sphere, the chapters covered in this volume bring to the fore the fundamental place and value of the family embodied in East Asian Confucian biomedical commitments and practices as well as the fresh American bioethical reflections on the role of the family for long-term human interests and flourishing. Taken as a whole, this volume argues that the family-oriented model of informed consent should be maintained and developed in East Asian contexts. This familist model should not be forced to change to the individualist model. Of course, numerous specific issues around the legislation and exercise of informed consent in relation to the family cannot be settled once and for all. But East Asian readers should be reminded that whether individual-directed or family-oriented solutions will be accepted and promoted in their biomedical contexts bears on quite different futures for their societies as well as for their bioethics.

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