

Descriptive Research is a Necessity for Ethics¹

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Abstract

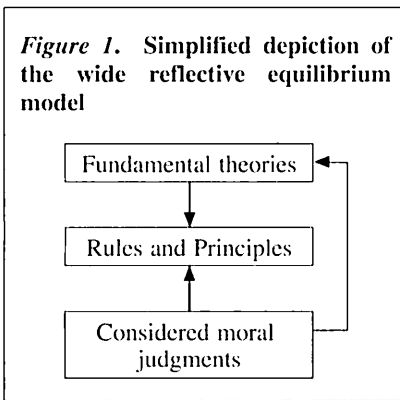
Faced with evermore advancing medical technologies, bioethicists are being asked to provide more insights. The difficulty faced by bioethicists is that there is a wide gap between ethics, which tends to appreciate universal values more as a discipline, and the real situation, in which values appear to be in a constant flux. Only by describing the facts can we formulate appropriate theories of ethics. This paper argues that descriptive (empirical) research is an essential method in the discipline of bioethics. First, I will introduce a model which encompasses both top-down and bottom-up approaches as a useful model to formulate effective theoretical and practical responses to current bioethical issues. Second, I will present some results from two questionnaire surveys. Third, I will discuss the implications of these studies and any aspects that need to be investigated in the future.

According to *The Cambridge Dictionary of Philosophy* (1999), bioethics is "the subfield of ethics that concerns the ethical issues arising in medicine and from advances in biological science." In this more traditional view, bioethics is a subfield of ethics and hence a discipline of philosophy². The Asian Bioethics Association (ABA) poses a different view on the definition of bioethics. In its constitution, ABA defines bioethics as "the interdisciplinary study of philosophical, ethical, social, legal, economic, medical, therapeutic, ethnological, religious, environmental, and other related issues arising from biological sciences and technologies, and their applications in human society and the biosphere (Article 2, ABA Constitution, 2002). From this view, bioethics is not limited only to the disciplines of ethics or philosophy but is an integration of many disciplines³. Bioethics can be viewed as more practical than theoretical as seen in a traditional concept of bioethics.

Arriving at a consensus as to the definition of bioethics is more difficult than at first appears. Nevertheless, it is not unreasonable to divide the discipline into two broad categories: descriptive (empirical) and prescriptive (normative) bioethics (Macer, 1995). On one hand, descriptive bioethics is a study of beliefs that people hold and their views

of the world. On the other hand, prescriptive bioethics is what is usually associated with traditional ethics and is a study of theories (i.e., what is good and bad, its criteria for deciding good or bad, the determining process of what is good or bad). Both types of bioethics are usually perceived as separate subfields. Studies focusing on theories often leave out the "reality" while practical studies in many cases are incomplete in their in-depth theoretical reflections.

This paper proposes a model which possesses both aspects of bioethics, that is, the reflective equilibrium model proposed by John Rawls in his 1971 book *A Theory of Justice*. Rawls' theory of justice is a coherence theory based on this model (see Figure 1). The rules and principles

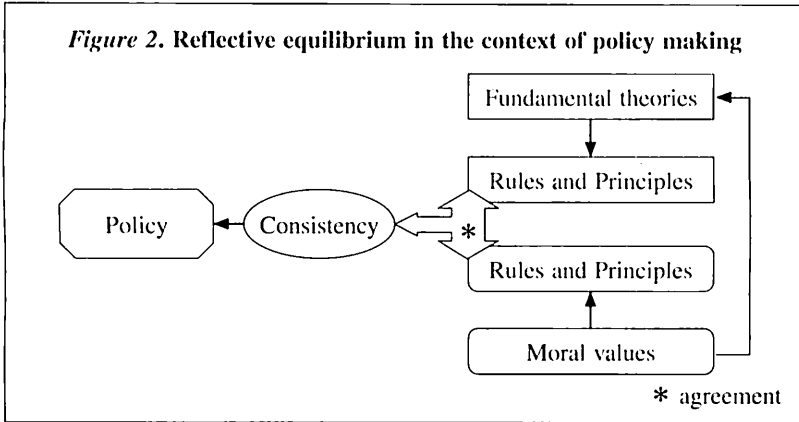


deduced from fundamental theories and those abstracted from the considered moral judgments are tested against each other for their degree of agreement. When the rules and principles do not match each other and the test fails, they are adjusted and revised in light of fundamental theories and considered moral judgments. After the necessary adjustments are made, the rules and principles are once again checked among each other for their consistency.

Parallel to this process of derivation and feedback, the "reality" is reflected back to the fundamental theories. These theories are also modified and revised when necessary in light of the facts of reality. However, the narrow version of the reflective equilibrium model which Rawls originally proposed does not include the fundamental theories. The wider version of the model integrates both prescriptive and descriptive bioethics and thus is a better model.

The top half of the model which is often associated with prescriptive bioethics is within the realm of traditional ethics while the bottom half is often associated with methods used in social sciences. However, this association between empirical research methods and bottom-up processes is an oversimplification⁴.

Figure 2 is a more complex model, wide reflective equilibrium, interpreted in the context of policy making. As described above, the rules and principles derived from fundamental theories and those derived from



the facts of reality are tested for consistency. When they are in agreement, those rules and principles are then tested against preexisting laws (i.e., whether or not what has been derived is consistent with values reflected in the already existing laws and policies). Finally, those rules and principles are utilized as reference in policy recommendations. If there are no agreements between the rules and principles, they are again reviewed in the context of fundamental theories and reality respectively. The same processes are repeated until an equilibrium is achieved and tests of consistency are fulfilled at all three stages.

The importance of incorporating empirical studies in bioethics is now more recognized. One rationale is that an individual theoretical research or empirical study is not sufficient in formulating effective theoretical and

practical responses to current bioethical issues as they arise. For example, empirical studies are possible at all levels of the model. Without feedback from reality to the fundamental theories, those theories and philosophical assumptions would remain unchanged over a period of time. This in turn means that the rules and principles derived from the fundamental theories are not reflecting the values of current

Table 1
Types of questions asked in the first and second studies

- Death with dignity
- Euthanasia
- Individualism
- Influences of others
 (Family members, friends, others)
- Means of alleviating pain
- Pain
- Rights
- Roles of medical doctors
- Roles of patients
- Self-determination

time, and are less likely to be consistent with those abstracted from the facts of reality. This is contrary to changing values of society and there needs to be room for input, to the theories, from actual beliefs people hold.

In the next section, two questionnaire surveys conducted in 2008 are briefly described. As I have already mentioned, though empirical research can be performed at any level of the model, this paper focuses on the depiction of peoples' beliefs and their values when they are making end-of-life decisions.

Questionnaires

Table 2

Additional questions to the second survey

- Whom do you consider as your family?
- Only blood relatives or including non-blood relatives
- If only blood relatives,
- Living together; Not living together; Living together or not, does not matter
- If include non-blood relative,
- Presence/absence of legal relationship?
 - Living together or not?
- Whom do you consider as your family? (please specify)
- Grandparents
 - Father
 - Mother
 - Siblings
 - Uncle
 - Aunt
 - Cousins
 - Second Cousins
 - Niece
 - Nephew
 - Cousins' Children
 - Second Cousins' Children
 - Childhood Friends
 - Neighbors
 - Friends
 - Pets
 - Deceased Family Member(s)
 - Cohabitants
 - Others

Two questionnaire surveys were conducted in 2008⁵ on the issues of self-determination at the "end-of-life." The first study was conducted on the 20th and 21st of January while the second study was conducted between the 16th and the 21st of October. The participants were 276 university students (mean age = 20.4) and 296 career college students (mean age = 21.1) respectively.

The survey was designed with the assumption that there has been drastic changes in the emphasis placed on values in recent years compared to past traditional values. The questionnaires were designed to determine peoples' current values. Table 1 lists the types of questions asked in the studies. Since these surveys were conducted in the context of self-determination at end-of-life, the questions were chosen specifically for that purpose.

In addition to slight adjustments in the wording of questions, a few questions were added to the second questionnaire (Table 2). One specific category of questions added was on family. The main purpose of this revision was to find out whom people consider to be their family (i.e., to determine the boundary of family and non-family members).

The rationale for adding questions regarding family was due to the fact that current laws and guidelines in Japan view family as an important factor in decision-making. For example, in the 2007 guideline announced by the Ministry of Health, Labour, and Welfare regarding decision-making at "end-of-life," there are specifications to inform the family about the decisions made in cases where patients (maybe intentionally) refuse to do so (the Ministry of Health, Labour, and Welfare, 2007). Also, the Organ Transplant Law (1997) requires consensus from family members in order for a donor to actually donate an organ even when one possesses an organ donor card indicating one's willingness to donate. Therefore it is important to determine who is included in the concept of family especially in the context of bioethics.

Table 3 shows the number of participants who answered the question "whom do you consider as your family?" There was no significant differences between those who considered only blood relatives to be their family (n=126, 42.6%) and to those who included non-blood relatives (n=138, 46.5%). Among those who considered only blood relatives as their family, 93 participants (31.3%) responded that living in the same household or not does not matter in determining who their family is. Forty-nine participants (16.5%) responded that only blood relatives living together are considered as family followed by 12 participants (4.0%) responding that blood relatives, even those not living together in the same household are their family.

Two additional questions were asked to those participants who included non-blood relatives as their family: presence or absence of a legal relationship and cohabitation. Ninety-nine people (33.3%) included non-blood relatives without legal relationships as their family while only 39 participants (13.1%) required some type of legal relationships. The second question asked whether or not people needed to be living in the same household for the participants to consider non-blood relatives to be their family. Ninety-six participants (32.3%) responded that they did not need to be living together to consider non-blood relatives to be their family while only 39 participants (13.1%) responded that they need to be living in the same household.

It appears that for those who only considered blood relatives as their

Table 3
The number of participants responding to the question “whom do you consider as your family?”

Whom do you consider as your family?	n	(%)
Only Blood Relatives	126	(42.6)
Living Together	49	(16.5)
Not Living Together	12	(4.0)
Living Together Does Not Matter	93	(31.3)
N/A	142	(47.8)
Include Non-Blood Relatives	138	(46.5)
Presence Of Legal Relationship	39	(13.1)
Absence Of Legal Relationship	99	(33.3)
N/A	158	(53.2)
Living Together	39	(13.1)
Not Living Together	96	(32.3)
N/A	161	(54.2)

family, the issue of living together does not matter. Those who included non-blood relatives to be their family, show a drastic contrast to the former group. The latter group does not require a legal relationship or sharing of the same household for them to consider non-blood relatives to be their family. Though the reasons are not specified, these results may have a significant effect on policy making in the future, because quite a significant number of people perceive non-blood relatives as their family members.

Table 4 shows the number of participants who included specific members to be their family as specified by circling the choices provided in the questionnaire. Most participants included their parents with no difference between Father and Mother (n=247, 97.2% and n=249, 98.0% respectively). Slightly less people included Grandparents (n=231, 78.0%) and Siblings (n=246, 69.9%) as their family. One reason for this may be due to the fact that the deceased grandparents are included in the category of “Deceased family members.” Another reason may be those without siblings did not include “Siblings” in their responses. Uncles, Aunts, Cousins, Nieces and Nephews are considered as family by about 40 to 45% of participants. The percentage appears to decrease as the degree of kinship decreases (i.e., cousin’s children, second cousins, second cousins’ children).

Table 4
The number of participants responding to the question "whom do you consider as your family (please specify)?"

	n	(%)
Grandparents	231	(78.0)
Father	247	(97.2)
Mother	249	(98.0)
Siblings	246	(69.9)
Uncle	118	(46.6)
Aunt	112	(44.3)
Cousins	109	(43.1)
Second Cousins	73	(28.9)
Niece	103	(40.7)
Nephew	103	(40.7)
Cousins' Children	86	(34.0)
Second Cousins' Children	65	(25.7)
Childhood Friends	29	(11.5)
Neighbors	15	(6.0)
Friends	32	(12.6)
Pets	172	(68.0)
Deceased Family Members	204	(81.0)
Cohabitants	90	(35.7)
Others	10	(4.0)

About ten percent of participants consider Childhood friends and Friends as their family (n=29, 11.5% and n=32, 12.6% respectively). Only 15 (6.0%) of participants included Neighbors as their family. However, cohabitants are considered as family by a fairly high percentage of participants (n=90, 35.7%) consistent with data shown in Table 3. Pets are considered as family by a much greater number of participants (n=172, 68.0%)⁶. It is possible to assume that cohabitation (i.e., living in the same household) has some influences on as to who are included in a family.

Discussion

One significant implication of this study is that the results are applicable to a wide range of bioethical issues. Although these surveys were conducted on self-determination at end-of-life, many topics included in the surveys are common among other bioethical issues (i.e., influences of others, perception of rights, expected role of medical doctors and patients, self-determination, concept of family). As seen in Table 3, about an equal number of participants consider non-blood relatives as their family and those who view only blood relatives to be their family. This may suggest that blood relatives who are not living in the same household should be a part of the decision-making process.

In the former group, about thirty percent believe that a legal relationship or cohabitation is required to include non-blood relatives as

family. However, Table 4 indicates that for those non-blood relatives, those who are living together are more likely to be considered as family. Thus, those living together without any legal relationship should be thought of as "a part of the family." This suggests that cohabitants, as well as blood relatives living apart are possible participants in the decision-making of an individual⁷.

One major limitation of this study is that the surveys were designed within the context of Japanese culture. Therefore, the results obtained from this study may be applicable to other bioethical issues in Japan, but they may not be generalized to end-of-life issues and other bioethical issues in other cultures. However, the model proposed and the rationale for utilizing the model are still applicable to other cultures. More specifically, whom to include in one's family may differ depending on cultures but the importance of family in decision-making processes, which is common across many issues of bioethics, is not minimized. In any society, either more individualistic or more communalistic, families play significant roles in an individual's life.

In addition, there are several aspects that need to be investigated in the future studies to determine the validity and utility of the reflective equilibrium model in bioethics: the meaning of democracy in public policy, the validity of data obtained from questionnaire surveys, and effective means of integrating qualitative methods with quantitative methods.

Firstly, the meaning of democracy in public policy must be considered, specifically, the significance of majority opinion versus diversity in opinions. Empirical research methods (either qualitative or quantitative) due to their nature of statistical analysis, aim to extract opinions which have a statistical significance. Statistical significance does not necessarily mean majority opinion in a society. Minor opinions and those without statistical significances are omitted from in-depth discussions.

In the context of multiple cultures, there is a risk of leaving out opinion diversity across cultures. On one hand, those beliefs that may be common across cultures may be neglected because they may not be majority opinions within a culture, especially when a researcher is only focused on one culture. On the other hand, in a multi-cultural research, cultural uniqueness and opinion diversity within individual societies may be lost.

Secondly, the use of questionnaire surveys has become the focus of criticism. This is due to the nature of the quantitative methods often used in questionnaire surveys (as is used in this study). In such surveys, questions are designed so that participants simply read a statement or a

question and respond by circling whether they agree or not, or indicating the degree to which they agree or disagree. In other words, the responses are already formulated and researchers simply need to input data. This makes data input efficient, easy⁸ and there is also minimal room for researchers' bias in interpreting the responses marked on the questionnaires but there is no room for free opinions

Although qualitative methods can overcome this weakness by allowing free responses from the participants or at least maximize the opportunities for them to respond as they wish, it has its own problems. One is the bias that comes in when written responses are encoded for statistical analysis. There are risks of researchers unconsciously encoding responses that may lead to a desired analytical outcome⁹.

It is reasonable to conclude that a combination of qualitative and quantitative methods in empirical research is more effective in quantification of facts. However, how to combine these two methods remains an issue requiring further investigation. For example, is it more reliable to conduct a questionnaire survey with statements to indicate the degree of one's agreement and open-ended questions or to conduct two separate surveys, one quantitative and one qualitative? To conduct a survey with the same group of participants or two similar but different groups? Or, is it more reliable if two different researchers conduct separate studies using different methods on the same topic? Answers to these questions must be answered to aid empirical researches in bioethics as well as bioethical research in general.

Conclusion

I have introduced the reflective equilibrium model proposed by Rawls as an effective model of conducting research in bioethics. This model is effective in formulating theoretical and practical responses to current bioethical issues. In an attempt to argue for the effectiveness of the model, I have provided brief descriptions of two questionnaire surveys conducted in 2008 regarding the issue of self-determination at "end-of-life." Lastly, I mentioned some of aspects that need to be investigated in the future to further study the validity of the model.

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- 1 This papers is based on the presentation titled "Descriptive research is a necessity for Ethics" which I presented at the Ninth Asian Bioethics Conference on November 3, 2008. The conference was held at Universitas Islam Negeri (UIN) Sunan Kalijaga (National University of Islamic Studies) in Yogyakarta, Indonesia (November 3-7, 2008). Some parts of the original presentation have been revised and statistical information has been added.
- 2 *The Cambridge Dictionary of Philosophy* (1999) defines ethics as "the philosophical study of morality."
- 3 Consistent with this view, most presentations at the Ninth Asian Bioethics Conference were on a wide range of issues and are with practical applications rather than theoretical.
- 4 Empirical methods can be classified into two types, quantitative and qualitative methods. The former include official data (i.e., recorded data or statistics) and questionnaire surveys. Qualitative methods includes interviews, behavioral observation (e.g., ethnography), and interpretation and/or content analysis of historical data, literature, and mass media among others.
- 5 The first survey was originally intended as a pilot study for the second study. However, due to the nature of collected data, there will be a third survey conducted in the near future with revisions based on the previous two studies.
- 6 Although this questionnaire was not intended to ask about non-human family members since they are not part of the decision-making process at end-of-life, the choice "Pets" was included after feedback that many people who own pets consider them as part of their family.
- 7 Though this is a tentative conclusion, this makes an already complex clinical situation even more so. This indicates that if more people take part in the decision-making process of an individual, arriving at a consensus is or becomes much more difficult.
- 8 It is not to say that designing the questionnaire surveys or wording the statements or questions is easier compared to qualitative methods such as those using open-ended questions.
- 9 Researchers conducting quantitative research have similar challenges when they are

designing questions. They may unconsciously omit certain types of statements or include leading questions.