Article

Multivoicedness in Bioethical Arguments about Cancer Disclosure in Japan: A Narrative Analysis Using a Sociocultural Approach

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Abstract

In the last decade, there has been a substantial shift in the tone of bioethical discourse surrounding the morality of disclosing advanced cancer diagnosis to the patient in Japan. This paper attempts to examine how individuals' bioethical reasoning is developed within a particular sociocultural environment. Drawing its theoretical underpinning from a sociocultural approach to mediated action (Wertsch, 1991, 1998), a narrative analysis of moral functioning (Tappan, 1991) was conducted using a focus group interview data obtained from a group of five Japanese nationals. The participants were asked to respond to open-ended hypothetical questions designed to probe whether or not participants wanted the physician or family members to disclose a truthful diagnosis to a patient with advanced cancer if the patient were their grandparent, parent, spouse, underage child, or themselves. The study aimed to achieve the following three research goals: (a) identifying types of ethical voice used by the Japanese in their bioethical arguments and the nature of each of these ethical voices; (b) observing patterns in which different types of ethical voice are used by the Japanese; and (c) examining ways in which individuals develop their own words by "selectively assimilating others' words" (Bakhtin, 1981). The result of the present study provided an empirical illustration for the multivoicedness of human mind and the role of culturally, historically, and institutionally situated mediational means in shaping bioethical arguments.

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Introduction

Medical informed consent is a doctrine and a practice that serves for protecting moral and legal rights of the patient. In the process of informed consent practice, a physician gives the patient information about his/her diagnosis, treatment options with risks and benefits, and prognosis, while the patient agrees on a course of action based on the provided information. The practice of informed consent is also for ensuring that the patient has the ability to direct his or her medical care.

The concept of medical informed consent assigns significant importance to disclosing truthful information about the patient's illness. Over the last decade or so, Japan has been actively adopting this concept in medical practice although it was originally an alien concept imported to Japan from the Western. Since medical informed consent involves disclosure of a truthful diagnosis to the patient even when the illness is incurable, there have always been controversies among the public regarding this adoption. Bioethical discourses surrounding cancer disclosure has been a typical example where such controversy is found (Hattori, Salzberg, Kiang, Fujimiya, Tejima,, & Furuno, 1991; Kakai, 2002; Kato, 1989; Long, 1999, 2000; Miyata, Takahashi, Saito, Tachimori, & Kai, 2005; Sakaguchi, 1989; Tanida, 1994).

A sociocultural approach to human action

Bioethics is "the study of ethical issues related to medicine, health care, biotechnology, and biomedical research" (Turner, 2003, p. 99). Issues of bioethics thus pose questions about moral standards and principles in the areas of medical treatment and research. Kinds of bioethical discourses that are available in a particular society reflect its cultural values, religious beliefs, and history. Therefore, people's beliefs about the morality of cancer disclosure as an essential part of medical informed consent cannot be reduced to individual psychology. This leads me to turn to a sociocultural approach to human action (Wertsch, 1991, 1998), which has its origin in Russian philosophical thoughts (e.g., Bakhtin, 1981, 1986; Vygotsky, 1978, 1981). Wertsch argues that the goal of so-

ciocultural approach is to explicate how human action is situated in cultural, historical, and institutional settings. In other words, this theoretical approach emphasizes the fundamentally social nature of human thought as a result of dynamic interactions between individuals and others in their environments through communication. This approach is relevant and useful for understanding the intricate relationship between types of bioethical reasoning that individuals make and a larger sociocultural context in which those individuals live.

The sociocultural approach to human action posits that cultural, historical, and institutional settings of the community are inseparable parts of ways of being that shape the thoughts and actions of individuals who participate in the community (Wertsch, 1991, 1998). Culture is seen as a mediating element that shapes mental activity of members of the community. Focusing on the interconnectedness of people's minds from the microgenetic to the macro genetic level, the sociocultural approach thus seeks "to explicate the relationships between human mental functioning, on the one hand, and the cultural, institutional, and historical situations in which this functioning occurs, on the other" (Wertsch, 1995, p. 56).

The concept of mediation is central to the sociocultural approach. Mediating artifacts can be both ideal and material (Cole, 1996), and they help shape human action and alter human mental functions by connecting the social world and the individual world. A metaphor of "possession" in psychology explicates differences in mental functioning across groups "in terms of whether members of a group 'have' or do not 'have' certain forms of mental capacity" (Wertsch, 1991, p. 94). An alternative to this stance is what Wertsch terms the "tool kit approach." The tool kit approach, writes Wertsch "allows group and contextual differences in mediated action to be understood in terms of the array of mediational means to which people have access and the patterns of choice they manifest in selecting a particular means for a particular occasion" (p. 94). Consequently, the agent who engages in a particular action is viewed as "individual(s)-acting-with-mediational-means" rather than "individual(s)" (Wertsch, 1991, p. 12).

Influenced by Bakhtin and Wertsch, Tappan and his colleagues (e.g.,

Day & Tappan, 1996; Tappan, 1989, 1990, 1991, 1992, 1997a, 1997b, 1999, 2006; Tappan & Brown, 1996) advocate a sociocultural approach to studying moral functioning through narratives. It appears that this semiotic approach can serve as a quite useful methodological tool in investigating the nature of moral or ethical¹⁾ discourses. It is because this approach allows the researcher to incorporate cultural, historical, and institutional factors that may shape individuals' reasoning about "what is right and what is wrong" into the analysis. The following, I will elaborate this narrative approach put forth by Tappan and others.

A narrative approach to studying moral functioning

Tappan's research is grounded in theories of Bakhtin and Wertsch. He emphasizes the importance of understanding the inseparable relationship between an agent and his/her cultural tools when examining moral functioning as a form of higher psychological processes. In line with this approach, Tappan advocates analyzing narratives of people as an approach to empirically investigating individuals' moral development.

In this new approach to moral development, the nature of "self" is assumed to be dialogical. This view contrasts with the cognitive-developmental view of Piaget and Kohlberg, which regarded the concept of moral self as an epistemic subject. By putting forth the dialogical nature of self, Tappan and his colleagues highlighted the primary role of language in understanding one's own self. For example, Day and Tappan (1996), quoting Kerby, argued that "The self is, therefore, neither 'a substantial entity having ontological priority over praxis,' nor an autonomous Cartesian agent 'with epistemological priority, an originator of meaning.' Rather, it is an inhabited, decentered actor, in a theatrical world of possible stories where all action is rehearsed, justified and reviewed according to the narrative possibilities inherent in the actual context(s) in which action occurs" (p. 71).

Tappan, like Wertsch, studied the role of cultural tools as mediational

¹⁾ In this paper, the words "moral" and "ethical" are used interchangeably since both entail a judgment about right and wrong.

means in moral development. He (2006) adopted the Bakhtian concepts of mastery, ownership, and power (Wertsch, 1998) to explain the process of appropriation. Mastery refers to "knowing how" to use a particular cultural tool with facility, while ownership refers to taking a cultural tool that belongs to others and making it one's own. The process of appropriating mediational means involves the incorporation of power and authority. Here, Bakhtin's accounts of "authoritative" and "internally persuasive" discourses come into play (Wertsch, 1998). According to Bakhtin (1981), the former refers to the authoritative word (religious, political, moral; the word of a father, of adults, of teachers, etc.), which "demands that we acknowledge it, that we make it our own; it binds us, quite independent of any power it might have to persuade us internally; we encounter it with its authority already fused to it" (p. 342); in contrast to the notion of authoritative discourse, which forces us to give either total affirmation or total rejection of it, internally persuasive discourse provides us with room for engaging in a dialogue since it is "half-ours and half-someone else's" (p. 345). Wertsch argued that a particular utterance by an individual agent is often shaped by the power and authority associated with cultural tools or mediational means, which explains why there are differences in the public availability, accessibility, perceived appropriateness, and powerfulness in forms of knowledge and solutions to a problem.

Bakhtin's notion of "authorship" argues that the utterances of the speaker are never monotonic coming from a single, solitary mind, but that they are dialogical emerging from both self and other. Day and Tappan (1996) claimed that understanding a mechanism of how the word of others become one's own is crucial. It is so because our voice is always "half-ours and half-someone else's" and we are constantly viewed as having responsibility and accountability, or "answerability" in Bakhtin's terms, for the "authorship" of our utterances despite their fundamentally dialogic nature. As a result, Day and Tappan proposed that "identifying the multiplicity of voices that constitute the moral dialogues that mediate and shape peoples' moral experience" (p. 75) is a central focus of researchers who take narrative accounts in empirically approach-

ing to an understanding of moral development. Tappan (2006) further argued the importance of looking at both the moral agent and the mediational means which the moral agent uses in responding to the moral problems, conflicts and dilemmas he/she faces. Since mediational means that are likely to be employed by the agent are linguistic means such as words, language, and forms of discourse, examining how those means are used in persons' responses to moral problems, conflicts and dilemmas in their lives provides insight into how "social/cultural/historical/institutional 'artifacts,' 'tools,' or 'symbols' mediate individual moral functioning" (Tappan, 2006, p. 3).

Research questions

Adapting this narrative approach to moral functioning research, I attempt to examine how the array of mediational means, viewed in terms of a cultural tool kit (Wertsch, 1991), are appropriated by individuals in responding to a moral problem regarding disclosure of advanced cancer diagnosis²⁾ to the patient among the Japanese. The primary focus of this examination is placed on disclosure of not any illness but advanced cancer diagnosis because of the following reasons. First, cancer is currently the number one cause of death in Japan. Therefore, the issue of cancer disclosure is something many Japanese may have to deal with whether it is for themselves or for their family members. Second, disclosure of advanced stage cancer diagnosis naturally invokes a sense of one's own mortality, throwing existential questions at individuals. This may result in allowing even more distinct patterns of bioethical reasoning to emerge within a particular sociocultural context.

In my previous research, drawing from the results of surveys conducted by major newspaper companies in Japan, I argued that the Japanese reveal a double-standard when making bioethical judgments about the morality of cancer disclosure to self versus others (Kakai, 2002). Many regard it as ethical to be informed of a truthful cancer diagnosis

²⁾ In this paper, I define "advanced cancer diagnosis" as a diagnosis of cancer that is at an advanced stage with poor prognosis.

when they themselves were cancer patients while they regard it as rather unethical to do so when their family members were cancer patients. The present study further examines this tendency of the Japanese by breaking down the target family members into four different relational types including one's grandparent, parent, spouse, and underage child. The study attempts to examine whether or not the participants' bioethical judgment about the morality of cancer disclosure to the patient is affected by who the hypothetical patient is. As a result, the present study poses the following research questions: In the context of making an argument or forming a judgement about the righteousness of advanced cancer disclosure to one's grandparent, parent, spouse, underage child, and self as the patient, (a) what types of ethical voices (or "social language" in Bakhtin's term) do the Japanese use in their bioethical arguments and what is the nature of each of these ethical voices; (b) how are these different ethical voices used by the Japanese; and finally, (c) how do individuals develop their own internally persuasive discourse by selectively assimilating others' words (Bakhtin, 1981)?

Method

A focus group approach

A focus group interview was conducted to achieve the goals of the present study. Because of its interactive nature of data collection process, a focus group approach not only helps researchers obtain perspectives of an issue held by the study participants, but also allows "the exhibition of a struggle for understanding how others interpret key terms and their agreements or disagreements with the issues raised" (Mertens, 2005, p. 245). This characteristic of a focus group approach appeared particularly appropriate for discussing a controversial issue such as disclosure of advanced cancer diagnosis.

Participants

The study cohort consisted of five Japanese nationals who were studying English in a non-credit language program at the University of Ha-

waii at Manoa at the time. These students were chosen because they had only been in the United States for a relatively short period of time (less than a year), and thus they were less likely to be acculturated to the non-Japanese cultural environment compared with Japanese students enrolled in regular academic programs at the university. All five individuals voluntarily participated in the study.

The five participants in the focus group included one male (42 years-old) and four females (23, 25, 26, and 28-years-old). The length of stay in the United States among the participants varied from one month to eight months with the average being 6.75 months. All of the participants had never been away from Japan for more than a year. Since none of the participants had extensive experience living abroad, I reasoned that acculturation effects among these individuals would be minimal. Although these participants cannot be considered as representative of the average Japanese population, this should not be an obstacle for the purposes of the present study. The primary goal of this research is not to describe generalizations about the Japanese attitudes toward truth-telling to the patient in Japanese oncology practice; in stead, it is to examine the kinds of mediational means/cultural tools that these individuals have appropriated and their use in responding to the moral problem of disclosing advanced cancer diagnosis to the patient.

The following gives brief background information of all five participants. Pseudonyms are used here in order to protect the participants' privacy.

Taka is a 42 year-old male accountant who is married with a six year-old child. Born and raised in Tokyo, Taka has never lived outside of Tokyo before coming to Hawaii. He has lived in Hawaii for eight months.

Eri is a single 28 year-old female. She is a preschool teacher. Before coming to Hawaii, she lived with her parents and grandmother in Osaka, which is the second largest city in Japan. She has lived in Hawaii for six months.

Yuka is a 26 year-old single female and worked as an office clerk in

Japan before coming to Hawaii. She lived with her parents and younger sister in Kanagawa prefecture, which is an urban area located south of Tokyo. She has lived in Hawaii for a month.

Maki is a 25 year-old female. She is single and worked in the service industry in Japan before coming to Hawaii. In Japan, she lived with her parents, grandparents, and older brother. She lived in Ishikawa and Gifu prefectures, which are relatively rural areas of Japan. She has lived in Hawaii for eight months.

Kei is a 23 year-old female and the youngest of the five participants. In Japan, she held a clerical job and lived with her parents and older brother. Before coming to Hawaii, she lived in Tokyo and in Chiba prefecture, which is a suburb of Tokyo. She has lived in Hawaii for four months.

Procedure

The focus group interview was conducted in the fall semester of 1997. It lasted approximately two hours. In the first thirty minutes, the five participants were asked to individually fill out a questionnaire which included demographic questions and open-ended hypothetical questions with five different scenarios of bioethical problems regarding the truthful disclosure of a diagnosis of advanced cancer to the patient. All data were collected and analyzed in Japanese and later translated into English for the purpose of writing the present manuscript.

Demographic questions included the participants' age, gender, occupation, family members, length of stay in the U.S., and three major places where they had lived before coming to Hawaii. Previous areas of residence were probed in association of the fact that hospitals in urban areas had a higher tendency than those in rural areas to engage in truthful cancer disclosure to the patient (Elwyn et al., 1998). The open-ended hypothetical questions were designed to probe whether or not participants wanted the physician or family members to disclose the truth to the patient with advanced cancer if the patient were their (a) grandparent, (b) parent, (c) spouse, (d) underage child, or (e) themselves.

Data analysis

The participants' responses to each hypothetical situation were analyzed according to each of the five scenarios. They were compared and contrasted within and across individuals. The participants drew upon multiple voices in their responses. There were also interesting patterns in which the participants used these different voices across five different hypothetical scenarios. The analysis of this study revealed that members of the focus group expressed voices that seemed closely linked with the Japanese sociocultural context as well as the unique experience of each individual. Patterns in which the participants used different ethical voices will be discussed as follows.

Disclosure to the grandparent

Three out of five participants expressed the opinion that they would not want the physician to tell the truth to their grandparents. Commonly expressed reasons for this position involved such factors as (a) the patient's vulnerable or non-resilient personality, (b) the patient's advanced age, and (c) a belief that disclosing the truth to the patient is cruel. These participants believed that their grandparents were not strong enough to cope with the fear of dying; that there was minimal necessity for the elderly to know that they were dying soon since they had only a short time to live anyway; and that telling the elderly the true diagnosis was just like giving them a "death sentence." As a result, these participants believed that concealment was an act of empathy for the patient. The following utterances exemplify these attitudes. For example, Yuka stated that:

I know my grandmother. <u>If she found out that she had advanced</u> cancer, she would only think about dying and be depressed. So, I would not tell her the truth so that she could enjoy her remaining days.

Maki, basing her argument on her grandfather's age, stated that since

his days were numbered he did not have to know his cancer diagnosis. Instead, Maki believed that he should die in peace without learning the shocking truth.

Participants also gave responses that combined rationales based on the age and personality of the person diagnosed with cancer. Several participants expressed the belief that the older a person became the more he or she might become afraid of dying. For example, Taka stated that:

As people age, they develop more fear towards death. So, the truth disclosure would have an adverse effect on old people with cancer and they may become significantly weaker after learning the truth. Since psychological impact on health is enormous, not knowing the truth may help them to get better by treatment. By the same token, letting them know the truth may weaken them.

Taka also pointed out the cruelty of telling the truth to aged family members. He expressed a concern for others' negative evaluation on his telling such cruel news to his grandparent. Taka said:

I think I probably wouldn't tell my grandfather and grandmother the truth. I think people might feel it a little cruel to tell them the truth. . . I think it is like a death sentence. We usually don't know when we will die. So, to be told when they will die seems cruel.

Disagreeing with the three participants about the idea of concealment, the other two supported the disclosure of cancer diagnosis to the grand-parent by repeatedly emphasizing the importance of the patient's right to know the truth. For example, Eri stated:

Well, before discussing being cruel by disclosing the truth or being sympathetic by concealing the truth, we have to realize that the patient has a right to know. So, it is not a matter of arguing whether or not we should tell the truth to the patient. Instead, it is the patient's right to know the truth. My grandmother actually nearly died half a year ago. At that time, I told her everything that I knew about her condition, believing that she had a right to know. If my

grandmother developed cancer, I would imagine that she would be devastated and depressed. And it is beyond my imagination how she would get through it. But, as far as my grandmother's case is concerned, I would tell her the truth because I am confident that I can support her as she goes through this. And she has a right to know the truth anyways.

Kei, who also supported disclosure of a cancer diagnosis, had a different perspective about the elderly people's fear of death from the other participants who were opposed to the disclosure. She believed that the elderly were well prepared to accept death, so that it would be less fearful for them than for younger people to learn that they had a cancer. Kei believed that not being open about the patient's condition created more harm than benefit for the elderly patient since it might cause more anxiety for him or her.

Unlike Yuka, Maki, and Taka, who viewed the truth-telling to grandparents as cruel and adversarial, Eri and Kei perceived the truth-telling as something that their grandparents deserved. Furthermore, Eri's response revealed her confidence in and commitment to supporting the patient throughout his / her struggle with the illness. Such strong confidence and commitment were not observed in responses of other participants.

Disclosure to the parent

When being asked whether or not they would disclose an advanced cancer diagnosis to the parent, the response pattern of the participants changed slightly from that for the grandparent. Those who supported the disclosure argued that the truth-telling was important because of (a) parents' responsibility for organizing financial or familial matters before dying; (b) parents' right to know the truth; and (c) parents' right to enjoy their remaining days. In some cases, the parents of some of the participants had already asked them to tell the truth in case they developed cancer in the future. For example, Kei stated that:

In my family, one parent has asked me to disclose the true diagno-

sis. It was not my father, but my mother who asked me this. She says that she needs to organize various things and tell us about them before she dies. That's why she wants me to tell her the truth. My father, though he has never talked about it with me, feels the same way, I believe.

Unlike Kei's parents, Eri's parents refused to discuss whether or not they should be told the truth if they developed cancer. They avoided the conversation whenever the issue was brought up by Eri. She stated:

I always tell my parents that I would want to know the truth if I developed cancer. They avoid discussing the matter whenever I bring that up. When I force my parents to discuss the matter with me, my mother tells me not to disclose the truth to her. As for my father, he tells me that he wants to know the truth.

Although her mother refused to know the truth, Eri still believed that it was her responsibility to inform her mother of the truth. She thought that no one could keep the truth from her mother for long since her mother would eventually find out through the medical treatment that she would receive and the speech and action of others around her. Eri said:

Rather than wasting precious time by wondering what the problem might be, I want my parents to think about how they want to approach death and how to die in peace. So, I think I will tell them the truth although it will not be easy.

Like other participants who supported concealment of a cancer diagnosis, Eri expressed her desire for her loved one to die in peace. However, Eri believed that it was all the more important for the patient to know the truth about his/her impending death in order to end his/her life peacefully, which contrasted with the belief most of the other female participants shared.

The participants who did not completely agree with advanced cancer disclosure to the parent had their own reasons to believe what they believed. For example, Taka strongly supported concealment by referring

to his own experience with his mother who had died of cancer. He was satisfied with the family decision not to tell her the truth, although no one in his family was sure whether or not his mother had been actually aware of her condition. Maki and Yuka provided conditional answers. For example, Maki thought she would not inform her parents only because they had told her not to do so if they developed cancer. However, she believed that generally speaking people of her parents' age should be informed of the truth since they had matters such as future life plans and children to discuss. Yuka, knowing her mother's personality resembles her grandmother's, had no intention of telling her mother the truth. She thought her mother was psychologically too vulnerable to accept reality. However, she was hoping that her father, whom she assumed would be calm under difficult circumstances, could be informed of the truth.

It is interesting to note that gender of the cancer patient is seen as quite important when making a decision about disclosure. For example, Yuka's decision differentiated between her mother and her father mainly because of the differences she perceived in psychological attributes between the two: Her father being resilient and mother being weak. Taka also spoke about gender differences in regards to disclosure. However, his concern was not so much related to psychological issues but to sociological issues surrounding the gender differences. He stated:

If there is a factor that distinguishes the need to disclose a patient's condition by gender, it would be the males' socially responsible position. It would be better to disclose the truth to male patients since they may have multiple things such as their property and social responsibilities to take care of before they die.

Taka and Yuka's perspectives about their mothers' and fathers' personalities seem to originate from stereotypical images of men and women developed within the Japanese sociocultural context where there are still relatively distinct gender role differences. It is also interesting to note that Taka's insight seems to stem from his own circumstance as a breadwinner who needs to plan ahead to fulfil various social and familial re-

sponsibilities before his death.

Disclosure to the spouse

All female participants agreed that they would disclose the truth to their spouse. Taka disagreed. Taka, the sole male participant, was also the only participant that was married. The reasons given by the four females for supporting the disclosure included: (a) they believed the spouse had a right to know; (b) they wanted to be honest with the spouse; and (c) they wanted to help the spouse in his or her struggle with the illness. There were also some differences of opinion among the four female participants. Maki and Yuka generally preferred conditional disclosure depending on the patient's personality, while Eri and Kei explicitly supported unconditional disclosure. For example, Eri stated:

I cannot lie to the most important person in my life. I think that it is best to tell the truth and decide together how to spend the remaining time in a meaningful manner. Moreover, if my husband should have to receive painful medical treatment such as chemotherapy, he would suffer doubly if I had lied: pain from the treatment itself and pain from not knowing the reason he had to endure such painful therapy.

Yuka, again, offered a conditional answer. She said she would tell the truth only if her spouse were psychologically strong enough to accept the reality. If her spouse were weak, she would rather let him enjoy his remaining days by concealing the truth from him.

Taka, the only one who supported the concealment, had already discussed the matter with his wife. She had asked him not to tell her the truth even if she was diagnosed with advanced cancer. He stated:

My wife occasionally asks me not to tell her the truth if she should be diagnosed with advanced cancer. So, I think it would be better not to tell her. However, I am not sure whether she truly feels this way or not. I am still not sure what her real intention is. <u>But, since</u> she is telling me not to, I would have no choice but to conceal the

truth from her. I think she is not psychologically strong enough. She tells me that she would go crazy if she found out the truth.

Although being uncertain about what was best for his wife, Taka had little intention to disclose the truth to her should she be diagnosed with advanced cancer in the future. Again, there seems to be an effect of the cancer patient's gender on the participants' decision whether or not to disclose advanced cancer diagnosis. Being a housewife, Taka's wife had minimal financial responsibility for the family and minimal social responsibility for others beyond her household. This allowed her to have a choice of being unaware of the possibility of her impending death.

Disclosure to the child

Concerning the question of whether or not the participants would tell the true cancer diagnosis to their underage children who were old enough to understand concepts of illness and death (age range being roughly set from 6 to 18 years-old³⁾), the response pattern changed again. Only one participant, Eri, expressed that she would disclose the truth to the child, while the other four expressed some concerns about the disclosure. Even Kei, who had been emphasizing the importance of truth-telling in the previous three scenarios showed some hesitation about the illness disclosure to a minor. Their rationales included: (a) it is too cruel to tell children the true diagnosis; (b) children have no social or financial obligation to organize before dying; and (c) children may not possess the ability to accept the fact that they are dying, so that the information would only prevent them from enjoying their remaining life. For example, Kei said:

Although I have been insisting so far that disclosing the truth is important, I believe we should not disclose the truth if the patient is an underage child. Of course, it essentially depends on the situation of the child. But, I don't think I would disclose the truth to my

³⁾ The American Cancer Society suggests that parents of school-age children (6-12) with cancer should engage in open communication about the diagnosis since they are capable of understanding their diagnoses and treatment plans.

child especially if the child were a minor. I have been saying that truthful disclosure to patients is important, thinking that they may be able to live their lives to the fullest or start organizing their social responsibilities if they know their days are limited. This is not the case for underage children. They do not have such social obligations. Parents should prepare an environment where the dying child can live fully.

Similarly, Taka, who has a six-year old son, expressed his reservation for truth disclosure to a minor child by emphasizing his/her lack of social responsibility and psychological vulnerability. He stated:

I have a six year-old son. Naturally, I would not tell my son the truth. Even if my son were older, say, 10 to 18 years-old, <u>I don't think I would tell him the truth</u>. It is because children do not have social responsibilities. They do not have to put their affairs in order before they die. Even if they were told the truth, I don't think they could live their remaining lives to the fullest. Instead, they would probably get depressed and lose hope.

When Eri took over the discussion by saying, "I would tell my child the truth...," there was a momentary stir among the other group members. Eri stated:

Even though I bore the child and raised him, I don't believe that he is my possession. So, I would tell him the truth. It would be hard to admit that my child whom I have raised with love is dying of cancer. However, it is reality and cannot be changed, so I would rather want my child to live his remaining life fully with my support. It may be a little different from the norm, but I feel this way because of my experience working with disabled children as a preschool teacher. I believe that whether or not a child can accept the diagnosis of a fatal disease at age of 15, for example, is dependent upon how his parents have raised him until that point. This issue is related to how much the child can appreciate the importance of living his life fully with satisfaction. And that would be something that

parents can teach their children. That is why I think I would tell my child the truth.

Eri's attitude in favour of disclosure to an underage child was consistent with her attitude discussed in response to the previous scenarios. Eri's view, which was distinct from the others in the group, also appeared to be influenced by her unique circumstances. Having been a preschool teacher and observing many parent-child relationships certainly seemed one of the most influential experiences that shaped her unique belief and attitude in regard to informing children of their fatal illness.

Disclosure to self

Finally, the participants were asked whether they wanted to be informed if they themselves had advanced cancer. Interestingly, for the first time, the group was unanimous in their opinion. All five of them expressed their desire to be told the truth. Their reasons were similar and included (a) a desire to exercise the patient's right to know the truth, (b) a desire to live their lives to the fullest, and (c) a desire to take care of logistics including social and financial responsibilities before dying. For example, Kei said:

I would definitely want to know [the truth]. It would probably be shocking and fearful news. But, as death approaches, <u>I would feel</u> that I want to try many things instead of getting depressed about dying. I do not want to die with anxiety. I would like to have the opportunity to do things.

Similarly, Yuka stated that:

I would want to know [my diagnosis]. If I knew I had only a limited time to live, I would like to visit places I always wanted to go to or buy things that I always wanted to buy.

Eri, who had been consistent in her belief in truth disclosure no matter who the patient was, expressed her opinions as follows: I would certainly want to know [the truth]. I believe that I should be the one who should make decisions for my life, and it is not anyone else's job to do so even if they are well-meaning. Therefore, I demand to know the truth. This is also true about my treatment. I want to decide what to do with my life. My doctor should support me but not make the decision for me. He can help me make decisions by providing me with information. But, I am the one who should make the final decision. For this reason, too, I need to be informed of my true diagnosis.

Maki also agreed with the others and expressed her desire to be told the truth. However, her stance was slightly different from the other three female participants who held quite similar views. Maki said:

I, too, want to be informed of the truth. But, maybe I feel this way at this point since I am healthy now. I feel that I want to try things that I have been dreaming of before I die. But, if I actually find out the truth, I might have a dream about dying every night. So, I would rather have others around me judge whether I should be told the truth or not. They could tell me the truth only if they can ascertain that I would be all right knowing the truth. So, I trust others' judgment.

By "others around me," Maki meant her family including her parents if such an event were to happen in the present or her adult children if it should happen in her old age. Maki's remarks contrast significantly with Eri's remarks. While Maki appreciates indulging oneself with others' benevolence, Eri insists on one's right for self-determination.

Taka, who was the only male and married with a child, brought an interesting perspective as the breadwinner of a family. Taka stated that:

In my case, I have a family [to take care]. So, my wife says that I should know the truth if I developed cancer. That's why I am sure that I will be told the truth. I say I will be fine [being told the truth], but I honestly don't know how I would feel since I have never been in such a situation. I believe it is unnatural to pronounce

a death sentence on someone. The exact time of death cannot be predicted by the doctor. Perhaps, nobody can or should predict it. However, people irresponsibly tell you things such as, "You have only two years to live, so you should start organizing your life." . . . We live with uncertainty. Moreover, there is no such thing as life goals for us, at least for me. Something like owning a house is not a life goal, is it? Then, it is all right to die leaving things unfinished, isn't it? So, I don't know which is better: losing the opportunity to organize my life not knowing the truth or having the opportunity to organize my life knowing the harsh reality. But, I want to know the truth at this point.

It appears that Taka's position of responsibility as the breadwinner and his socially perceived obligations as a male have shaped his attitude of affirming truth-telling if he were in the position of having to be told that he has cancer. Taka's realistic perspective contrasts with the rather idealistic and self-oriented perception of the female participants who emphasized the importance of fulfilling one's life goals before dying and exercising one's right to know by being informed of the true diagnosis. It is also worth noting that there are interesting variations in the responses of female participants who unanimously supported the disclosure of cancer diagnosis to self. For example, while Eri revealed her valuing of self-determination and self-autonomy by consistently grounding her arguments on individuals' rights when supporting cancer disclosure to self, Maki showed her dependent attitude by expressing her desire to defer to others in making an important life and death decision for her if necessary.

Discussion

The objective of my analysis of the focus group discussion was to examine the different voices that Japanese draw upon in arguing the morality of disclosing an advanced cancer diagnosis to the patient who is either their family member or themselves. The participant's utterances

can be seen as reflecting Bakhtin's notions of "multivoicedness" and the "heterogeneity of voices" in talk (Wertsch, 1991); in other words, one can observe in the discourse of these participants the presence of "voices that were formerly represented explicitly in intermental functioning" (p. 90) and the existence of "qualitatively different forms of thinking" (p. 96). The participants' unique social experiences were also found to be key factors shaping their voices.

In this section I will propose answers to the three research questions of the present study: (a) what types of ethical voices did the participants use in their bioethical arguments, and what is the nature of each of these ethical voices; (b) what are the patterns in which different voices are used by the participants; and (c) how are words of others are selectively assimilated into one's internally persuasive discourse (Bakhtin, 1981)?

The types and nature of ethical voices used by the participants

The participants' utterances regarding the morality of cancer disclosure to the patient revealed a total of nine identifiable patterns. These included (a) respecting the individual's right to know, (b) respecting others' (one's own) right to accomplish life goals, (c) respecting others' (one's own) wishes, (d) valuing honesty with others, (e) protecting the socially vulnerable, (f) protecting others from the perceived cruelty of reality, (g) helping others go through the struggle with the illness, (h) letting those with limited social and financial responsibilities go on without knowing the truth, and (i) recognizing others' social and financial responsibilities. Across these nine patterns of utterances, three major ethical voices were identified. Two of those captured characteristics closely related to what Gilligan (1982) referred to as voices of "justice" (the morality emphasizing rights and rules) and "care" (the morality emphasizing responsibility and relationships). However, unlike Gilligan's "care" voice, the "care" voice in this study corresponds with the "omoiyari" (consideration for others) argument in my previous papaer (Kakai, 2002), which is deeply embedded in East Asian philosophical and religious traditions such as Confucianism emphasizing filial piety and Buddhism emphasizing benevolence, which will be further discussed in a

later section. A third voice also emerged from the present data, which has no overlap with the voices of "justice" and "care." This third voice centered on practical, social and economic themes. It was a voice distinctive to the present data.

In the present interview data the "justice" voice is reflected in discourses (a), (b), (c), and (d), as each of them represents advocacy of the doctrine of liberty, and emphasizes various individual rights such as a right to know, a right to accomplish his/her life goals, a right to follow his/her wishes, and a right to be treated with honesty. The "care" voice is apparent in discourses (e), (f), and (g), as each touches on the theme of protecting others from hardship and providing support through the difficult time. Finally, discourses (h) and (i) can be seen as representing a "practical" theme which has a moral implication related to survival issues of people who are left behind. With this voice, one finds little necessity for elders, small children and housewives to know the difficult reality due to their lack of or limited social and financial responsibilities within or beyond their own households. On the other hand, one finds it crucial for male adults to know the truth since they participate in labour activities and are financially responsible for the survival of their family members.

Patterns of use for different ethical voices

The participants invoked different voices according to the type of hypothetical situation they were asked to think about. Variation in the types of voices used in arguing for or against the disclosure of advanced cancer diagnosis appeared to be related to the patient's age, gender, and social and financial responsibilities. The different use of voices was also found to be related to whether cancer is the illness of others or that of one's own (Kakai, 2002).

The participants tended to use the "care" voice when the target patient was the socially vulnerable such as a child and elderly person as well as a female patient such as a mother or grandmother. The participants' reasons for using the voice of "care" to justify concealing a cancer diagnosis in order to protect the patient from the harsh reality were

closely related to stereotypical images of the elderly, minors, and females. Most of the participants who had appropriated this voice expressed the assumption that the elderly and young children fear death. When reasoning about elderly person's fear of death these participants believed that this fear would increase as one aged, though results of some empirical studies indicate otherwise (see Aiken, 1995 for review). Many of the participants also believed that children would not benefit from knowing the truth. They assumed that children could be protected from experiencing the fear of dying as long as the truth of their illness was kept from them.

Most participants, on the other hand, used the "justice" voice when they or their spouses were the hypothetical cancer patients. These participants supported truthful disclosure. They invoked the doctrine of individual liberties for exercising self-autonomy and self-determination. This voice assumes that disclosure is essential for allowing the cancer patients to live their lives to the fullest. Here, truth-telling is no longer "cruel" but regarded as essential in order to respect the autonomy of the cancer patients and to allow them to live their lives to the fullest. There are several reasons for the use of "justice" voice when the patient is one's spouse. First, this may be related in part to the notion that individuals regard their spouses as a part of themselves as illustrated in a Japanese proverb that says, "Man and wife are of one mind and flesh." No body would criticize someone who tries to be fully informed about his/her own illness, while one might invite social criticism when, for example, trying to have the grandparent be fully informed of his/her illness. The lack of clear boundary between the husband and wife or their socially perceived oneness, therefore, may allow individuals to be free from such socially imposed expectations about ways to deal with his/her spouse's illness. A generational factor also should not be overlooked here. The participants in the focus group included young adults and the middleaged, presumably putting their spouses — real or imagined — within the similar age range as their own. The participants' valuing the "justice" voice over the "care" voice for themselves and their spouses may reflect a Western discourse, or a social speech type (Bakhtin, 1981), appropri-

ated by their generations who were born and raised in the post World War II era. Authoritarian discourses coming from the government and the medical association surrounding the adaptation of "informudo consento" (informed consent) in recent Japan may also account for the use of the "justice" voice among the participants. All of these seem to offer some explanation as to why many participants applied this particular voice, or the individual autonomy argument (Kakai, 2002), to themselves as well as to their spouses.

Finally, there was a notable tendency in the present data that the participants frequently used "practicality" voice when making judgments about the morality of cancer disclosure to those who have financial and social responsibilities for others. For example, many participants argued the necessity of disclosing the true cancer diagnosis to their parents, especially to fathers, and to spouses in some cases, in order for them to ensure the survival of those left behind. Such situation naturally necessitates the open exchange of accurate information with the patient about his/her health condition.

Gilligan and Attanucci (1988) found that people were capable of switching back and forth between two different voices of "justice" and "care." In the present study, the participants were engaging in non-linear bioethical reasoning by moving back and forth between the "justice," "care" and "practicality" voices depending on context. Although Gilligan and Attanucci found strong gender-related tendencies in the use of different voices — male "justice" voice and femal "care" voice —, the present study revealed that the use of different voices was not so much related to gender of the individual who makes a moral jndgment as to that of the hypothetical patient. While it requires caution not to overly generalize findings of the present study due to its small sample size and age-and gender-biased nature of the sample, it is still worth noting here that I actually found interesting contrasts between the narratives of Taka, the 42 year-old married male, and Eri, the 28 year-old female, that support-

⁴⁾ This is the Katakana form of "informed consent." Katakana is one of the two syllabaries in the Japanese language and is used primarily for words that are imported from foreign languages.

ed the absence of association between two voices and gender of the moral agent in the Japanese social context. That is, Taka tended to use the "care" voice in many of the hypothetical contexts, while Eri consistently argued in the "justice" voice throughout all hypothetical situations.

The use of a third discourse, the "practicality" voice, was uniquely found in the present study that examined individuals' bioethical judgements about the morality of a truthful advanced cancer disclosure to the patient. The nature of this voice was distinct from, though intricately related to, the "care" and "justice" voices. The participants used the "practicality" voice in combination with the "justice" or "care" voice; the "practicality" voice, in fact, seems to direct individuals to decide whether they should adopt the "care" or "justice" voice when judging the morality of advanced cancer disclosure to a particular family member. For example, Taka, using the "practicality" voice in combination with the "justice" voice, argued that those socially and financially responsible for others would have no other choice but to be told the truth about his/her illness and thus should be told the truth. Although Taka claimed he would want to be told the truth, it appeared that he was speaking not so much in internally persuasive words but rather in authoritative words that was in line with expectations of the society.

Overall the narratives of the five participants revealed that social roles of the patient play a key factor when individuals form a judgment about the morality of advanced cancer disclosure. Within the Japanese socio-cultural context, where division of labour according to age and gender generally persists, elders, young children, and females (particularly housewives) tend to have limited social and financial responsibilities compared to adult males at their working prime. This makes the "care" voice more appropriate to invoke and the concealment of the truth a more appropriate choice for the situations where individuals from these categories become afflicted with advanced cancer; on the other hand, being a male at his working prime, a husband, or a father is perceived to be closely related to the general presence of social and financial responsibilities for others both within and beyond his own household. This

makes the "justice" voice more appropriate to invoke and the disclosure of the truth a more appropriate choice for the situations where individuals of any of these categories become afflicted with advanced cancer.

Selective assimilation of others' words

Socially shared values and beliefs surrounding issues of how to approach the death and dving of others as well as of one's role in a social institution such as family, and personal experiences can be seen as playing a significant role in determining the type and content of the utterances spoken during the focus group. The three voices of "justice" "care" and "practicality" appropriated by the participants in the present study are examples of items in the cultural tool kit that function as mediational means that are situated culturally, historically and institutionally (Wertsch, 1991, 1998). In Bakhtin's views, social language and speech genres are mediational means which shape communicative and mental action. They are what Bakhtin called authoritative discourse. which demands not our "free appropriation and assimilation of the word itself" but our "unconditional allegiance" (Bakhtin, 1981, p. 343). Participants' utterances in this study are their own internally persuasive discourse. In the process of developing internally persuasive discourse. individuals are actively engaging in a dialogue and are making independent choices about what words of others to accept and not to accept. Thus, internally persuasive discourse becomes half-ours and half-others (Bakhtin, 1981). Now the question is "How do individuals selectively assimilate authoritative discourse in order to develop their own internally persuasive discourse?"

Compared to the utterances of the other participants, Taka and Eri's utterances provided quite vivid illustrations of the tension between authoritative discourse and internally persuasive discourse. The contrast between the content of their utterances offers an interesting example of how individuals develop internally persuasive discourse.

Responding to the hypothetical situation of the grandparent as cancer patient, Taka explained that people might judge it cruel to tell elders that they had an incurable disease. Taka's utterance seems to indicate his concern with the judgment of others in light of his decision to reveal the truth to his grandparent. Taka's unwillingness to be truthful with the grandparent can be seen as connected with the Confucius value of filial piety and the Buddhist emphasis of benevolence deeply embedded in the Japanese cultural values. These philosophical and religious values emphasize the importance of respecting and protecting one's parents (grandparents) and being merciful to the vulnerable. For this reason, Taka seems to feel obligated to protect the grandparent from the painful reality of dying by concealing the true diagnosis. In addition, Taka also believed that he had no choice but to be told the truth because of his social and financial responsibilities for others. Taka's responses suggest his having heavily appropriated social languages and speech genres prevalent in the Japanese sociocultural context. In contrast, Eri insisted that she should tell the truth to the parents who avoided engaging in communication with her about the issue of cancer disclosure. Eri's narratives are examples of Bakhtin's notion of "answerability" as she takes full responsibility and accountability for her own words.

Both Taka and Eri's utterances seem to reflect their own choices regarding which authoritative discourse to assimilate. In the process of selective assimilation of authoritative discourse, their experiences seem to play a crucial role. Being a male and the breadwinner of his family, Taka's everyday experience might have helped him realize the necessity of facing the reality of dying in order to organize financial matters for those who would be left. Being a preschool teacher working with children with disabilities, Eri's everyday experience might have taught her the importance of accepting the reality and living one's own life to the fullest no matter how challenging it might be. Furthermore, Eri had experienced helping her grandmother deal with a life-threatening illness before. This experience might also shape her belief. Compared to Taka and Eri, the other three female participants' utterances somehow lacked vivid illustrations of the tension between authoritative discourse and internally persuasive discourse. It appeared that these three female participants spoke mostly with others' words rather than their own words. This may be due in part to their lack of real life experiences that may provoke thoughts

about death and dving.

In sum, it seems reasonable to argue that individuals appropriate cultural tools and artefacts that highly resonate with insights drawn from their everyday experiences. Thus, any observed differences among individuals in terms of their beliefs and attitudes may be attributable to a function of one's "personal culture," which is constructed by way of internalizing "collective-cultural meanings" into a "personal-cultural systems of sense" and which further contributes to the reconstruction of meanings by way of externalizing one's personal sense system (Valsiner, 2007, p. 62).

Conclusion

An issue such as truth-telling to the patient who is dying from a terminal illness is quite complex and may involve more than one standard that individuals can apply in forming a moral judgment about it. Authoritative discourse such as a policy or a law concerning the doctrine of informed consent demands our "unconditional allegiance" (Bakhtin, 1981, p. 343), which may leave little room for dialogue or questioning. When the present study was conducted, there was a limited awareness and impact of the policies concerning the doctrine of informed consent among the Japanese public. This may explain why participants' opinions about the morality of disclosing a cancer diagnosis differed within and across individuals depending on who the target patient was, and why the voice of the patient's traditional culture was more frequently appropriated as authoritative discourse than the legal doctrine of informed consent by the participants in their internally persuasive discourse.

The present study provided an illustration for ways in which voices emerged as a result of individuals' social interactions, the tenet advanced in the sociocultural approach to mind. This tradition of thought finds the fundamental difference between man and animals in the ability of the former to create and use artifacts, which "not only radically change his conditions of existence, they even react on him in that they effect a change in him and his psychic condition" (Luria cited in Cole, 1996,

p. 108). It has been more than a decade since the focus group interview for the present study was conducted. Since then, the social and political climate surrounding the issue of medical informed consent has been going through major changes in Japanese society. Back then, there were no laws or policies that would lead people to develop a keen awareness of their right and responsibility to receive their personal medical information and make decisions about their own health care. In 2005 the Japanese government enacted the Personal Information Protection Act, which seems to have further accelerated the cancer disclosure trend. In light of the fact that the present data were collected little over a decade ago, if someone is to replicate the study today, the results may appear to be much different due to the interaction between people's minds and newly emerged cultural tools and artifacts (e.g., biomedical technologies, policies and laws such as Japan's cancer-fighting law of 2006⁵⁾ and the revised medical service law of 2007⁶⁾). Comparing discourses of the past and those of today and examining the difference between them seems a quite insightful research enterprise to conduct from a point of view of sociocultural psychology.

Finally, future studies may benefit by including as many types of bioethical voices as possible through examining bioethical arguments of individuals with more diverse backgrounds.

Acknowledgements

I would like to show my appreciation to all participants for taking the time and effort to respond to my interview questions. I also thank Robert Lecusay for his critical comments on an earlier version of this manuscript.

⁵⁾ The law was enacted by the Diet to require the Japanese government to promote the battle against cancer.

⁶⁾ The amendment of the medical service law in 2007 further promoted the importance of information disclosure to patients in order for them to make informed decisions about their own health care.

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