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Deadline for the July 2007 issue is **31 May, 2007**.

## **Editorial: The application of bioethics**

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There have been perpetual debates on the origins of bioethics and the resolution of this debates by separating modern bioethics from earlier bioethics is one issue which we could spend a great deal of time discussing. However, the profession of bioethics clearly exists and is growing as a global specialty, although those who call themselves "bioethicists" come from a range of professional backgrounds. There are also many in the field of bioethics who reject the personal label to be called a bioethicist. No matter how we wish to resolve this label however, there is a further question which those in bioethics and those outside wish to ask, and that is what is the methodology of the field of bioethics? Let alone the question what is bioethics?

The first paper in this issue by Azevêdo concludes that we still largely see bioethics research being conducted in a narrow reductionist approach dependent upon the specialty of the researcher. In following papers in this issue we see illustrations of a range of approaches to conduct research and analysis, though in discussion most of the authors arrive at a more holistic analysis. This issue includes three papers on Japan, looking at concepts of self-determination, and privacy. These concepts have significant implications to all efforts of bioethics globally. Among the new conferences listed in the conference page, readers may be interested in the forthcoming bioethics roundtable in Kumamoto, Japan in December 2007 on self-determination.

The final two papers are on environmental ethics and public health issues, with an application of the precautionary principle to an oil spill, and the huge public health crisis of arsenic poisoning in Bangladesh.

Comments and responses are invited from all readers, and *EJAIB* welcomes views from all perspectives on the issues discussed. The May issue of *EJAIB* will include the abstracts presented at ABC8 in Bangkok.

# Interdisciplinary Bioethics on the Crossroad of Research Methods

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## Abstract

The body of theoretical knowledge under the name of Bioethics is unquestionably interdisciplinary but the methods used to produce new knowledge in the area are rooted in monodisciplinary traditions. This may become the greatest epistemological challenge to bioethics in the present century. Scientists have not yet figured out or adapted an interdisciplinary research method for bioethics. Thus, scholars from the various disciplines see their own traditional methodology as the preferable one. *The wonder is for how long the methods selection will reduce Bioethics research into single discipline concept.* In addition, contentment with the application of the existing methods will dismiss the need for creative ideas on new interdisciplinary methods in bioethics.

In the seventeenth century, the scientific revolution occurred mostly promoted by the creation of rational methods of investigation (Singer, 1997). The application of mathematical techniques defined the new methods and strongly associated quantitative analysis with science. Later, the scientific method became recognized worldwide as the proper way to do research. Thus, since the seventeenth century, scientific knowledge acquired its methodological identity differing from popular knowledge as well as from philosophical and theological ones (Cervo and Bervian, 1975)

Along the centuries, however, various disciplines recognized the necessity of having special methods for creating specific new knowledge. The high credit given to quantitative data analysis became of questionable value for some research areas. New approaches to scientific methods were developed. The innovation came mostly from the social sciences inquietudes (DeVries and Subedi, 1998). Presently, a general textbook on the introduction to scientific research covers the diversity of research methods from hard experimental quantitative sciences to qualitative social sciences (Sugarman and Sulmasy, 2001). Meanwhile, professional specializations, graduate schools with Master and Doctors degrees, plus some specific employment demands deepened research in single disciplines or sub-disciplines. Thus, the world of science reproduced the contour of disciplines on matters and methods.

## Research in Bioethics

Bioethics has been recognized as an interdisciplinary or transdisciplinary type of knowledge since its early years. If recognizing it is rather simple, to put it in practice is

troublesome. The strong disciplinary academic tradition inherited from the early universities since the sixteenth century (Almeida, 1997) imposes cognitive difficulties upon the present generation of scholars. Attempts had been made to overcome these difficulties either considering that, in bioethics, there is no tension between monodisciplinary and interdisciplinarity (Watcher, 1982), or deepening into the concepts of multidisciplinary, interdisciplinary and transdisciplinary terms (Felice et al., 1985). In the 1990s there was an increased emphasis placed on descriptive bioethics (Macer, 1994) not only prescriptive bioethics and philosophical analysis. The real challenge is that our modern day researchers in bioethics grow up nourished by such monodisciplinary academic practices but need to produce interdisciplinary knowledge. How can we deal with that? The many roads to interdisciplinarity had been helped by joint discussions among scholars from various disciplines but the only place interdisciplinary bioethics may exist is inside a unique mind free of disciplinary barriers. Let us take again the example of genetics as an interdisciplinary area (Azevêdo, 1998).

## Learning from Genetics

Since the very beginning genetics “hybridizes” knowledge. Mendel (1865) associated the concepts of horticulture and probability and came out with the revolutionary Mendel’s Laws. Later, at the very end of the nineteenth century Bateson (1899), showed the importance of having special methods for genetics research in a paper entitled “*Hybridization and cross-breeding as a method of scientific investigation*” (Bateson, 1899). However, the greatest grasp of the interdisciplinary make up of genetics was given by Muller as early as 1922 by writing: “*Must we geneticists become bacteriologists, physiological chemists and physicists, simultaneous with being zoologists and botanists? Let us hope so*” (Muller, 1922). Since the beginning of the twentieth century, after the description of the Hardy and Weinberg gene frequencies equilibrium in 1908, genetics became extremely rich through the development of specific research tools unique to the solution of its own problems such as selection, fitness, mutations, inbreeding, gene flow, gene frequencies, etc. (Li, 1955; Morton, et al., 1956). Today, it is well known how genetics expanded absorbing a variety of disciplines into its subject matter. The understanding of the DNA molecule, for example, required the confluence of knowledge from physics and biology (Watson and Crick, 1953).

The main point here is the richness of scientific research tools developed by the geneticists themselves. By knowing exactly what the problem was new methodological tools were developed. Certainly, quantitative analysis was in the root of all these tools but there were new creative and efficacious tools universally recognized as helpful for genetics research (Mather and Jinks, 1977).

However, in spite of so many advances in genetics, molecular biology and genomic, the complexity of living organisms showed to require more complex research methods. The deep understanding of isolated biological segments does not clarify the organism integrative functions. Thus, more recently, a new methodological approach named “system biology” opened a new paradigm in science.

### System Biology and Bioethics

The world of biological sciences have been experimenting a new paradigmatic revolution on research method named "system biology". For Kitano (2002), system biology does not examine isolated parts of cells or organisms but searches for their dynamics (Kitano, 2002). The secular tradition of researching parts of organisms, cells and genes led to no true understanding of life functions and diseases. To know the sequence of DNA molecule does not clarify how the gene works. From the gene sequence to the effect of its product on the human body there is such a complex net of functional interactions played by so many variables under both biological and environmental influences that the simple approach to search single causes of diseases seems naïve. To understand complex genetics interaction one has to migrate from the level of components to the level of systems incorporating knowledge from nonlinear complex systems, mathematics, physics, molecular biology and computational science (Ahn, et al., 2006; Voit et al., 2006). Some results of this highly complex research method are already coming out in biology and medicine (Cho et al., 2006; Ekins et al., 2005; Baranzini, 2006). Here also, traditional concepts on body function rooted on linear scientific methods of research works as cognitive barriers. System biology is transdisciplinary in its essence but the present generation of researchers is mostly monodisciplinary minded.

The analogy with bioethics is clear. The difference is that in bioethics there is no proposal of some systemic methods of research integrating knowledge from law, biology, medicine and philosophy. However, since both bioethics and system science are new let us hope that in a near future system bioethics may become true. As usual, methodological dissatisfaction nourishes new ideas. Meanwhile, most research in bioethics continues being reductionist in the sense of following the monodisciplinary tradition of each research worker.

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## Self-Determination of Death in Japan: A Review & Discussion

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### Abstract

Self-determination is a central concept in the field of bioethics and the most critical decision among the myriad of decisions concerning medical care is the decision to choose to die; "self-determination of death." The purpose of this paper is to clarify the basic positions on self-determination of death held by present Japanese people and we tentatively sorted these positions into 10 arguments. We discuss the problems and implications of these positions revealed within our present review and conclude that a society needs to deny unnecessary intrusion and tolerance for different views might be a keyword in our oncoming society.

### 1. Introduction

Self-determination is a central concept in the field of bioethics and respecting self-determination in clinical medicine is a basic bioethical principle. The most critical decision among the myriad of decisions concerning medical care is the decision to choose to die; "self-determination of death." Conceived and developed in the West, modern bioethical thought and the idea of respecting self-determination were imported into Japan as "foreign

thought.” The history of bioethics in Japan is rather short and the Japan Association for Bioethics is not yet 20 years old. Today, medical providers, philosophers, ethicists, policy makers and the majority of the general public recognize the importance of bioethics (Ministry of Health, Welfare, and Labor, 2004). Yet people’s awareness for “the importance of considering and discussing bioethics” does not necessarily mean an acceptance of the commonly quoted principles: personal autonomy, beneficence, non-maleficence, and justice.

In July 2004, the Ministry of Health, Welfare and Labour of Japan released a report on a public opinion survey on terminal care in general. Results showed that over 80% of the public, regardless of professional background, e.g. layperson, physician, nurse, nursing-home employee, agree with the notion to respect an individual’s wishes for treatment-related decisions in end-of-life care. On the other hand, 59% of general citizens, 75% of physicians, 75% of nurses and 76% of nursing-home employees agreed with the idea of a written advanced directives (ADs). This highlights a difference in layperson’s attitudes toward wanting to respect an individual’s wishes for end-of-life care and the actual use of a written AD. These percentages decreased even further with the issue of legalizing ADs, respectively 37%, 48%, 44%, and 38% (Ministry of Health, Welfare, and Labor, 2004). What concept and idea of self-determination underline these results?

In a study conducted by Masuda et al. (2003), 55% of physicians who had received an AD from a patient recognized its validity, but 69% had never acting in accordance with that AD by altering treatment. Matsui and Inoue (2003) also found that thirty-seven percent of hospitalized patients with an average age of 73 years-old in one of Japanese hospitals said that they would respect a family member’s AD while more than half of them (55%) responded that “it depends on the contents of the AD;” and that 6% would not respect a family member’s AD. These findings suggest that people in Japan vary in their positions on self-determination of death.

The results of the aforementioned surveys make us wonder what Japanese people really think of the significance and meaning of self-determination of death, and what are the grounds for their respecting or for denying self-determination in terms of life and death choices. In our opinion, it remains unclear how present-day Japanese people consider and feel towards the issue of self-determination of death. There is a possibility that Japanese people maintain their own deep-rooted ideas of the individual who exists within a society of its own unique interpersonal relationships, philosophies of life and death, cultural traditions, and history.

The purpose of this paper is, therefore, to clarify the basic positions on self-determination of death held by present Japanese people and discusses their implications. In the following, self-determination of death refers to any autonomous decisions regarding life and death in health care. A literature study of articles and books published after 2000 by Japanese scholars including bioethical researchers and educators, journalists, writers, and health care professionals was conducted to achieve the objective. Databases to gather the information include Japan Centra Revuo Medicina, Medline and Amazon.com. The combination of

keywords used for the retrieval of the literature included “Japan” and “death-with-dignity,” “Japan” and “dignified death,” “Japan” and “self-determination” or, “Japan,” “self-determination,” and “death,” resulting in procuring and reviewing 43 articles or books. We identified and sorted all abstracted descriptions of self-determination of death, death-with-dignity, and withholding or withdrawing life-sustaining treatment by making use of qualitative content analysis technique (Mayring, 2004). Although numerous books and articles have been published on self-determination of death and death-with-dignity before 2000, we limited our selected literature to books and articles published after 2000 in order to grasp the most recent arguments of Japanese scholars.

We realize that Japanese scholars’ opinions in this regard do not necessarily represent the entire Japanese population, but this sample was chosen to explore and understand in-depth the ethical and philosophical discussions on self-determination of death in current Japan. At the same time, we assume that their attitudes are of importance since the arguments and attitudes combined with their stated positions in bioethics textbooks, teaching materials, articles, and monographs have had an impact on society and higher education.

## 2 Arguments of self-determination of death

By means of qualitative content analysis of retrieved literature, we found that present day bioethical scholars have a variety of opinions regarding self-determination and self-determination of death. Instead of examining who held what notion or which ideology had the upper hand, we focused on what positions on self-determination of death exist in present day Japan and what rationale underlie them. Based on these findings, we tentatively sorted these positions into 10 arguments (Table 1).

Table 1 Various positions regarding self-determination of death in present Japan

- Self-determination is incapable of existing
- Self-determination is not desired
- Self-determination does not apply to death
- Self-determination of death cannot be realized
- Respecting self-determination of death inflicts harm on others
- Self-determination of death is forced upon the patient
- Life is always most important
- Self-determination of death is recognized only under certain conditions
- Self-determination of death is for another’s benefit
- Self-determination of death should be recognized

### 2-1 Self-determination is incapable of existing

There exists the position that true self-determination, which deserves the name of self-determination, is nonexistent. Because every decision occurs only within a complicated web of interpersonal relationship, pure self-determination is incapable of existing – all decisions are shared in actuality (Komatsu, 2004; Kudo, 2004; Nakaoka, 2004).

*““Self” and “determination” are unrecognized. The individual chooses; but an individual’s life is not only*

his or her possession. Each one of us exists within a collection of communities and we live attempting to fulfill our roles and to answer to the expectations of our community. "Choice" drags all this along with it. Even the act of deciding exists only when acknowledged by others. In most cases, we make a decision without ever being determined. The term self-determination may be too ambiguous a notion." (Kudo, 2004).

### 2-2 Self-determination is not desired

Some of the scholars argue that the majority of the Japanese population do not desire self-determination of death or that, given the differences between Japanese and Western cultures, the principle of autonomy needs not to be respected. They explain that Japanese people tend to avoid having to face and think about death and death-with-dignity. According to their arguments, respecting self-determination of death is not necessary since patients and families tend to "entrust" their treatment-related decisions to medical professionals. For instance, Saito pointed to patients who "do not want to answer" and who "do not want to think about death" (Karino, 2002; Saito, 2002; Shimazaki, 2001; Tanida, 2003).

*"The principles such as autonomy and beneficence are part of Western bioethics, which is centered on American and European modern utilitarianism. As a bioethical principle, it (autonomy) should never become part of our own paradigm."* (Shimazaki, 2001).

### 2-3 Self-determination does not apply to death

Several authors hold the position that, even if self-determination is possible and even if the right to self-determination existed, the right to self-determination of death is impossible. They argue that death is not personal, but rather collective – an entity shared among interpersonal relationships including one's family and acquaintances (Komatsu, 2004; Tokyo Soka Gakkai Seimeirinri Kenkyukai, 2001). Other positions fall into this category maintain that what an individual can choose remains ambivalent because life and death are ultimately passive (Kudo, 2004). Shimazaki also argues that a gap exists between the effect of informed consent and underlying rationale and these of ADs (Shimazaki, 2001).

*"Death is not confined to the individual. When a person dies, many people are involved including the patient's family who cares for patient, the physician who provide treatment and the nurse who provides medical care. Once the patient dies, people are left abandoned and remember the deceased with ardent emotions. Death involves anyone acquainted with the patient: an event that exists within the medium of interpersonal relationship. Because death takes meaning within the context of relationships and only exists within those relationships, death can neither be possessed nor discarded"* (Komatsu, 2004).

### 2-4 Self-determination of death cannot be realized

A different group of scholars maintain that, even if self-determination of death being conceptually possible, it is impossible to implement such a right. For instance, numerous arguments were against the use of ADs for death-with-dignity: it is impossible to reconfirm a patient's

intentions; it is difficult to understand a patient's true intentions; the patient him or herself may have ambivalent intentions; feelings and intentions change and may differ from when the patient made the AD; since Japan currently lacks legislation on withholding or withdrawing life-sustaining treatment, medical providers are incapable of respecting a patient's self-determination of death. There was also the opinion that ADs are not used because of inner-familial miscommunication (Saito, 2002; Soka Gakkai Seimeirinri Kenkyukai, 2001; Tokunaga, 2003; Tanida, 2003; Nakaoka, 2004).

*"How one understands the self and understands another is not symmetrical. What one would pass up or give up is that which one would want to do for another (family member), what one would want somebody else to do for another (family member)."* (Nakaoka, 2004).

### 2-5 Respecting self-determination of death inflicts harm on others

There was the opinion that respecting a patient's self-determination of death would ultimately harm patients suffering from the same disease. This position maintains that respecting self-determination of death is eugenic and selective – it supports discrimination against the disabled, disposal of the weak and the idea that people in a vegetative state and/or who have dementia are insignificant and unnecessary (Uema, 2003; Kuzuo, 2004; Ogasawara, 2003; Saito, 2002; Shiono, 2003; Shimazaki, 2001; Tokunaga, 2003; Yomiuri Shimbun Hokuriku Branch, 2002). Acceptance of death-with-dignity, which is based on respecting self-determination of death, was also thought to be a conspiracy to decrease healthcare costs (Komatsu, 2004; Yomiuri Shimbun Hokuriku Branch, 2002).

*"To say that human dignity should be respected as personal autonomy is but "a theory of the strong." As long as we define human dignity by understanding personhood as "a theory of possession" (e.g., having reason, having free will, having something), we will continue to measure human value with a relative scale: if an individual holds so-and-so of an ability and, if so, how much of that ability."* (Kuzuo, 2004)

### 2-6 Self-determination of death is forced upon the patient

This position maintains that true and purely voluntary self-determination of death, which requires the patient to be free of all psychological pressure, cannot exist within Japanese healthcare and medical system as a result of under-treatment, insufficient medical welfare, low quality of care and an imposed financial burden on the patient's family. This position coincides with the so-called "duty of death" theory (Tokunaga, 2003; Mukai, 2003). There is also concern that a lock-step mentality may cause people to desire death-with-dignity given the national characteristic of being unacquainted with personal rights like the Japanese people (Fukumoto, 2002). It is also claimed that self-determination to die is not true self-determination: there would be no reason for a patient to choose death if he or she is receiving sufficient care (Nakajima, 2003).

*"When a patient has lost all hope and chooses death, can we really call this true autonomy? We should consider that when a patient is unable to see his or her future, he or she*

has lost his or her autonomy as a result of insufficient social support, anxiety and physical disabilities... Regardless of terminal patient, true self-determination is possible only with a happy and affirmative understanding of life" (Nakajima, 2003).

#### 2-7 Life is always most important

There exists the position that concepts such as death-with-dignity and self-determination, which impose death on a person, go against life's significance. One scholar argued that "an abrupt death" contradicts a person's final "comfort" and "satisfaction" (Tokunaga, 2003). Other scholars stated that death-with-dignity discontinues sustaining life and, thus, should be considered to be murder: death-with-dignity is equivalent to euthanasia (Karino, 2002; Takahashi, 2001). *"Despite that [death-with-dignity] is the same as euthanasia, a variety of convoluted expressions exist. For instance, the term death-with-dignity has recently been used to describe the act of dying and maintaining one's human dignity until the very end; [death-with-dignity], however, is a form of euthanasia."* (Takahashi, 2001).

#### 2-8 Self-determination of death is recognized only under certain conditions

Several scholars argue that self-determination of death is not something that can be accepted unconditionally, but rather is a concept that should be recognized only under certain medical conditions and/or with a defined medical treatment. According to them, self-determination of death cannot apply when in a non-terminal state or when discontinuation of tube feeding is concerned. They claim that patient's self-determination of death should be respected only in special circumstances and/or when the family has recognized the patient's wishes: the patient's decision must be recognized by other individuals (Tokunaga, 2003; Karino, 2002; Shimazaki, 2001; Sokagakkai Seimeirinri Kenkyukai, 2001; Fukumoto, 2002; Saito, 2002; Nakaoka, 2004; Kai, 2002). For instance, Okada has proposed a concept of "life with dignity" which makes fluid replacement a principle condition (Okada (1), 2003; Okada (2), 2003). Respect for "self-determination with limitations" is supported by many scholars.

*"Terminal-care treatment such as tube feeding, intravenous drip, dialysis and antibiotics should not be forgone. Starvation is immoral. To stop general treatment intentionally is nothing more than "murder"."* (Saito, 2002).

#### 2-9 Self-determination of death is for another's benefit

This position maintains that it is desirable to have the patient express his or her intentions prior to the actual event in aims of making it easier for family and/or medical providers (Tanida, 2003; Fukumoto, 2002). For example, even if one's spouse has verbally requested "death-with-dignity," an AD is useful because of the difficulty for family members to request a "curtailment of treatment." Shibata argues that self-determination of death is a good means of lessening a family's psychological and financial burden (Shibata, 2001).

*"Once a patient's condition stabilizes and he or she neither improves nor worsens, it is common for the patient's family to become tired with having to care for the*

*patient. If the patient falls into a coma, there are those who say it is similar to dry-nursing a big pet. Even with beneficent families become exhausted and begin to question at how much meaning is in such care"* (Shibata, 2001).

#### 2-10 Self-determination of death should be recognized

Based on the notions of respect for patient autonomy and fulfillment of choice, it is argued that self-determination of death should be respected purely for its own sake (Ohta, 2003; Ohhira 2002; Kai, 2002; Kimura, 2000; Shibata, 2001; Sodei, 2000; Tanida, 2003; Narita, 2001; Narita, 2003). Reasons include: death is ultimately of the dying person; self-determination of death is recognized by the Japanese Constitution as a human right; each individual may not have the choice to be born, but does have the liberty to choose how to die; patients with decision-making capacity who choose to forgo life-prolonging treatment have the justified right to do so (right to self-determination); to forgo or discontinue life-sustaining methods is a natural death; the right to self-determination when on one's death bed is more important than the right to life; living wills and ADs value the personal self; it is important for a person to take pride in dying and not to entrust their final decision to another, etc.

*"Death is neither something related to medical treatment nor something related to welfare. For a dying person, family is essential, but death is ultimately the individual's possession. Even family should not make a decision against the will of the dying. To decide in place of the dying patient does not always coincide with the actual wishes of the patient."* (Sodei, 2000)

It should be noted, however, that some Japanese scholars support self-determination of death based on respect for patient autonomy and fulfillment of choice and give their approval to the decision made in such a case as Ms B who was not in a terminal state in any sense (Singer, 2002). On the other hand, others, even supporting the notion of self-determination of death as patient autonomy, tend only to accept dying with dignity under certain medical conditions and/or with a defined medical treatment.

### **3. Interpretations**

This literature review has explained partially how present-day Japanese people understand and perceive "self-determination of death." Some ideas can be said to be grounded in traditional Japanese thought including an inclination to recognize decision-making as a function of family, to view life and the individual as interrelated entities, to recognize an ambiguity between the self and another, to have a preference for codependence, to emphasize cooperation over independence, and to prioritize consensus over personal choice.

Our study has also highlighted ongoing discussions and strong concerns for the possibility that individuals who are disabled or socially vulnerable could be denied sufficient medical care as a result of discrimination. According to this perspective, we ought to be aware of and strongly consider others even when personal decisions do not directly harm them. Several scholars in Japan and in other nations have criticized voluntary euthanasia and self-determination of death on the basis that leads to discrimination against the

disabled (Kodama, 2002; Coleman & Drake, 2002, Spriggs & Savulescu, 2002).

At the same time, self-determination of death has been gradually recognized in Japan under certain strict conditions. For instance, the Yokohama District Court ruling on the case of euthanasia at Tokai University in 1995 proposed, as a supplement, the following two conditions for withdrawing life-sustaining treatment: (1) the patient be untreatable and be in a terminal state certain to die without any hope of recovery, (2) the existence of patient's expressed wishes to discontinue treatment. While the second remains a condition, an AD and/or a family's decision based on the patient's intentions can also suffice. Technically speaking, however, there exists no direct legislation on self-determination of death and ADs and no legal precedents in this regard made by the Japan Supreme Court (Asai et al. 2004). The current trend to accept self-determination of death under certain circumstances is major, but this raises the question whether the meaning of self-determination of death is the same when and if it is recognized only when death is inevitable.

In 2004, the Japan Medical Association (JMA) declared that respecting patient's self-determination requires extreme carefulness and consideration of the patient's benefits and the circumstantial issues at hand. It read, "Advanced directives (ADs) should be seen as an essential means of understanding a patient's wishes up until that point in time. Yet to decide an actual treatment plan for terminal patients requires great consideration. ADs are not a final decision. Without reconfirming over-and-over again circumstantial change, ADs actually become a barrier and can impede a physician from acting in accordance to the patient's wishes once he or she has become terminally ill (Japan Medical Association, 2004 (1); Japan Medical Association, 2004 (2)).

As far as we can understand, the JMA's stance agrees with the argument that self-determination of death cannot be realized. This position does not define clinical ethical conflicts as problems which need to be solved, but rather uses them as grounds for avoiding self-determination of death. Albeit the existence of so-called "Western" value-pluralistic-liberalism, which tries to respect personal freedom and choice as much as possible, arguments based on the holiness of life, which deny self-determination of death, are also recognized. Thus, the Japanese ideas of self-determination of death vary greatly and the breadth of this diversity is enormous.

Yamazaki explains that in order for Japanese to accept the idea of self-determination of death, it is important that the nature of the decision is highly public; healthcare providers and families who face a patient's personal and private wishes often hesitate with whether a patient's wish pertains to oneself and other family members and whether that wish is socially acceptable. The act of dying is commonly based on the fundamental idea of self-determination in Europe and the United States. In Japan, however, there exists the issue of whether one's self-determination is acceptable to others (Yamazaki, 2004). Therefore, it is possible that self-determination will continue to be disregarded in Japan due to it being separate from the social norm: it excludes others such as family and medical

providers. Similar to the expression that, "Since it is difficult to reach a social consensus on death-with-dignity, we are lost at what to base our opinions (Chiran, 2004)," Japanese people might assert "Social consent is equivalent to the justification of ethical judgments."

#### 4. Discussion

What are the problems with the positions revealed and discussed within our present review? What type of impact do these attitudes have on patients who want to withhold or withdraw life-sustaining treatment? Certainly we can learn a great deal from fore-mentioned positions (from 2-1 to 2-8) which criticize self-determination: i.e., the necessity of improving medical care and social welfare, considering patients' feelings and psychologies, appreciating the importance of communication with family and including them in decision-making, maintaining voluntariness, and being critical of the existence of pure free choice. Especially, the possibility of patient's self-determination to die under duress, manipulation, miscommunication or misunderstanding should completely be eliminated.

In our opinion, however, even when a patient is very close with his or her family, he or she is still an autonomous individual. It should ultimately be up to the patient to define his or her "interests" in life and death and to decide the goal of medical treatment and medical care is carried out for the very patient's best interests. A patient's privacy, a right to let alone, should also be respected and maintained as much as possible. Albeit pure and absolute self-determination may be nonexistent, we believe that an individual's self-determination of death should be recognized when justified measures have been taken. If a lack of purity serves as grounds for denying self-determination, people capable of deciding for themselves in the world would disappear.

Arguments against self-determination of death were often based on the key words such as community, publicness, socially-accepted ideas, and social consensus. These arguments are naïve in presuming that everyone involved would always reach the same conclusion, that all members of a community would always have identical values, and that families are always mutually supportive. The falsity of these presumptions is reflected by current discussions on abortion, voluntary active euthanasia, organ transplantation from a brain dead donor and prenatal diagnosis. We argue that imposing a "social consensus" on the individual becomes tyranny of the majority and a deprivation of liberty. This surpasses paternalism: it is moralistic intervention. We must avoid having an indefinable "community" from arbitrarily deciding the "objective" meaning of good death and bad death and then enforcing that decision onto the patient. Social consensus is not the same as ethical validity: just look at evil laws in the past. For instance, unethical discrimination based on the leprosy prevention law has continued for over 90 years in Japan despite long-held opposition from patients with Hansen's Disease (Kumamoto Shimbun, 2004). How would social-consensus supremacists respond to this history?

There are also limitations with positions that argue that self-determination of death harms disabled and socially vulnerable people since it is unclear whether this argument

is based on the fact. Even if discriminatory acts occur as a result of a patient choosing to withhold or withdraw life-sustaining treatment, we cannot blame the patient. People who actually discriminate individuals who are disabled or socially vulnerable should be to blame. Another common argument states that, when a patient with a specified disease chooses death, any patient with that same disease becomes emotionally and psychologically harmed. However, self-determination should not be limited as long as an individual's decision does not directly impose harm on others. To care for another is important, but it is impossible to remain constantly aware of how each and every action affects another.

Furthermore, restrictions imposed on self-determination of death in Japan nowadays are so strict that self-determination permitted in our country does not deserve its name. It is claimed that self-determination of death should be thought accepted in Japan when our society supports life and death decisions made in the case such as Ms B who was not in a terminal state in any sense and when withdrawal of feeding tube can be removed from a patient in a persistent vegetative state according to the patient's clear and convincing ADs (Singer, 2002). The authors agree with opinions listed in 2-10, especially with the position that death is ultimately of the dying person and that we have the liberty to choose how to die.

In conclusion, positions on self-determination of death in Japan vary greatly and we have analyzed several arguments against self-determination of death. Although we believe that our critical discourse is both necessary and sufficient, we recognize that all authors to whom we refereed believe and continue to believe in their own arguments. We realize that the relationship between their positions based on publicness and consensus and our argument for personal liberties is contradictory. It seems that a conflict between the two positions transcends the confines of logic. That is, disparities in ideas of death are likely to be primitive differences and, as a result of such, any optimism among people who believe in self-determination of death will, more than likely, continued to be denied in Japan.

We argue that society should observe personal liberties as long as they do not overly intrude upon or harm an individual. Those who choose to forgo or discontinue treatment should be able to do so just as much as those who choose to entrust their decision-making to another should be able to do likewise. In any case, a society needs to deny unnecessary intrusion. Therefore, tolerance for different views might be a keyword in our oncoming society.

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## Privacy shakes Japan's statistics on health and welfare

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### Abstract

In 2005 Japan completed its first census after the Personal Information Protection Law went into force in April 2005. The debate about the new law raised privacy concerns for the first time among the public. The news-media also provided several examples of possible lack of safeguards in the data collection of sensitive personal information required for the census. The result was the highest non-response rate ever for the Japanese census. Consequently, its accuracy and role as a source for the reliable national statistics for health/welfare policy-making is now critically threatened. In this paper we argue the necessity to adopt specific safeguards to protect personal data in any future census if the trend of increasing non-response rates is to be reversed. We provide some suggestions for such safeguards, and criticize the Japanese government's response of focusing exclusively on the mechanism of data collection as a means of meeting the privacy challenge.

### Introduction

On October 10, 2005, Japan completed the first national Population Census across the country after the Act concerning Protection of Personal Information (APPI) was issued on May 30, 2003, with total enforcement on April 1, 2005. The census in Japan has been implemented every five years since 1920, and it has greatly contributed to Japan's health and welfare policy-making. Japan spent 65 billion Yen (310 million GBP) on the census 2005.<sup>1</sup> The 2005 census, however, encountered significant data collection problems, partly due to the effect of the new law, threatening its scientific validity and social value for health and welfare policy-making as a source of reliable national statistics. In this paper we will describe the contents of the new law, argue that the discussion about privacy in conjunction with the adoption of the law affected the 2005 census, and conclude that the privacy protection aspects of the census need to be strengthened in order to improve the quality of the census.

### The provisions of the APPI

The APPI is composed of a set of three laws: (1) the 2003 Law No. 57 applies to all enterprises collecting, storing, or handling data of more than 5,000 persons, except national and local administrative bodies and independent administrative corporations (IAC) including national universities, national hospitals, and attached-to-national-university hospitals; (2) the 2003 Law No. 58 applies to administrative bodies; and (3) the 2003 Law No. 59 applies to the IAC.<sup>2,3,4</sup> Enterprises collecting/storing/handling data of fewer than 5,000 persons or individuals using personal data not for business purposes are exempt from the APPI.

The main purpose of the APPI is to state the basic concepts and basic policies regarding the proper handling and protection of personal information, the protection of the rights and interests of individuals, the governmental duties in relation therewith, and at the same time the appropriate utilization of personal information.<sup>2</sup> Its essential framework is based on the recommendation and the eight principles governing the Protection of Privacy and Transborder Flows of Personal Data in 1980 by the Council of Organisation for Economic Co-operation and Development (Table 1), which aimed to harmonize privacy protection and prevention of economic interruptions in international flows of data.<sup>5</sup> Therefore, the enterprises concerned are basically obliged: (1) to specify the purposes of personal data utilization, (2) not to use that data beyond these specified purposes without obtaining the consent of the data subject, (3) not to transfer that data without her consent, (4) not to collect personal data in a wrong or fraudulent way, (5) to keep that data accurate and up-to-date, (6) to take necessary measures for safeguarding that data, (7) to monitor their data handling personnel and consignees, (8) to secure confidentiality of that data, (9) to open the purposes of that data utilization to the data subject or to the public, (10) to make the names of the enterprises and the purposes of that data utilization readily available, (11) to disclose or correct the data relating to the data subject at her request, (12) to suspend the utilization of that data at her request because of the misconduct regarding (2) or (3), and (13) to deal with complaints regarding personal data which they have.

**Characteristics of the census data**

A census is conducted in more than a hundred countries, and each has its own characteristics (Table 2).<sup>6,7,8,9,10,11,12,13,14</sup> With the legal basis in the Statistic Law, the Japanese census collects the information of 17 items in a short form every 5 years, and 22 items in a long form every 10 years. Those items include each name of the family members, gender, birth date, educational history, household income, relationship to the head of the family, spousal relationship, nationality, the number of family members, the number of the elderly relatives at the age of 65 and more with whom the family live, the name of the employer, the type, content, and working hours of the job, the post at the company, the type, and size of the residence, and so forth. Hence, the statistics from the census have widely been utilized in making various policies, including policies on health and welfare. Meanwhile, Japan has other alternative ways to obtain similar information to what the census collects. However, the census data are indispensable in policy-making processes.

For instance, Japan has a national registration system of the residents, which is enacted by the Act on the National Basic Resident Register (NBRR). Through the NBRR system which each municipal authority manages, we can get

information of the registered residents of each municipality about their names, birth date, address, the number of family members. However, this registration system provides only the armchair data of the residential population who are legally registered there. It usually happens that many people who are listed on the NBRR do not actually live there any more. For some people who are institutionalized in nursing care facilities or inpatients, or most business bachelors or transient residents such as seasonal workers, students, foreigners and so forth, are entirely out of the register unless they notify their movement to the municipality. This phenomenon generally occurs in those areas where the social mobility of the population is high. Accordingly, the NBRR's data are always running behind the actual data of the population. On the other hand, the census targets all people including foreigners who live in each area at the time of the census survey, so that the data on population through the census survey are quite different from the one obtained through the NBRR system.<sup>15</sup> Conceptually, therefore, the census provides more authentic and more reliable data than any other statistical source, and is thus the most important source for policy-making.

**Table 1: Correspondence between OECD's eight principles and the APPI's requirements**

| <b>OECD's principles</b>            | <b>Corresponding requirements by the APPI</b>  | <b>2003 Japan Law no./ article no.</b>        |
|-------------------------------------|--|---|
| Purpose                             | (1) To specify the purposes of personal data utilization.  | L57/a15-1; L58/a3-1, a4; L59/a3-1, a4         |
| Specification                       | (2) Not to use that data beyond these specified purposes without obtaining the consent of the                  | L57/a15-2, a16-1/-2; L58/a3-2/-3; L59/a3-2/-3 |
| Use                                 | (3) Not to transfer that data without her consent.   | L57/a23-1; L58/a8-2; L59/a9-2                 |
| Limitation                          | (4) Not to collect personal data in a wrong or fraudulent way.   | L57/a17; L58/a36-1; L59/a5                    |
| Collection                          | (5) To keep that data accurate and up-to-date.   | L57/a19; L58/a5; L59/a6                       |
| Limitation                          | (6) To take necessary measures for safeguarding that data.   | L57/a20; L58/a6-1; L59/a7-1                   |
| Data Quality                        | (7) To monitor their data handling personnel and consignees.   | L57/a21, a22; L58/a6-2; L59/a7-2              |
| Security                            | (8) To secure confidentiality of that data   | L57/a34-2, a58; L58/a7; L59/a8                |
| Safeguards                          | (9) To open the purposes of that data utilization to the data subject or to the public.                        | L57/a18-1; L58/a4; L59/a4                     |
| Openness & Individual Participation | (10) To make the names of the enterprises and the purposes of that data utilization readily                    | L57/a24-1; L58/a10-1; L59/a11-1               |
|                                     | (11) To disclose or correct the data relating to the data subject at her request.                              | L57/a25-1; L58/a12, a14; L59/a12, a14         |
|                                     | (12) To suspend the utilization of that data at her request because of the existence of a breach of (2) or (3) | L57/a27-1/-2; L58/a36-1; L59/a36-1            |
| Accountability                      | (13) To deal with complaints regarding personal data which they have.  | L57/a31; L58/a48; L59/a47                     |

Table 2: Characteristics of Census in East Asian and Western countries

| Country                          | Japan  | China   | Korea   | USA                                    | UK<br>(England & Wales)           | France  | Canada<br>(until 2001)                              | Canada<br>(2006)               | Australia<br>(until 2001)      | Australia<br>(2006)             |
|----------------------------------|--|---|---|--|-----------------------------------|---|---|--------------------------------|--------------------------------|---------------------------------|
| <b>Population size</b>           | 130 million  | 1.2 billion                                     | 47 million                                      | 280 million                            | 52 million                        | 62 million  | 31 million  |                                | 18 million                     |                                 |
| <b>Number of households</b>      | 49 million   | 348 million                                     | 15 million                                      | 105 million                            | 21 million                        | 30 million  | 11 million  |                                | 9 million                      |                                 |
| <b>Census history</b>            | Since 1920   | Since 1953                                      | Since 1925                                      | Since 1790                             | Since 1801                        | Since 1801  | Since 1871  |                                | Since 1911                     |                                 |
| <b>Current cycle</b>             | Short census: every 5 yrs<br>Long census: every 10 yrs | Every 10 yrs<br>(since 1990)                    | Every 5 yrs                                     | Every 10 yrs                           | Every 10 yrs                      | Annually (since 2004)   | Every 5 yrs (since 1951)                            |                                | Every 5 yrs (since 1961)       |                                 |
| <b>Target population</b>         | Whole  | Whole   | Whole   | Whole                                  | Whole                             | Large commune: Sampling<br>Small commune: Whole                         | Whole   | Whole                          | Whole                          | Whole                           |
| <b>No. of question items</b>     |  |   |   |  |                                   |   |   |                                |                                |                                 |
| <b>Short form</b>                | 17 items at every 5 yrs                                | 19 items for 90% h/h                            | 21 items for all h/h                            | 7 items for five in six h/h            | 40 items (common)                 | 13 items for h/h  | 7 items for 80% h/h                                 | 8 items for 80% h/h            | 49 items (common)              | 59 items (common)               |
| <b>Long form</b>                 | 22 items at every 10 yrs                               | 49 items for 10% h/h                            | 44 items for 10% h/h                            | 53 items for one in six h/h            | 40 items (common)                 | 26 items for individuals  | 59 items for 20% h/h                                | 53 items for 20% h/h           |                                |                                 |
| <b>Delivery method</b>           |  |   |   |  |                                   |   |   |                                |                                |                                 |
| <b>By officials</b>              | Yes  | Yes (direct interview)                          | Yes (direct interview or sheet)                 | Yes (in rural areas or for apartments) | Yes                               | Yes (Rolling Census System since 2004)                                  | Yes   | Yes (1/3 of h/h)               | Yes                            | Yes                             |
| <b>Mailout</b>                   | No   | No  | No  | Yes (in urban areas)                   | No                                | No  | No  | Yes (2/3 of h/h)               | No                             | No                              |
| <b>Internet</b>                  | No   | No  | Yes (since 2005)                                | Yes (in some areas)                    | No                                | No  | No  | Yes                            | No                             | Yes                             |
| <b>Current way of collection</b> |  |   |   |  |                                   |   |   |                                |                                |                                 |
| <b>By officials</b>              | Yes  | Yes (direct interview)                          | Yes (direct interview)                          | Yes (followup mainly)                  | Yes (followup only)               | Yes (Rolling Census System since 2004)                                  | Yes (2%) (direct interview;                         | No (in remote, northern areas) | Yes                            | Yes                             |
| <b>Mail return</b>               | Not recommended  | No  | No  | Yes                                    | Yes                               | No  | Yes (98%)   | Yes                            | Yes                            | Yes                             |
| <b>Internet</b>                  | No   | No  | Yes, but not strongly recommended. (since 2005) | Yes (short form only)                  | No                                | No  | No  | Yes (estimation is 20%)        | No                             | Yes (estimation is 5-10%)       |
| <b>Latest census</b>             | Oct 2005 (Short census)                                | Nov 2000  | Nov 2005  | Apr 2000                               | Apr 2001                          | Jan-Feb 2006  |   | 2006                           |                                | 2006                            |
| <b>Budget</b>                    | \ 65 billion   | No information                                  | W 15 billion                                    | \$ 6.5 billion                         | £ 207 million                     | €29 million   | No info.  | CAS 567 million                | No info.                       | No info.                        |
| <b>Number census examiners</b>   | 850,000  | 5 million                                       | 88,500  | 960,000                                | 62,500                            | 18,000  | 34,000  | 25,000                         | 30,000                         | 43,000                          |
| <b>Total response rate</b>       | 95.6%  | No info.  | No info.  | 67%                                    | 94%                               | No info.  | 97%   | No info.                       | 98%                            | No info.                        |
| <b>Mail return rate</b>          | 1.1%   | None  | No info.  | 55%                                    | 88%                               | No info.  | No info.  | No info.                       | No info.                       | No info.                        |
| <b>Duplicated examination</b>    | None reported  | No info.  | No info.  | 770 thousand households (1.1%)         | No info.                          | No info.  | 1.0%  | No info.                       | No info.                       | No info.                        |
| <b>Officials' status</b>         | Part-time (public servant)                             | No info.  | Part-time (nonpublic worker)                    | Part-time (no details)                 | Part-time (no details)            | Part-time (no details)  | Part-time (no details)                              | Part-time (no details)         | Part-time (no details)         | Part-time (no details)          |
| <b>Legal authority</b>           | Statistics Law   | Act on the 5th Whole Population <i>Puti Cha</i> | Statistics Law                                  | US Constitution (Article 1; Sec 2)     | Census Act 1920 Census Order 2001 | LOI n°2002-276 du 27 février 2002 relative à la démocratie de proximité | Statistics Act                                      |                                | Census and Statistics Act 1905 | Electronic Transaction Act 1999 |
| <b>Penalty for unfulfillment</b> | Max 6 month imprisonment or 100,000 fine or less       | No info.  | No info.  | \$ 500 fine or less                    | £ 1,000 fine or less              | €150 fine   | Up to 3 month imprisonment or fine of up to CAS 500 |                                | Fine of up to A\$ 100          |                                 |
| <b>Precedent for penalty</b>     | None   | No info.  | No info.  | No info.                               | 92 cases in 2001                  | None  | 52 cases in 2001                                    | No info.                       | No info.                       | No info.                        |

Yrs; years.  
h/h; households.  
No info.; no information.

Similar to the UK,<sup>16</sup> current government policy in Japan has moved towards evidence-based policy, confirming the central role of evidence in policy-making, especially with in the realm of medicine and public health. This is because “[a]ccurate statistics are part of the lifeblood of political debate”, and because without such reliable and complete population-based data, appropriate assessment of health status and trends in the population cannot be achieved.<sup>17, 18</sup> Therefore, any system that requires voluntary participation to statistical databases would threaten the completeness, value and persuasiveness of such data for policy-making.<sup>18</sup>

### **Application of the census data**

Combined with each other, the utilization of the information collected in the census is materialized, for instance, in the national policy development for mothers and children, called the “New Angel Plan”.<sup>19</sup> The primary purpose of this national plan is to take immediate countermeasures against the critical dwindling birthrate. The Japanese government has therefore launched many projects under this plan such as 1) the development and promotion of the child-care leave systems; 2) the planning and the control of the national pediatric medical facilities, the nurseries, and their staff-reallocation; 3) the promotion of the working environments and conditions for the working mothers; and, 4) measures for late child-bearing.

At the same time, Japan also faces a critical increase of medical expenses for elderly people, as Japanese society undergoes an extraordinarily rapid aging process. The Statistics Bureau in the Ministry of Internal Affairs and Communication reports that the aging population rate in Japan over the age of 64 will reach 22.5 % in 2010, and 28.7 % in 2025.<sup>20</sup> Without immediate and effective political countermeasures, therefore, the Japanese social security system would collapse soon. Hence, the government has launched several political measures against this problem such as a national plan of supplying new elderly nursing-care facilities and the promotion of employment and the appropriate allocation of medical and nursing staff, and a social plan of striking a balance between expenses for pension and medical insurance and their allowances. What should not be overlooked here is the fact that those political countermeasures on health and welfare have all relied, more or less, on the census data which are continuously being collected.

Another good example of the census data application would be that of an improvement of the emergency medical service. The census data is combined with various mapping data by using the Geographic Information System to develop the Census Mapping System (CMS).<sup>21</sup> Recently the CMS has come to contain not only horizontal but also vertical various types of geographical information of each area. Subsequently, this detailed computerized map is applied for plotting on the map each elderly person who lives alone or each disabled person, so that the subsequent digital image can help to improve the medical emergency services and the ambulance systems for those people.<sup>22, 23, 24</sup>

Similar to these applications of census data in Japan, Australia also uses census data for the policy development of

women’s and children’s health services as well as for the policy of the aged: according to the Australian Bureau of Statistics, Census data was used, for instance, for mapping the target population for breast cancer clinics for an area health service in a larger city, and identified the areas most in need of new breast cancer clinics; the bureau also utilized the data of the number of children, by age, for funding allocation for existing child care centers.<sup>14</sup>

All of these examples clearly demonstrate how the national health and welfare policies will encounter serious difficulties if the quality of the statistical data developed from the census is diminished because of a high refusal/non-response rate or false reports.

### **Confusions and controversies over the census**

The discussion about the pros and cons of the census has been going on for more than 25 years. The initial movement for an overhaul of the census procedures began in 1980. One study reports, for instance, that since the Census 1980 each no-answer rate for the question on educational history, spousal status, working status, and birth date, has drastically increased.<sup>21</sup> However, such counter-waves have been relatively small until Japan experienced the biggest revolt ever from the public in 2005. This happened in conjunction with the passing of the APPI, and the heated debates about privacy in general that started in 2003 and led to a resurgence of privacy concerns among the public. The complete enforcement in 2005 of the APPI added additional fuel to the major criticisms about the intrusion of privacy by this particular census. Although the Statistics Law itself stipulates confidentiality concerning the Designated Statistics (Article 14) and penalties for the breach of confidentiality (Article 19-2), these provide only a superficial framework, and no specific safeguards to protect confidentiality are mentioned. Also, Article 18-2 of the Statistics Law on which the census as one of designated statistics is based explicitly states that “the personal information collected for the purpose of the Designated Statistics shall be exempt from the regulations of the protection of personal information concerned”.<sup>25</sup> This lack of requirement for specific safeguards in the collection of the census data probably reinforced the public’s privacy concerns. Several recent ethical scandals infringing on the protection of personal information,<sup>26, 27, 28</sup> also contributed to the increasing skepticism among the Japanese about the collection of personal information in the census.

Let us here give some illustrative examples from news sources about what types of issues raised concern among the public. First, the protection of confidentiality was seen to be insufficient. Although the information to be collected includes sensitive personal information, the practice is that the response sheet must be collected face-to-face by a designated government official. The national government allows on the one hand that to protect privacy people can use a specific ‘non-postal’ envelope. On the other hand, however, the government also strongly discourages that one puts the sheet into the envelope and seals it for confidentiality. The census manual instructs the official who receives the sheet not to open its envelope to check its contents if the envelope is sealed. If on the other hand the envelope remains unsealed, then the official is strongly encouraged to check omissions, if any, immediately at each respondent’s house, and ask the respondent on the spot to fill in the blanks, so that the results of the census can be

accurate, and collected and published as quickly as possible for the subsequent policy-making purposes. Following the same reasoning, mailback is essentially not allowed either. This is in contrast with other countries, such as the US, where the government has started since 1970 to use mainly the mailout/mailback method to collect the responses because of privacy concerns, although a serious constant decline of response rate has started after then (e.g. the response rate in 2000 was 67%).<sup>29</sup> For all of these reasons, the Japanese government considers it preferable that a designated official can check and confirm each sheet face-to-face at each respondent's house for omissions or mistakes in her response sheet.

Second, there are problems with the types of persons who are in charge of collecting responses. They are recruited from ordinary local residents, who are temporarily employed as national officials. They go to their neighbors' houses and collect responses. The government explains that the main reason to use local residents is that those people know their local geographic and neighborhood characteristics and residents more than anyone else, so that the collection process can go smoothly and accurately. However, the number of those *instant* officials piles up to about 850,000,<sup>30</sup> and there is a lack of adequate education about privacy and confidentiality. One of those impromptu officials confessed in her weblog that the explanation that she was given before the response collection by a local government which employed her for the census was about 15 minutes, though the census manual had about 100 pages.<sup>31</sup> If this applies to other impromptu officials as well, then many of them would accordingly lack a sense of protection of personal information. Similar issues arose in Japan's scandal of the cancer-research project in Kumano-cho, Hiroshima, which was severely criticized and halted because of its wrong data-collection process when it used ordinary citizens for the data-collection.<sup>32</sup> In fact, the mass media reported every day during the census that many officials of the census breached confidentiality during the collection: some opened even the sealed envelope to check the sheets;<sup>33</sup> some lost the sheets;<sup>34</sup> and in one case the official burned the sheets instead of bringing them back to the office.<sup>35</sup>

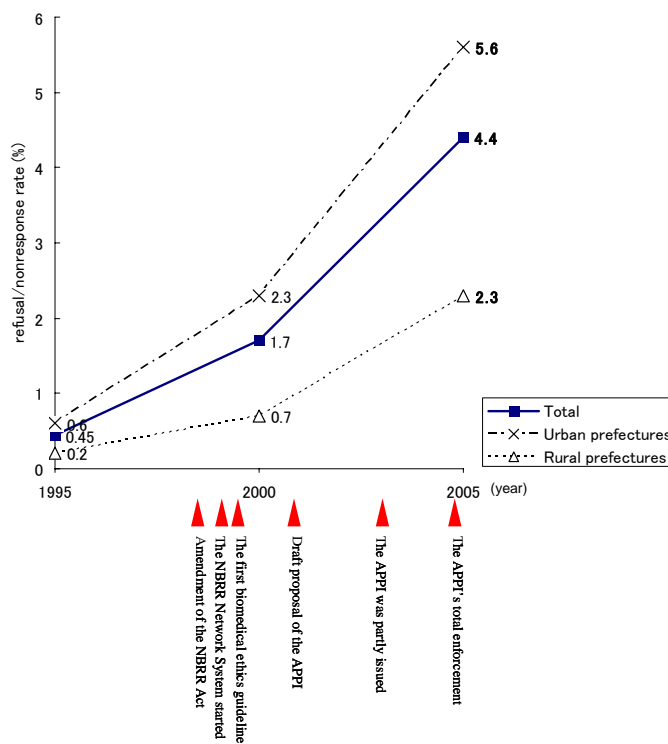
Third, there is a risk that the information in the response sheets as well as the census research itself may be used for crimes. In fact, the mass media reported in more than 40 cases during the census that people were defrauded of their response sheets.<sup>36</sup> In some cases people were defrauded even of the money.<sup>37</sup> People in urban areas, especially elderly and women who live alone, usually in a honeycombed apartment house, and who are therefore apt to be isolated from the community, have much more fear than others if their census information is abused. Accordingly, they tend to lock the door and reject any visit by unfamiliar persons including the authentic census official. These fears of crimes as well as the old-fashioned collection method which totally depends on the existent neighborhood relationships are considered as one of the major causes that the refusal/non-response rate recently in urban areas is higher than other areas (e.g. at the census 2000 the refusal/non-response rate in Tokyo was over three times higher (5.9%) than the average).<sup>38</sup>

Finally, there are problems with cooperation by the people themselves. Some people ignored or just pretended to be out whenever a collecting official visit them.<sup>1</sup> The cooperation with the census is legally mandatory, and if an

individual refuses the cooperation the law can give a penalty of maximum a 6-month imprisonment or a fine of not exceeding 100,000 Yen (500 GBP). However, the number of people who breached the fulfillment of this duty has been increasing in the past 10 years: at the last census in 2000, 1.7% of households did not fulfill the duty, which was 4 times higher than that in 1995.<sup>39, 40, 41</sup> A senior officer of statistics at a local government reported that the number of individuals who say, 'What does it matter? It's not my business,' or 'I just do not want to be bothered,' are certainly increasing.<sup>42</sup>

#### Aftermath of the census and the APPI's after-effects

On 30 May, 2006, the Japanese government reported the aftermath of the census 2005. Markedly high refusal/non-response rates were observed in most of the urban areas as anticipated: 13.3% in Tokyo, 6.8% in Miyagi, 6.1% in Kyoto and Fukuoka, 5.4% in Osaka. Also the highest refusal/non-response rate ever also hit rural areas.<sup>43</sup> The government also reported that the total refusal/non-response rate was 4.4%.<sup>41</sup>



**Figure 1: Transition of Refusal/Non-response Rate for Census in Japan.**

Figure 1 demonstrates the transition of the refusal/non-response rate for the census in the last 15 years.<sup>44</sup> Until the Census 1995 the refusal/non-response rate had remained quite low. However, the amendment of the Act on the NBRR in 1999, by which the government aimed to construct a national digital network system for registering all people in Japan by giving each certificate code of residence, boosted a nationwide debate on the control and breach of privacy by the government. The debate for and against the NBRR network system negatively affected the Census 2000 that resulted in an increase in the refusal/non-response rate. This debate has clearly strengthened the people's subsequent misinterpretation of the APPI and their extraordinarily defensive attitudes against the disclosure of their personal information. Consequently, such an

excessive repulsion that was waiting to happen has occurred in 2005.

The APPI has also severely affected other areas, including public opinion polls. The government announced that since the complete enforcement of the APPI, the response rate for any type of government-initiated public poll or survey, which usually gets 10% higher response rate than non-governmental ones, has greatly dropped to the 50% mark from 70% mark.<sup>45, 46</sup> A newspaper also reported another example of the APPI's aftereffects on people's health and welfare: It says that many residents' associations now encounter hardship to make the name list of those elderly and/or disabled who will need help first and foremost when a disaster occurs.<sup>47, 48</sup> Meanwhile, many schools have reported the same difficulty in making the name list of emergency call networks for their pupils and students.<sup>49</sup>

Japan is not the only one country that is experiencing a large impact of data protection legislation. The UK has more than a 20-year history of such. The UK adopted first in 1984 the Data Protection Act (DPA), that was then amended in 1998. The Academy of Medical Sciences has reported recently that because of the misinterpretation of the DPA, many medical institutions in the UK have refused to provide patient's data and information for responsible medical studies on disease prevention such as cancer registration which were primarily for the public good.<sup>50</sup>

In Japan too we observe that the enactment of data protection legislation affect registry data. On 8 January, 2004, after the partial enactment of the APPI, the Ministry of Health, Labour and Welfare announced to all local governments that the cancer registration is to be excluded from the regulation by the APPI just as the Statistics Law. However, a newspaper reported that 10 out of 35 prefectural governments in Japan which execute cancer registration have admitted that many local hospitals actually refuse to provide cancer patients' data and information to the registration because of the misunderstanding of the APPI.<sup>51</sup> It has even come to light in the Hyogo prefecture in 2005 that the Hyogo's cancer registration was already halted in 2001 on the basis of its Ordinance on Protection of Personal Information enacted in 1997.<sup>52</sup>

### **Steps and challenges for future census**

Shocked by the critical consequence of the Census 2005, the Japanese national government formed an expert conference on the census since January 2006, and has decided to take steps to review the census procedures so as to retrieve people's trust in the census. The main recommendation is to change the method of data collection. It is, however, doubtful whether this would solve some of the underlying problems.

The Government views it as preferable to prepare diverse options for the delivery/collection processes such as mailout/mailback or internet as is done in the United States, the UK, or Korea.<sup>53</sup> Especially, it considers that a mailout/mailback system would be the first choice because it is expected to be more convenient for each household, and because it may thus reduce a burden to the census examiners as well as labor cost for the census, and therefore enable a cutback in the number of examiners. Actually, thanks to the introduction of a mail return system the UK succeeded in reducing the number of the census staff in 2001 to two-thirds of that in 1991.<sup>6</sup>

On the other hand, however, preparing multiple options would make the whole census process much more complicated, or sometimes more costly than expected, and may cause more errors or omissions. In fact, the US Census 2000 experienced a significant increase of the total errors and uncertain cases more than that in 1990.<sup>54</sup> It was also reported that by mistake 770 thousand households who had mailed their responses back were re-examined by a census examiner.<sup>6</sup> Meanwhile, it is true that this mailout/mailback system must depend on the individual high sense of responsibility to respond to the census without delay and without any omissions on the sheet. If each responder does not take this responsibility, extra work and costs for the subsequent follow-up visit will be required. In fact, the US Census 2000 had to employ 960 thousand examiners for the follow-up of 1.2 million fewer households in the end, causing the taxpayers to cost extra 35 dollars for each repeated visits to a single household.<sup>55</sup> Furthermore, however many promises are made to protect confidentiality through a change of the system of approaching the population, public resistance to what is viewed as intrusive in the census would not be satisfied because what most influences people's decision to cooperate with the census may not be attitudes about just confidentiality, but rather attitudes about privacy in general.<sup>56</sup> Now that the public sees a threat to privacy as a threat to confidentiality and vice versa, and this attitude towards privacy and confidentiality concerns would result in "a more diffuse, general, and perhaps extreme reaction to the census".<sup>57, 58</sup> Therefore, a mere introduction of a mailout/mailback system does not necessarily seem to solve many of the current problems over the census.

The government also views the application of the internet to the census as preferable.<sup>53</sup> However, even the application of internet does not seem a better option either. For example, Korea, which leads the world in the diffusion rate of internet and which has introduced internet into the census response, did not actually recommend a response via internet because it took long to input the Web-based census sheet and therefore a significant drop of the quality of response was anticipated.<sup>6</sup> Meanwhile, to build a Web-based census system requires huge amount of money. Despite of this fact, it is the reality that only one percent all households in Korea actually utilized the Web-based census in 2005.<sup>6</sup> Moreover, there is another concern about the use of internet for the census. What concerns people as well as the government is how one should protect personal information. The important question is whether the use of the internet really addresses this concern? The mass media reports almost every day a case of information leakage through the internet. Therefore, the premise that the use of internet in the census will secure individual information much better than the current collection method would probably be rejected by the public.

### **Conclusion and recommendations**

We have argued that concerns about privacy in conjunction with the introduction of data protection legislation in Japan have led to problems for the national census. The Government has mainly responded by changing data collection from the use of staff visiting homes to the use of a mailback system or use of the internet. We are doubtful that these will address peoples' privacy concerns and we think they will not increase the efficiency of data collection. In order to achieve that, we would recommend the following.

First, the data protection part of the Statistics Law governing the census should be strengthened. The Law as it stands now is exempt from the APPI and simply has a general requirement to protect confidentiality. Although some of the specific requirements of a general data protection law may not be applicable in the census settings, it would be necessary to provide specific enough safeguards to protect confidentiality to maintain public trust in the process. With the introduction of data protection legislation in Japan there is now a heightened awareness of issues of privacy among the public. It is therefore no longer sufficient for the Government to give a blanket exemption for the census with only a general provision for the protection of confidentiality.

One example of this approach might be the Data Protection Directive of the European Union.<sup>59</sup> This Directive applies to all processing of personal information, but exemptions are given if specified by national law or there is a substantial public interest in processing the data, subject to suitable specific safeguards. This requires even exempt to be subject to the general principles of data protection, and is preferable to the general exemption without conditions which is the current situation in Japan.

Second, concerning fraud or crimes during the census, measures applied in some communes in France could provide a useful model. In several communes there the census receives local publicity via the internet or on a public relations brochure, on which a photograph of each census examiner's face with her real name is open to the public.<sup>7</sup> This method seems very effective to prevent crimes relating to fraud on the response sheets or elsewhere. Moreover, it would be a good option to put a census poster with the designated examiner's face photo, her name, and a timetable of her visit to each household on the entrance wall of each apartment house. On the other hand, one possible concern over the introduction of these measures is that it may cause a critical fall in the number of potential census examiners, because they would also worry about their own privacy. Hence, cautious steps and further debate should be necessary over this matter.

Third, regarding training of the census examiners, the government should have a long-term vision of how to train census workers and, at the same time, how to maintain and ensure experienced and high-quality examiners. In fact, it was only 40.6% of the impromptu census officials in 2005 that have had a working experience as a census examiner before.<sup>6</sup> However, according to a post-census survey for the census officials in Yokohama City, in which their future willingness to work again as an examiner was studied, 53.6% of the officials refused an appointment, and only 17.3% answered they would take it again.<sup>60</sup> Without such a sustained vision, therefore, the census would not be able to keep the quality of data as well as the examiner's strong sense of responsibility for the census.

Fourth, the mass media should properly engage in and contribute to the process of re-building trust in the census between the public and the government. Most of the news concerning the Census 2005 appeared on the newspapers were one-sided that reported only the negative aspects or incidents concerning personal data collection in the course of the census. The media as well as public health scientists and policy-makers all must "have a part to play in ensuring accurate portrayals of research results and to engender an informed discussion" about the nature and the results of the census.<sup>18</sup> The news we referred to in this manuscript were all that the public in Japan could

know about the census in 2005, even though many of them might be based on un-evidenced assumptions or mere anecdotes about the census.

Fifth, the government needs to promote people's proper understanding of the nature of public research and the protection rules of privacy/confidentiality in the research process, fostering their responsible attitudes for others in the society. This cannot be achieved just through making policies or changing research system, but rather through moral education. To secure people's personal information is the government's responsibility. To join in the health/welfare policy-making is the people's moral responsibility and social obligation. Although fostering such ethics among the society would be a critical challenge, only trustful partnerships and a sense of shared moral endeavor can achieve valuable health/welfare policy-making and the real protection of privacy and confidentiality. Either the government's irresponsibility or the rapid chaotic growth of the sense of self and privacy would destroy Japan's public health in the very near future.

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## Commentary on Matsui and Lie's Paper

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Reading Matsui and Lie's paper, I tried to recall whether I had been interviewed by a census worker when the latest National Population Census was carried out, and then I was

astonished to realize that I have never experienced the Population Census interviews since I started living independently when I entered college almost 30 years ago. Judging from my experience, it seems that the census system has not properly functioned for a long period of time in Japan.

The authors' recommendations will surely be helpful to improve the current census system. Here, I would like to add some comments that came to my mind when reading their recommendations. First, the authors recommend training the census examiners and improving their skills as interviewers. While I believe this is an important step to improve the current system, I wonder whether the training of the examiners could actually increase the number of responses from ordinary citizens. Younger generations, especially living in big cities, have a strong sense of privacy, hence, some revolutionary ideas to persuade younger people to join the census are needed. Older generations are also hesitant to disclose their privacy because they fear someone might sneak a look inside their home and compare it with other people living nearby. They are afraid that they are compared with other people, and their way of living is judged to be different from the average lifestyle of their neighbors. When moving away to a new house, some housewives prefer their luggage on the carrier to be neatly covered so as not to be seen by anyone passing by. I believe this mentality should be one of the biggest obstacles we have to overcome. But anyway, I don't come up with any good ideas to solve this problem.

The second thing I would like to add is whether it is possible to explain to the respondents the reason why such and such questions should be indispensable to the census. Japanese people are becoming sensitive about their privacy, hence it might occur in the next national census that many respondents ask the census examiners about the purpose of the questions they are hesitant to response. They might ask the examiners why they have to answer, for example, their room size or the number of residents. In such a case, is it actually possible for the examiners to provide an adequate answer to that question? Matsui and Lie talk about a long-term training of census workers. I wonder if the content of such training programs is to contain an understanding of the theoretical background of census research, or just the know-how of answering frequently asked questions. Those who are hesitant to disclose their private information are usually very sensitive about the way how the information is to be utilized by the government. Hence, the required skill of census workers might become considerably higher than what is anticipated today.

It might be that the most effective way of collecting accurate data from ordinary citizens is to impose actual sanctions on those who refuse to disclose their private information, or to buy the data from private companies specializing in information gathering. Anyway, it is very difficult for the Japanese government to foster people's responsible attitudes for others, because many ordinary citizens do not believe in the morality of the Japanese government itself.

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# The Ethical Responsibility of Adopting the Precautionary Principle in the Guimaras Situation

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## Abstract

The basic condition of human existence is the urge to deal with the risks that are coupled with living in this world. Many of these risks emerge from the activities of human beings. After years of scientific, technological and industrial progress, human development has come to a point where it must control its effect on the biosphere that provides the basis for its existence.

The emergence of increasingly unpredictable, uncertain, and unquantifiable but possibly catastrophic risks has confronted societies with the need to develop an anticipatory model to protect humans and the environment against uncertain risks of human action. This model is the precautionary principle.

In this paper, the adoption of the precautionary principle as a guiding principle in performing the ethical responsibility of taking care of the environment was studied. The specific environmental dilemma that was investigated was the oil spill, which occurred in Guimaras, Philippines. The liabilities of those directly involved in the tragedy were examined and the precautionary steps that must be taken were discussed.

Aside from the ethical responsibility of the major players involved, the ethical responsibility of the common man was discussed as well. The "common man" is defined as someone not directly related or affected by the tragedy. Thus, I must start with my self to find out the reason behind my ethical responsibility since I am a common man. This is essential to relate the existence of the environment and human beings with each other.

The precautionary principle originated from the German principle of *Vorsorge*, or foresight. This refers to the early detection of dangers to health and the environment by comprehensive and harmonized research particularly about cause-and-effect relationships. This principle upholds the belief that society should seek to avoid environmental damage by careful forward planning. Thus, blocking the flow of potentially harmful activities. In the early 1970s, the *Vorsorgeprinzip* or foresight principle developed into a fundamental principle of German environmental law. It was balanced by principles of economic viability and has been used to justify the implementation of vigorous policies to tackle global warming and acid rain. In 1984, the precautionary principle was introduced at the First International Conference on Protection of the North Sea. Since then, the principle was integrated into numerous international conventions and agreements.

## Definitions of the Precautionary Principle

The precautionary principle has various definitions. One of the most commonly known is the Wingspread Statement on the Precautionary Principle (January 1998). It states that: "When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause-and-effect relationships are not fully established scientifically."

Threats of harm to human health or the environment refer to the following: (1) threatening to human life or health, or; (2) serious and effectively irreversible, or; (3) inequitable to present or future generations, or; (4) imposed without adequate consideration of the human rights of those affected.

There are five core elements that can be identified from the various definitions of the precautionary principle. These are: (1) protection of public health and the environment; (2) the requirement of more specific steps in precautionary decision-making when a particular activity is acknowledged as potentially harmful; (3) recognition of scientific uncertainty; (4) anticipatory action despite scientific uncertainty; and (5) shifting the burden of proof places responsibility on developers of potentially hazardous activities or technologies to demonstrate that an activity is necessary and no safer alternatives are present.

However, it is often the case that the probability that harm will take place cannot be calculated under conditions of uncertainty. Hence, it is important to find out how much evidence of harm is necessary before action is undertaken. The existing statements of the precautionary principle suggest that action should be done if there is reason to believe that harm will occur, or if harm is possible or plausible. This implies a weaker standard of evidence than strict causality or proof "beyond reasonable doubt" from experimental scientific data that are replicable and have low *p* values, which indicates the probability that the statistical test was due to chance.

There have been numerous tools for carrying out precautionary policies throughout the world. These include bans and phase-outs; alternatives assessment; clean production and pollution prevention; health-based occupational exposure limits; organic agriculture; ecosystem management; pre-market or pre-activity testing requirements; and reverse onus chemical listing. It is evident that these precautionary actions range from weak (intensive studying of a problem) to strong (prohibiting or phasing out a specific activity). Whenever possible, the said actions should be enforced at the design stage of a potentially hazardous activity to ensure their greatest impact.

It is important to examine whether the precautionary principle has validity before it can be adopted as an ethical responsibility on the environmental issue discussed in this paper. Hence, the objections must be identified as well as the answers pertaining to them. There are several charges against the precautionary principle relevant to its application in this paper. First is that the principle is ill-defined. This is a legitimate objection. However, it can be remedied because of the possibility to specify more precise versions of the principle. In addition, the various definitions of the precautionary principle have the same core elements, which were stated earlier. Another argument against the principle is the charge of absolutism. It states that since any action might have unforeseen catastrophic consequences, the action of carrying it out and not carrying it out will be prohibited. This is a

misconstruction because the principle requires that actions be taken in the absence of full scientific certainty and not in the absence of evidence when a possible hazard is present. Lastly, the most serious attack on the precautionary principle is the charge that it is unscientific. This argument seems convincing but an analysis of its key term “*unscientific*” tears it down. This is due to the fact that “*unscientific*” has two meanings. A statement is unscientific in the weak sense if it is not based on science while it is unscientific in the strong sense if it contradicts science. The precautionary principle is unscientific in the weak sense but then, so are all decision rules. In applying the precautionary principle, a decision-maker will use the same type of scientific evidence and assign the same relative weights to different kinds of evidence as a decision-maker who requires full scientific evidence before actions are taken.

### **The Guimaras Situation**

Guimaras is an island province found in the Philippines. It is located in the Panay Gulf of the Western Visayas region. The province is found between the islands of Panay and Negros. To the northwest of Guimaras is the province of Iloilo and to the southeast is Negros Occidental.

The main industries in the island province of Guimaras are tourism, coconut processing, fruit processing, handicrafts making, mining, quarrying and lime production. Its major products include coconuts, mangoes, palay, vegetables, fishes, livestock and poultry. The Guimaras island is famous for producing the sweetest mangoes in the world.

However, on August 11, 2006, the pristine island province was damaged due to the sinking of the oil tanker M/T Solar 1 at the Guimaras Strait. The oil tanker, contracted by Petron Corp. and owned by Sunshine Maritime Development Corp., carried 2.2 million liters of bunker fuel and caused 200,000 to 300,000 liters of oil to pour into the strait. Evidence of a continued oil leak had been observed weeks after the incident.

Due to the oil spill, marine sanctuaries and mangrove reserves in several municipalities were greatly damaged. In order to bring back to life the dead waters, cleanup and reestablishment efforts in mangroves, sea-grass beds and coral reefs must be performed.

People exposed to the toxicity have contracted skin and respiratory diseases. In addition, the livelihoods of 3,715 families in the island were affected. Also, the chief of the National Poison Management & Control Center on Tuesday warned that long-term exposure to bunker oil may result in cancer and congenital anomalies in unborn babies.

The sinking of M/T Solar 1 was attributed to three key factors: the loss of residual stability or overloading; the loss of reserved buoyancy due to bad weather; and the captain's incompetence. According to the report of the Philippine Coast Guard, the sea vessel was overloaded by approximately 150 tons. Also, M/T Solar 1 was unable to properly stay afloat because its loadline, or the markings, which show its safe buoyancy level, was adjusted from 1,220 mm to 700 mm. In addition, bad weather and prevailing Southwest Monsoon and the probable flooding of two ballast tanks was enough to force the vessel to turn upside down.

Thus, the government probers found Petron Corp., the shipping firm Sunshine Maritime Development Corp., its captain, and the maritime officials liable for the sinking of the M/T Solar 1. After scrutinizing the report of the Board of

Marine Inquiry (BMI), it was discovered by the Department of Transportation and Communication (DOTC) that Petron overloaded on industrial fuel at its port in Limay, Bataan. This caused instability to the M/T Solar 1 and rendered it unseaworthy for the voyage. On the other hand, the captain of the sea vessel, Captain Norberto Aguro, was found administratively liable of lacking adequate training, a disabling error of judgment and a disabling lack of knowledge. He failed to exercise due diligence in making the vessel seaworthy. Also, it was found out that Aguro's chemical tanker operations license with the Professional Regulation Commission already expired in 2002. Meanwhile, Sunshine Maritime was deemed administratively liable of completely disregarding all mandated regulations for the seaworthiness of its vessels. Also, it was declared that the Maritime Industry Authority (Marina) and the Philippine Coast Guard purportedly committed lapses in performing its mandated functions.

It is evident from the findings of the government probers that aside from bad weather, none of the other factors that caused the sinking of the M/T Solar 1 were natural and uncontrollable. Therefore, the disaster could have been averted if the main players involved took on the precautionary principle as a guiding principle in performing their duties and functions. Also, the damage that the disaster had brought on could be minimized through certain precautionary actions. In addition, other tragedies of the same nature and magnitude as Guimaras can be avoided as well by applying the precautionary principle.

### **Disaster Aversion**

As mentioned earlier, the main players liable in the Guimaras disaster were Petron Corp., the shipping firm Sunshine Maritime Development Corp., its captain, and the maritime officials. Aside from overloading the sea vessel, Petron Corp. committed the fatal error of hiring a single-hulled tanker to transport 2.2 million liters of fuel. This act increased the risk of spillage of the toxic material once the oil containers were breached. Another discovery was that the financial health of the tanker owner was inadequate for capitalization and operating funds to guarantee the safety of the cargo load. If Petron Corp. had considered the potential threats of harm that its activities could cause the environment and human health then, there would have been no Guimaras tragedy. Also, the company should have ensured that the shipping firm it contracted was more than capable of performing the duties that it was hired to do. The shipping firm, on the other hand, should have owned up to the limits of its capacities and did not agree to do a job it was incapable of doing. Also, it should have made sure that its employees had the competency of performing their work. The captain of the ship should not have been negligent and considered all factors significant to his duty and the transport of the oil. Petron Corp., the shipping firm, and its captain are not only guilty of negligence and the aforementioned errors but they are culpable as well of prioritizing profit over the risk of environmental degradation and its consequences on human health. The disaster could have been averted also if current shipping routes were set with the objective of protecting sensitive marine areas. Thus, the government did not perform its obligation of protecting productive and unspoiled natural resources in the country. Their regulatory powers could have been neutralized as well by

giving more weight to commercial interests than to the environment and human health.

### **Disaster Response**

It is crucial to apply the precautionary principle in a disaster response to avoid causing problems of greater magnitude. However, one must find the proper balance in this guiding principle. In the Guimaras incident, the slow response of the government, Petron Corp., and the shipping firm has been most disturbing. Petron chose to ignore the continued leakage of the oil.

The indecisiveness of the government, Petron Corp., and the shipping firm to ignore the serious threats of harm of not immediately removing the oil tanker will produce great repercussions to the environment and the people affected. They must employ the precautionary principle to remove the vessel because there is still two million liters of bunker fuel present. Something must be done now and not wait for the situation to worsen. Taking out the oil tanker entails a lot of uncertainty but the potential harm posed in waiting for more time before its removal is great enough for precautionary action to be employed. Evidence of this is the lost of livelihood and shelter of the people and the diseases obtained from exposure to the toxic materials.

On the other hand, the government fulfilled its responsibility of adopting the precautionary principle with respect to its immediate response of managing the health effects of the toxic oil debris. The Department of Health (DOH) recommended the pull out of pregnant women, children and the elderly, considered as high risk groups, from affected barangays. This is due to preliminary studies that aside from the short-term effects of skin and respiratory diseases, oil spills cause cancer and congenital anomalies in unborn babies in the long-term.

The precautionary principle was also important in evaluating the use of chemical dispersants in the oil spill. According to the Department of Science and Technology (DOST), there are results, which show that the effects of dispersants on living organisms are worse than the actual effects of the oil spill. Thus, in adopting the precautionary principle, considerations should have been made on whether the benefits desired outweighed the risk or harm.

### **Avoiding Another Guimaras Incident**

Oil companies, such as Petron Corp. must formulate standard operating procedures for the safe transport of their products to avoid another disaster of the same nature and magnitude as Guimaras. Also, the Department of Environment and Natural Resources (DENR) should prepare a coastal sensitivity atlas that will guide the formulation of navigation routes for the transport of oil and petroleum products or other toxic and hazardous substances across Philippine waters. With this, the immediate delineation of municipal waters will be implemented since it will define the zones of the delicate coastal environments that are necessary for the preparation of the atlas. Furthermore, the local governments will be allowed to effectively monitor any illegal disposal of wastes into their municipal waters. The conduct of resource valuation will also help determine environmental impacts that can be inputs into the formulation of policies.

As a precautionary measure, there should be contingency plans for oil spills. They are vital due to the practical plans of

action established for all types of oil spills. Therefore, when spills do occur, a quick response can minimize the damage.

### **Ethical Responsibility and the Responsibility of the Common Man in the Guimaras Tragedy**

The adoption of the precautionary principle in the various stages involved in the Guimaras tragedy is the ethical responsibility of Petron Corp., the shipping firm, its captain and the government. Employing the principle as a guide is the ethical responsibility of the common man as well. The common man is defined as someone who had no major and direct role in causing the Guimaras tragedy and was not directly affected by it. In order to understand the ethical responsibility of the common man in the Guimaras situation, I must understand the reason for my own ethical responsibility to the environment because I am a common man. Thus, the ethical responsibility that applies to me also applies to another common man.

The ethical responsibility to the environment and the precautionary principle are connected. The precautionary principle is a guiding principle that aims to protect the environment and human health from potential threats of serious harm. Humans have an ethical responsibility to take care of the environment. Thus, adopting this principle would achieve that objective. There are various philosophical concepts that support the ethical responsibility of humans to the environment. Thus, these concepts must be discussed in order to define and serve as a basis for the ethical responsibility of humans to the environment. Once this has been accomplished, the ethical responsibility of the major players in the Guimaras tragedy are established and the ethical responsibility of the common man may be examined.

### **Ethical Responsibility**

It is difficult for human beings to admit that they have committed a mistake. This is not only due to the consequences that their errors entail. One finds it hard to own up to one's mistakes because in admitting that one was wrong, one thinks that something is also wrong with oneself. Thus, one sees their actions as an extension of oneself. If one does not own up to one's actions then, one does not assume responsibility. Thus, ethical responsibility begins with owning up to one's actions. But this will only happen if people recognize that there are others who are more important than they are.

Emmanuel Levinas' concept of ethical responsibility discusses this. For Levinas, the Other is superior or prior to the self. The Other is the being that is not known to the self and whose Being is a mystery. In this case, the self has no knowledge of the Other, and yet the self is still responsible to the Other. According to him, the Other is represented by his or her face in the most ordinary, concrete, simple, and everyday life when the subject meets the Other. When we see the face of the Other, our conception of it is disrupted by it. The face of the Other demands not to confine it in the consciousness of the subject. Levinas argues that the encounter with the Other through the face reveals a certain poverty, which forbids a reduction to Sameness and, simultaneously, installs a responsibility for the Other in the self. Thus, the subject should not put or make the Other in the Sameness of the subject because it is tantamount to killing the Other. That is why the Other demands the subject: "*You shall not kill.*" It is the ethical responsibility of the subject to the Other. The face is

defenseless and powerless. The ego-centered subject, the I, can easily ignore it and kill it. But once the irreducibility of the Other is recognized, the I cannot avoid it. There is authority in it. It is not unusual that authority is often without power of force. According to Levinas, the face is actually an authority itself. It demands that I respond, not just with an ordinary response, but also with the greatest sense of responsibility since it is coming from the idea of the infinite as if it comes from God.

The environment must be recognized as the Other. An entity separate from human beings. The purpose of this is not to alienate the environment but to allow it to reveal itself. In doing this, it can be realized that the environment is prior to human beings. The Other is greater than us because it is unknown to us. The environment will exist without humans but the opposite is not true. Hence, extracting resources from the environment without replacing them and violence against the environment is not performing our ethical responsibility. It is not regarding the environment as the Other. It is treating the environment as something that exists only to serve humans. This self-serving attitude regards the environment as something lower than human beings. Therefore, the ethical responsibility is not performed.

In the Guimaras tragedy, the major players did not adopt the precautionary principle in their actions. They did not recognize the environment as the Other and proceeded haphazardly with activities that will only benefit them and performed violence towards the Other. The irreducibility of the environment as the Other was not recognized and in a sense killed it. They did not see that there was something more important than themselves. They did not recognize that their responsibilities extended beyond them. Even if they did view that they had a responsibility towards the environment, they did not have a face-to-face encounter with the environment. Thus, their idea of it was that the environment was as limited as their existence. Since that was the case, they thought that the environment revolved around their existence and that was the scope of their ethical responsibility. In applying Levinas' notion of ethical responsibility, we are recognizing that there is something more important than ourselves. The environment as the Other is not here to serve us. Instead, we have an ethical responsibility to take care of the environment from the moment of our conception.

### **Responsibility of the Common Man in the Guimaras Tragedy**

In the process of writing this paper, I had my own little version of the Guimaras tragedy experience. I was asked to analyze crude oil samples from Guimaras in my work. The mere opening of two 5-gallon containers of crude oil had quite a surprising effect. The crude oil samples were properly enclosed in containers, which had very small openings yet everybody at work had to wear double masks to minimize the fumes that they were breathing in despite the presence of several fume hoods. The fumes even diffused to another laboratory room. Some people complained of dizziness due to the crude oil.

However, this experience is incomparable to what the people who were directly affected by the Guimaras tragedy went through. They did not have fume hoods to minimize the toxic oil debris that they inhaled. They did not have masks to protect themselves. Also, the tanker contained 2.2 million liters of oil and not just a few gallons.

The said encounter may be insignificant in magnitude relative to what the people in Guimaras experienced and are still going through but it made me, the common man, empathize more with the people of Guimaras. It helped me see concretely my own ethical responsibility in the Guimaras tragedy. This is not because I feel that I know the situation of the people in Guimaras. I will not be able to fully grasp their experience. The thing that was achieved here was the realization that I truly have a responsibility in the tragedy because the people there, the environment and I have being.

Every being has the right to exist. The act of existence is diffusive. It is giving itself to others. Existing is sharing one's self. People do not exist solely for themselves. The existence of other entities must be respected in order to respect one's own existence. The common man has an ethical responsibility to the environment because they both exist on the being level and have Being. Thus, the common man must not exist and live only for himself because that will go against the nature of his existence.

On the other hand, if I did not have the encounter that I did and was not able to consciously experience any effects of Guimaras then, my basis for saying that I care about Guimaras must be examined because it appears that the tragedy has nothing to do with me. It would be rather easy to say that I care due to the environmental and economic implications brought about by the tragedy. However, that belongs to a more general scale of looking at things already. After the Guimaras oil spill, the environment that I experience everyday remained the same and I had the same financial standing as I did before the tragedy. Therefore, notwithstanding the encounter that I stated earlier, it is pertinent to ask why I, the common man, care about Guimaras. The answer to this is that it is my nature to care for Guimaras. This can be explained through the philosophy of Mencius.

According to Mencius, each of the fundamental Confucian virtues grows from sprouts already inside us. The two virtues that can explain the answer to the question stated are: (1) *jen* (or *ren*), "magnanimity" - spontaneous feelings of pity and human sympathy the innate human disposition when we see others suffer, or about to suffer; and (2) *li*, "propriety"-becoming habituated to doing what is right, so that we fortify our natural disposition towards moral behavior.

The two virtues explain the reason behind ethical responsibility taking place. However, it does not clarify how the act of ethical responsibility is initiated or started. The answer to this is that performing the ethical responsibility to the environment is not a means to something else. It is an end in itself. Taking care of the environment is a good and is a reward in itself. If this is kept in mind then the common man will be able to fulfill his ethical responsibility to the environment.

Although the environment and people exist both in the physical world, the environment is still superior to man. Thus, it must be treated as the Other and must be nurtured as it has nurtured us. Man must integrate itself to the environment because the environment has always regarded humans as part of its design.

### **Conclusions**

The disaster in Guimaras, Philippines could have been averted if the main players involved took on the precautionary principle as a guiding principle in performing their duties and

functions. Also, the damage that the disaster had brought on could be minimized through certain precautionary measures. In addition, other tragedies of the same nature and magnitude as Guimaras can be avoided as well by applying the precautionary principle.

In not adopting the precautionary principle, Petron Corp., Sunshine Maritime Development Corp., its captain, and the Maritime officials did not perform their ethical responsibility to the environment. This ethical responsibility is based on the fact that the environment is a superior entity and superior compared to humans. Prior to birth, human beings already have a duty towards the environment. The environment can exist without people but the opposite is not true.

Aside from the major players involved, the common man also has an ethical responsibility in the Guimaras tragedy. Since I am a common man, the reason for my ethical responsibility applies to another common man. Thus, examination of the basis of my duty towards the environment was vital. The ethical responsibility of the common man to the Guimaras incident and consequently to the environment is based on treating the environment as an end in itself and not as a means. Taking care of the environment is a good and is a reward in itself.

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## Factors Affecting Awareness regarding Arsenic Poisoning in Bangladesh

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#### Abstract

By the end of 1990s, more than 90% of the inhabitants of Bangladesh were habituated to use tube well water for drinking, cooking and other household affairs. However, since 1993, tube well water of most parts of the country was found contaminated with arsenic (an odorless and tasteless metallic poisonous substance) at a much higher level than is permissible (0.05 mg/liter). Arsenic consumed through drinking water can cause various types of diseases, including melanosis, keratosis, gangrene and cancer of the skin, and internal organs. Under the circumstances, it is necessary to make the people aware of the danger that they are in. The government, UNICEF and many other NGOs have launched campaigns using the media and other alternative means to make people aware of the danger of arsenic in drinking water. In spite of such efforts, it has been observed that awareness of the people at the desired level is still a far cry. In this paper, the factors that affect awareness level of people have been explored through analyzing findings of five separate studies. The nature of awareness campaign, prevalence rate of arsenic related diseases, income, education level appeared as socio-economic factors that affect awareness level of the respondents.

## Introduction

Arsenic (As) is a toxic, carcinogenic, semi-metal, odorless and tasteless element, belonging to the nitrogen family (HVR Arsenic Project 2000, Ahmed 2003). This element, dissolved in ground water in Bangladesh has created "the largest mass poisoning in history," putting about 30 million people at risk of disease and death (Smith 2000, Ahmed 2003). By the end of the 1990s, 90% of the people in Bangladesh developed the habit of using tube well water for drinking and cooking, through to the relentless efforts made by the government of Bangladesh and other world organizations. This indeed kept people almost free from water borne diseases like diarrhea and cholera, but exposed them to the risks of arsenicosis (diseases caused by arsenic).

As the tube wells in Bangladesh were not tested for arsenic when they were installed, it was not possible for anyone to know about arsenic contamination until 1993, when some people of Chapai Nawabganj district were found with several symptoms that pointed toward excess of arsenic in their food (and/or drink) intake. Similar symptoms had been observed in the neighboring province of West Bengal (India), where arsenicosis resulted from consumption of arsenic contaminated water of tube wells.

The DPHE and BGS (2000) in their survey found that, 53 districts had tube wells spewing water, containing arsenic above the danger level (0.05mg/litre). Arsenic content in groundwater in different parts of Bangladesh varied in between below the detection level (0.25microg/litre) and 1665microg/litre. The worst affected region is the south and southeast region. However, there were some pockets of contamination known as 'hot-spots' in areas, which were known to be generally free of the problem. Another study carried out by DCH and JU (2000) found that out of surveyed 60 districts, 41 had tube wells contaminated by arsenic above the danger level. In a certain area all tube wells may not be affected. Water of one tube well may be safe, with the one next to it highly contaminated. Moreover, if a tube well was spewing safe water six months ago, there is no guarantee that it would remain safe today. Therefore, it was necessary to test the water of all existing tube wells, and to monitor them regularly in order to ensure that people did not drink contaminated water. Screening of tube wells in the country has already been completed and different areas of the country were identified as extremely contaminated, highly contaminated, sporadically contaminated etc. (Ahmed 2003).

Arsenic is a well-recognized cancer-producing element (carcinogen). A long-term (e. g. 5 to 10 years) consumption of arsenic through drinking water may cause cancer of the bladder, lung, liver, kidney and skin. It also may lead to conjunctivitis, hyper-pigmentation, keratosis and gangrene (Mortoza 2000). Some of the symptoms of high amounts of arsenic are pigments/warts on skin, weakness, pains, aches, weight loss, nausea, and vision problems. Ingestion of arsenic is likely to produce not only physical diseases and symptoms, but also can cause mental mal-functioning, e.g., depression, mental retardation, stupor, convulsions, seizure etc. (Zuberi 2003). As we know, in most cases, cancer and gangrene are not curable. Smith et al. (2000) refer to the U.S. National Research Council (NRC) to state that exposure to 0.05 mg/liter of arsenic "could easily result in a combined cancer risk of 13 in 1000." In "Human Carcinogenicity of Inorganic Arsenic", Chen et al. (1997) have reported that by consumption of

arsenic contaminated water (0.01 mg/liter/day), the risk of developing skin, lung, bladder, kidney and liver cancer for women is 1.3/1000, 1.7/1000, 0.5/1000 and 0.4/1000 where as for men, the risk is 3/1000, 1.2/1000, 1.2/1000, 0.4/1000, and 0.4/1000 respectively.

Referring to simulation results based on arsenic related data on Samta village of Jessore district (a very badly affected village) Curry et al. (2000) predicted that after 30 years, 22% or more of the villagers would be suffering from arsenicosis and 5.5% of them were likely to die, had the people of this village not switched to a safe source of water.

There is no specific treatment available for patients with chronic arsenic toxicity. Safe water, nutritious food, multi-vitamins, and daily exercise are usually advised to such patients (DCH and JU (2000)).

Growing children are most vulnerable to arsenic toxicity. Skin lesions on the skin of such children could mean that they would eventually develop cancer. Pregnant women with arsenic related diseases are likely to have babies with higher amounts of arsenic than is normally found (Zuberi 2003).

Under the circumstances, the available alternative options that are open to the arsenic affected people in Bangladesh are:

- (1) Dug wells/Ring wells: The wells that have been excavated some years ago, without any concrete lining are called dug wells. Ring wells have concrete lining to protect it from microbial pathogens. It has been observed that though it also is groundwater, dug well/ring well water contains arsenic at a much lower level than found in tube well water. However, use of this water is affected by sub-soil fluctuations (Ahmed 2003).
- (2) Purified surface water: Two million hectares of land in Bangladesh is occupied rivers, canals, ponds, lakes and depressions. This water is safe from arsenic point of view, but must be either boiled or treated in some way to be protected from pathogenic microorganisms that cause water borne diseases (Ahmed 2003). Means of treating water include pond sand filter, ultra-violet disinfection unit, purifying tablets etc.
- (3) Deep tube well water: It has been observed that groundwater of wells more than 150 metres deep are mostly arsenic and micro-pathogen safe. However, there is possibility that these deeper layers are also going to be contaminated in the future.
- (4) Rainwater Harvesting: Rainwater in Bangladesh is pure (free from arsenic and micro pathogens). However, there is possibility that it can become contaminated during collection and storing.
- (5) Filtering (contaminated tube well water): There are quite a few types of arsenic removal technologies that have been approved by the concerned authorities. One problem in using these is sludge management—if not properly done, it could cause a greater catastrophe. In January 2007 'Sono Filter' invented by Professor Hussam and Dr. Munir was evaluated by the Environmental Protection Agency (USA) as environmentally safe. Thus this filter can make a breakthrough in providing safe water to the badly arsenic-hit people.

It must be stated here that not all options are suitable or feasible for all areas. Concerned authorities must take steps to inform people about what options would be available/suitable for them (Akmam 2002).

The description given above portrays arsenic related situation existing in Bangladesh. This calls for creating awareness among every inhabitant in Bangladesh, especially among those who live in areas already detected as highly contaminated. The government, UNICEF, the World Bank and many NGOs in different parts of the country undertook many awareness campaigns. A National Communication Strategy based on social marketing technique has been adopted to disseminate necessary information to the masses in the country on how they can address the problem (UNICEF 1999). In the first phase of the mitigation efforts (in a limited number of areas), the strategies used in order to build awareness among the people included radio-T.V. commercials, dramas, meetings with community leaders, workshops for health workers and other service providers, school-teachers and religious leaders, meetings with the villagers, distribution of leaflets, posters etc (BAMWSP 2002). The local governments and NGOs were involved in different stages of the program. All the tube wells in the area were tested and the people were informed whether it was safe for them to drink water from the tube wells, which they used. They were then helped to choose a safe water option. School meetings, village meetings and meetings with locally elected leaders (bodies) were used to disseminate the messages of the arsenic problem to the people. Workshops were arranged to train the stakeholders.

Nonetheless, the level of awareness observed among most respondents of quite a few studies is not satisfactory (Marshad 2006 and Zuberi 2003, Mahalder 2002, Hussain et al 2002). All these studies were carried out in areas where both NGOs and the government (DPHE) were involved. In order to make people fully aware of the danger that they themselves and their future generations are in, raising their level of awareness is a precondition. This would be an easier task if the factors that affect the level of awareness acquired by individuals can be identified. The present paper is an attempt to pin point these factors derived from five different studies including one carried out by the authors of this paper. Some suggestions have also been discussed with a view to raise awareness level of the arsenic affected people, and to convince them to drink from safe water sources.

### The meaning of "awareness"

According to the Concise Oxford Dictionary, the meaning of awareness is "knowledge or perception of something or fact." Another meaning of awareness goes further in depth, meaning "vigilance", and taking the most rational decision in response to the "knowledge" acquired. For example, if residents living in a building try to evacuate in a correct manner after hearing a fire alarm proves that they are fully aware of the situation. In case of arsenic poisoning in Bangladesh, it is expected that the 'aware' affected people would know

- (1) that arsenic is a colourless, tasteless poison;
- (2) that arsenic contaminated water of tube wells is dangerous to their health, and can produce many types of diseases, including cancer and gangrene which lead to a slow but miserable death;
- (3) that high amounts of arsenic flow from the womb of the mother to the baby, and that growing children are most susceptible to the poisoning;
- (4) that water for both drinking and cooking must be safe, as arsenic is not lessened even when water is boiled.

- (5) about the safe water options that are available and suitable for them;
- (6) that arsenicosis is not contagious and if already diagnosed, immediate treatment would be safe water, nutritious food and vitamins;
- (7) that arsenic problem is not a curse of God, and can be overcome through adopting appropriate measures.

The authors of the current paper are of the same opinion as that of Zuberi (2003) that those with the highest level of awareness must *know about arsenic, the mitigation steps and adopt these steps permanently*. This requires a change in habit, taste, budget, and even daily work plans. Those with the highest level of awareness should be willing to accept these changes.

The studies referred to in this paper were not conducted with the same objectives; and the term "awareness" was not defined in the same way. For example, the source of awareness in the study carried out by Hadi (2003), which differed from the study carried out by Marshad (2006) and Zuberi (2003). Hence it is not actually possible to compare their results. Nonetheless we can identify the factors that influence the different criteria of peoples' awareness. Therefore, findings of each study are discussed separately and comments are made at the end.

### Factors affecting awareness level

Marshad (2006) carried out his study in a village named Khajadanga in the district of Khulna. In the screening tests of tube wells carried out by Bangladesh Arsenic Mitigation and Water Supply Project (BAMWSP) in this area (union), 77% of the tube wells were found contaminated. However, in Khajadanga Marshad found that 10% of the tube wells in the village were not screened. Sixty four percent of the tube wells that had been screened were found to contain arsenic beyond the level of .05mg/litre. Thirty two percent of the respondents said that they did not know about arsenic, although the government institution of Department of Public Health Engineering (DPHE) and NGOs have been working in the area for the purpose of raising awareness of arsenic among the people, apart from other initiatives as radio/T.V. commercials, leaflets, billboard advertisements. Only 26% of the respondents used safe water, the source of which was deep tube well. This is a very discouraging situation. The main reasons that the respondents pointed out were that they were habituated to using tube well water and were not willing to change it; the source of safe water was too far away and that arsenic removal instruments were not available.

In order to measure the level of awareness of the respondents (heads of households, who usually make decisions on family matters), Marshad developed a nine-point scale. The highest level the respondents could reach was five. Only two patients of arsenicosis had been found in Marshad's study. It might be one of the reasons for their low level of awareness. The factors that could statistically explain for the differences in acquisition of awareness levels among respondents were education and income. Respondents with higher levels of education and income were more likely to have higher levels of awareness. He also interviewed the female head of household of each of the households in his study and found that the level



of awareness of the female head is significantly related to the level of awareness of the male head.

Md. Jakariya's (2000) study was titled "The use of alternative safe water options to mitigate the arsenic problem in Bangladesh: a community perspective." He worked in two villages (Vhagolpur of Narayanganj district and Kamarpara of Jessore district). In order to have an idea about the awareness of the people regarding arsenic, he did not measure their level of awareness, but rather asked whether they thought arsenic was a problem. He found that 90% of the respondents in Vhagolpur and 96% in Kamarpara answered in the affirmative, although 80% of the respondents in Vhagolpur and 14% in Kamarpara were still using contaminated tube well water.

Jakariya (2000) tested whether age of the respondents had any influence on awareness. The result was that 82% of the respondents in Vhagolpur and 100% in Kamarpara below the age of 50 recognized excess of arsenic in tube well water as a problem, however, in both villages, most (66%) of those above that age did not recognize it as a problem. Thus age was identified as an influencing factor.

Jakariya (2000) also tested if any difference was made by literacy. The finding was that in Kamarpara all the literates and 89% of the illiterates recognized excess of arsenic in tube well water as a problem. Among the illiterates 56% in Vhagolpur and 11% in Kamarpara did not think it was a problem. Thus it was observed that education had a greater influence on awareness in Vhagolpur. As far as income of the respondents was concerned Jakariya (2000) concluded that in Vhagolpur it is a significant factor, however, it is not so in Kamarpara.

In this study, ownership of radio and television did not seem to have any impact on awareness. In Vhagolpur, 84% and 78% of the respondents owned radio and television respectively, having an awareness rate of 90% and in Kamarpara, radio and television were owned by 38% and 25% of the respondents respectively, with 96% of the respondents being aware.

The study by Zuberi (2003) is basically an assessment report commissioned by AMP-Christian Aid (UK) focusing on awareness, communication and scaling up. It was carried out in different districts of western Bangladesh. The table below will explain findings regarding level of awareness of his respondents:

Zuberi (2003) found that the level of awareness of women was of similar level to males in his study areas, despite the fact that women are customarily habituated to stay at home, and are not much exposed to outside events. This was possible as a result of especially targeting women, employing women trainers and animators.

Instead of identifying the factors that affect awareness level of the target population, Zuberi (2003) delved into the reasons for which awareness level of the respondents were low, in spite of awareness campaigns carried out in his study areas. In so doing, he referred to these factors:

- (1) Literacy of the respondents
- (2) Nature of communication materials
- (3) Nature of presenting the information
- (4) Availability and proximity of safe water sources
- (5) Existing beliefs and ideas
- (6) Unacceptability of the prescribed option

(1) Literacy of the respondents: Lower literacy rates of villagers have inhibited them from understanding the communication materials properly, which resulted in their lower level of awareness;

(2) Nature of communication materials: The materials used to inform the people-- especially the illiterate-- about arsenic were not appropriate for them to grasp easily. The materials should be presented to them repeatedly with intensive interaction in a convincing manner.

(3) Nature of presenting information: Presentation of information in a negative way is likely to have a negative impact. For example, people become pessimistic when they hear that there is no specific treatment for arsenic toxicity. They must know at the same time about the hopes that they have if they stop drinking contaminated water and eat nutritious food. The latter should be more emphasized in order to convince people to switch to safe water options.

(4) Availability and proximity of safe water sources: When people are prescribed to switch to a safe water option, they must have the options available at close vicinity. If acceptable safe water options are not available, the respondents lose their chance of acquiring the highest level of awareness and remain at the same risk.

(5) Existing beliefs and ideas: There is fatalistic belief among people in Bangladesh that they cannot 'erase' what is already destined for them. Considering arsenic toxicity as a curse of God, and that there is no way they can come out of it, they are reluctant to pay attention to the messages delivered to them by the campaign workers. Moreover, as in the previous days, many had their tube wells sunk within their house or at a close proximity almost free of cost. So, their idea is that if they had to switch to other water sources, it is the duty of the government/donor agencies to supply them with safe water free of cost and at an acceptable distance.

(6) Unacceptability of the prescribed option: Often the campaigners prescribe safe water options, which are not acceptable to the target people. Peoples' desires and feasibility must be taken into account in planning mitigation programmes.

Zuberi (2003:14) has also mentioned a state of 'confusing interaction' as a factor affecting awareness building on arsenic. This is a situation "[w]hen there is a conflict between existing knowledge and new information; there is more confusion when new knowledge is incomplete, not articulated and difficult to understand." Since the 1970s people have been hearing from government officials/NGO workers that tube well water was the safest option for them as surface water contained germs that cause water borne diseases. When they were all habituated to drinking tube well water, it was difficult for them to believe that all of a sudden the so-called safe water had become deadly, as they could see no change in the colour/odor of the water. The new information they are coming across is also difficult for them to understand. Thus they remain at a state of 'confusing interaction' regarding what would be safe for them to drink.

Table 1 Awareness level of the villagers in the study areas

| Area             | Villages                | Seven scale awareness scores |    |    |    |   |   |   |    |
|------------------|-------------------------|------------------------------|----|----|----|---|---|---|----|
|                  |                         | 1                            | 2  | 3  | 4  | 5 | 6 | 7 | N  |
| Pabna            | Saradangi, Kashinathpur | 2                            | 6  | 12 | 12 | 8 | - | - | 40 |
| Meherpur         | Bholadanga, Alampur     | 3                            | 4  | 8  | 6  | 2 | - | - | 23 |
| Pabna            | Syedpur, Sujanagar      | 1                            | 10 | 6  | 2  | - | - | - | 19 |
| Chapai Nawabganj | Uporajrampur, Durgapur  | 1                            | 6  | 8  | 6  | 8 | - | - | 29 |
| Chapai Nawabganj | Bhatutola               | 2                            | 4  | 10 | 3  | 1 | - | - | 20 |
| Bera             | GK School Class 4 & 5   | 2                            | 3  | 6  | 10 | 9 | - | - | 30 |

Source: Adapted from Zuberi (2003 Table 2)

Table 2: Odds ratios for selected issues of arsenic knowledge

| Study Variable           | Arsenic Knowledge  |                      |                      |                   |
|--------------------------|--------------------|----------------------|----------------------|-------------------|
|                          | Safe water options | Signs of arsenicosis | Mode of transmission | Type of treatment |
| Study area               |                    |                      |                      |                   |
| Comparison               | 1.00               | 1.00                 | 1.00                 | 1.00              |
| Mitigation               | 6.71**             | 9.02**               | 4.55**               | 3.93**            |
| Age (years)              | 0.99               | 0.98**               | 0.97**               | 0.94**            |
| Sex                      |                    |                      |                      |                   |
| Male                     | 1.00               | 1.00                 | 1.00                 | 1.00              |
| Female                   | 0.94               | 1.01                 | 0.90                 | 0.71              |
| Years of Schooling       |                    |                      |                      |                   |
| No school                | 1.00               | 1.00                 | 1.00                 | 1.00              |
| 1-5                      | 1.34               | 1.11                 | 1.28                 | 1.18              |
| ≥ 6                      | 1.56*              | 1.49*                | 2.58**               | 1.11              |
| Land ownership (decimal) | 1.01               | 1.01                 | 1.01                 | 1.01              |
| Income source            |                    |                      |                      |                   |
| Selling labour           | 1.00               | 1.00                 | 1.00                 | 1.00              |
| Others                   | 0.76               | 1.11                 | 1.21                 | 1.28              |
| Exposure to Media        |                    |                      |                      |                   |
| Not Exposed              | 1.00               | 1.00                 | 1.00                 | 1.00              |
| Occasional               | 1.48*              | 1.22                 | 1.05                 | 0.88              |
| Frequent                 | 2.80**             | 1.66*                | 2.52**               | 1.34              |
| -2 Log likelihood        | 1213.2             | 1152.1               | 1239.9               | 464.3             |
| Pseudo R squared         | 0.231              | 0.294                | 0.196                | 0.154             |

Source: Hadi (2003: Table 5)

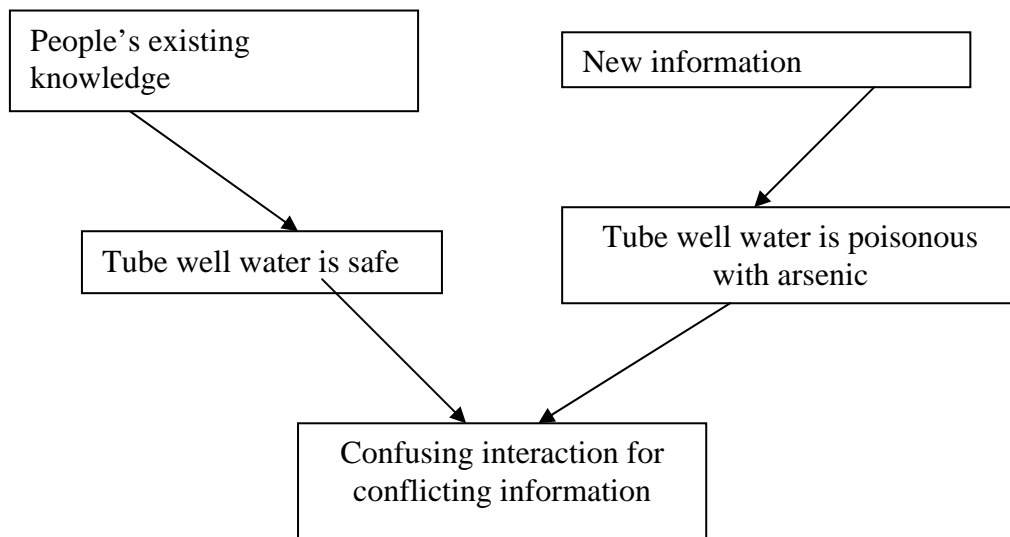


Figure 1: State of confusing interaction [Source: Zuberi (2003:15)]

Hadi's (2003) study was also an evaluation study—measuring how far the awareness campaign of Bangladesh Rural Advancement Committee (BRAC) was successful. For the purpose of his study, he took a 'mitigation area' and a 'comparison area'. In this study the author did not have any section indicating the sources from which the respondents were actually drinking water. In his definition of awareness, drinking from safe water sources was not included. Selecting the socio-economic variables of age, sex, years of schooling, land ownership, family income source and exposure to media, Hadi (2003) tested whether these variables had any influence on the respondents' knowledge on safe water options, signs of arsenicosis, mode of transmission, and the type of treatment using bi-variate correlation (logit model). In Table 2 we find that according to Hadi's study, the factors that significantly affect awareness level of respondents were exposure to awareness campaigns, age, years of schooling and exposure to media.

To conclude, Hadi's (2003:99) comments were: *"Although this demonstrates that perceptions on arsenic issues can be changed and argues that programme efforts can be changed and argues that programme efforts can create the context for the greater behavioural change, it is clear that such intervention alone can have little significant impact in reducing the magnitude of the problem. Therefore, policy-makers, scientists and activists should come together to develop strategies and motivate the government and others to initiate innovations to properly address the problem."*

In the study carried out by Akmam and Islam (2006) data have been collected in 2000 and 2005 in the same village to discover the changes regarding arsenic related situation in a badly affected village named Taranagar in Meherpur district. For this study a five-point awareness scale was developed. To achieve the highest level, five, one had to (a) actually drink from safe water source; (b) demonstrate his/her full knowledge of the items mentioned in the section 'Meaning of Awareness' and (c) have willingness to donate for the establishment of safe water source, to pay every month for maintenance, and to give labour for the establishment and maintenance of the safe water source. While determining their level of awareness, financial and physical conditions of the respondents were taken into account.

The comparison of arsenic related situation in Taranagar village in 2000 and 2005 as depicted in Akmam and Islam (2006) is shown in Table 3. More than 99% of the respondents used tube well water for drinking and cooking in 2000. Therefore, Table 4 shows the sources of drinking water for respondents in 2005 only.

**Table 3: Arsenic related situation in Taranagar in 2000 and 2005**

| Criterion  | 2000   | 2005   |
|--|--------|--------|
| Tube wells tested  | 58.95% | 92.68% |
| Contaminated tube well   | 80.64% | 92.69% |
| Households with patients                                       | 70.2%  | 90%    |
| Households still drinking arsenic contaminated tube well water | 99%    | 46.8%  |

**Table 4: Kind of Water Used for Drinking in 2005**

| Water used for drinking  | Frequency | Percent |
|--------------------------|-----------|---------|
| Dug well water           | 50        | 28.6    |
| Filtered tube well water | 1         | 0.6     |
| Ring well water          | 42        | 24.0    |
| Tube well water          | 82        | 46.8    |
| Total                    | 175       | 100.0   |

Source: Akmam and Islam (2006)

It must be mentioned here that apart from national awareness campaigns disseminating messages through different forms of media (radio, T.V., newspapers, leaflets, billboards etc.), the Department of Public Health Engineering (DPHE) and three NGOs (EADS, Podokkhep and Kranti) were also involved in raising awareness among the people residing in the study area by delivering necessary information on the arsenic problem, testing tube well water, and providing villagers with a few ring wells (Akmam and Islam 2006).

Table 4 portrays that even after being exposed to such awareness campaigns, only 52% of the households were using dug well/ring well water for drinking (but not for cooking, as the sources were very far away). There was complaint that water of ring wells often had bad odor. Thus in spite of having patients in their households, and seeing five of their fellow villagers die of arsenicosis, 46.8% of households continued to drink from contaminated tube wells. The reasons that the respondents mentioned for not drinking water from safe sources were that they were not willing to change their habit regarding drinking tube well water; and that there were no alternative sources of drinking water available to them within reasonable distance. As it appears from Table 4, Taranagar residents did not know about arsenic filters as an alternative option for safe water. This could be due to incomplete information delivered to the affected people.

**Table 5: Awareness Level of the Respondents in 2000 and 2005**

| Awareness Level | 2000      |       | 2005      |       |
|-----------------|-----------|-------|-----------|-------|
|                 | Frequency | %     | Frequency | %     |
| 1.00            | 25        | 26.3  | 21        | 12.0  |
| 2.00            | 30        | 31.6  | 58        | 33.1  |
| 3.00            | 29        | 30.5  | 36        | 20.6  |
| 4.00            | 11        | 11.6  | 48        | 27.4  |
| 5.00            | 0         | 00.0  | 12        | 6.9   |
| Total           | 95        | 100.0 | 175       | 100.0 |

Table 5 shows that the awareness level had significantly raised in 2005 as compared to that in 2000. One reason for could be that five people in the village had already died of arsenicosis in between 2000 and 2005. Using SPSS software, statistical tests were performed to find the relationship between awareness level of respondents and other relevant independent variables, such as land holding, income, education and having patient in household etc. Results of Chi-square tests pointed out that in 2005 significant association existed between awareness level and relevant factors such as "average

schooling years (5.232; d.f. 1; significance level: 0.022), income (7.006; d.f. 1; significance level: 0.008), occupation (20.937; d.f. 1; significance level: 0.000) and (arsenicosis) patient in household (3.734; d.f. 1; significance level: 0.053)." (Akmam and Islam 2006:7).

### Discussion and suggestions

In the findings of studies discussed above it is observed that in all the studies education has been identified as a factor that significantly affects awareness of arsenic among the people in Bangladesh.

Some pitfalls of the awareness campaigns have been detected, particularly in the study carried out by Zuberi (2003). In his opinion screening of tube wells should have had mitigation programmes attached to it. The messages should have been delivered in a manner understandable to literates and illiterates and repeated at short intervals. Instead of only emphasizing the fact that there is no cure to arsenic toxicity, people must realize through awareness campaigns that they still have a hope to live a healthy life if they drink from safe water sources. Thus the nature of awareness campaigns had significantly affected the awareness level of respondents.

Age of the respondents also appeared to be a significant factor. When old people heard that arsenic poisoning is likely to cause death after some time (not immediately), their response was that they did not expect to live very much longer any way. So they should not bother about it (Hadi 2003). Thus awareness level of younger people was greater than that of the old.

Exposure to media appeared as a significant factor affecting peoples' awareness in Hadi's (2003) study, but it was not so in Jakariya's research findings (2000). In Jakariya's (2000) findings, awareness of the respondents in Vagholpur was significantly related to education of respondents, but not as much in Kamarpara. In Akmam and Islam (2006) average schooling years (ASY) of household had significant relationship with awareness level. Average schooling years was the mean of the schooling years of all members of households who were seven years old or above. Those with higher ASY were likely to have greater exposure to the awareness campaigns, and have greater capacity to grasp and act upon such information. Information can be disseminated by a person with relatively higher level of education to others living in the same household, contributing to higher level of awareness for all members.

Income has been identified as a significant factor that affects awareness levels in Marshad (2006) and in Akmam and Islam (2006). It was also mentioned in Hadi's study (2003:96) that awareness programmes alone could not bring about behavioural change, especially among the economically marginal groups. In Akmam and Islam (2006) occupation (labourer/non-labourer) also appeared as a factor affecting awareness level. Those engaged in manual labour were mostly weak in both income and education, leading to their lower level of awareness.

Often having one or more arsenicosis patient(s) in household influences the level of awareness greatly. This was observed in Akmam and Islam (2006) as well as in Jakariya (2000). Jakariya surmised that the influence of education was not as much a significant factor in Kamarpara as in Vhagolpur as there were many more people suffering from arsenicosis in this village.

It has also been observed in several of these studies that respondents did not drink from safe water sources (even after knowing that their regular source is not safe), for three main reasons—(a) habit, (b) no acceptable alternative source, (c) the safe source is too far away.

From what has been discussed so far, it is clear that in order to raise the level of awareness of people to the top level in which they would establish the habit of drinking from safe water sources, it is necessary to provide them with acceptable safe water source within a reasonable distance from their home compound and to 'convince' them properly. This task could be accomplished if we take the following measures, as suggested in Khanum et al. (2003):

(1) *Raising Risk Awareness*: It is necessary to make the people understand the risks involved in continuing to drink arsenic contaminated water, without raising panic. It must be explained to them explicitly that by continuing their old habit, they face the risk of having different types of cancer—of the skin, lungs, kidney, bladder etc., which do not always show overt symptoms, and are rarely curable diseases. But they have a higher probability of not getting such diseases, or even chances of being cured (on early diagnosis) if they immediately change their habit.

(2) *Holding Periodic Village Meetings*: In order to explain arsenic related information to the people, e.g., what arsenic is, its effects, symptoms of arsenicosis and its treatment and above all, the feasible options open to the villagers, village meetings or small group meetings can be arranged. Ordinary villagers are to attend these meetings, in the presence of Chairman/members of the Union Parishad (a local administrative authority unit), religious leaders, teachers, highly educated people hailing from the village, known as knowledgeable and are trusted by the villagers, solvent/wealthy section of the village, who might be convinced that donating a good amount for the maintenance of safe water sources would be a useful and great philanthropic deed contributing to save lives, and of course, students and field workers who will be practically working in the village for mitigation purposes.

(3) *Applying Guilt Appeal and Ridicule*: The former mechanism can be applied by explaining how the children are likely to grow up as a diseased generation because of their reluctance regarding ensuring consumption of safe water for all in the household. 'Ridicule' can be applied-- for example, by showing how arsenic can be "victorious" over humans as a result of peoples' decisions not to change their habits of drinking water from tube wells (which were not safe)—can also be successful in convincing the people that it is truly urgent for them to switch to a safe water system. The change in habit made by influential persons in the community, and by those whom the people believe to be *knowledgeable and trustable* is likely to have a very positive effect. *Knowledgeable and trustable* persons may include religious leaders, teachers, and highly educated persons of the village serving as high-ranking officials inside/outside the village. If these 'role models' come forward in encouraging people to drink from safe water sources, it is more likely to produce a good result.

(4) *Efficient Cost Management*: For community based safe water options, which require a substantial amount of money for construction, the establishment cost has to be provided from outside the village, and the villagers have to pay for the maintenance.

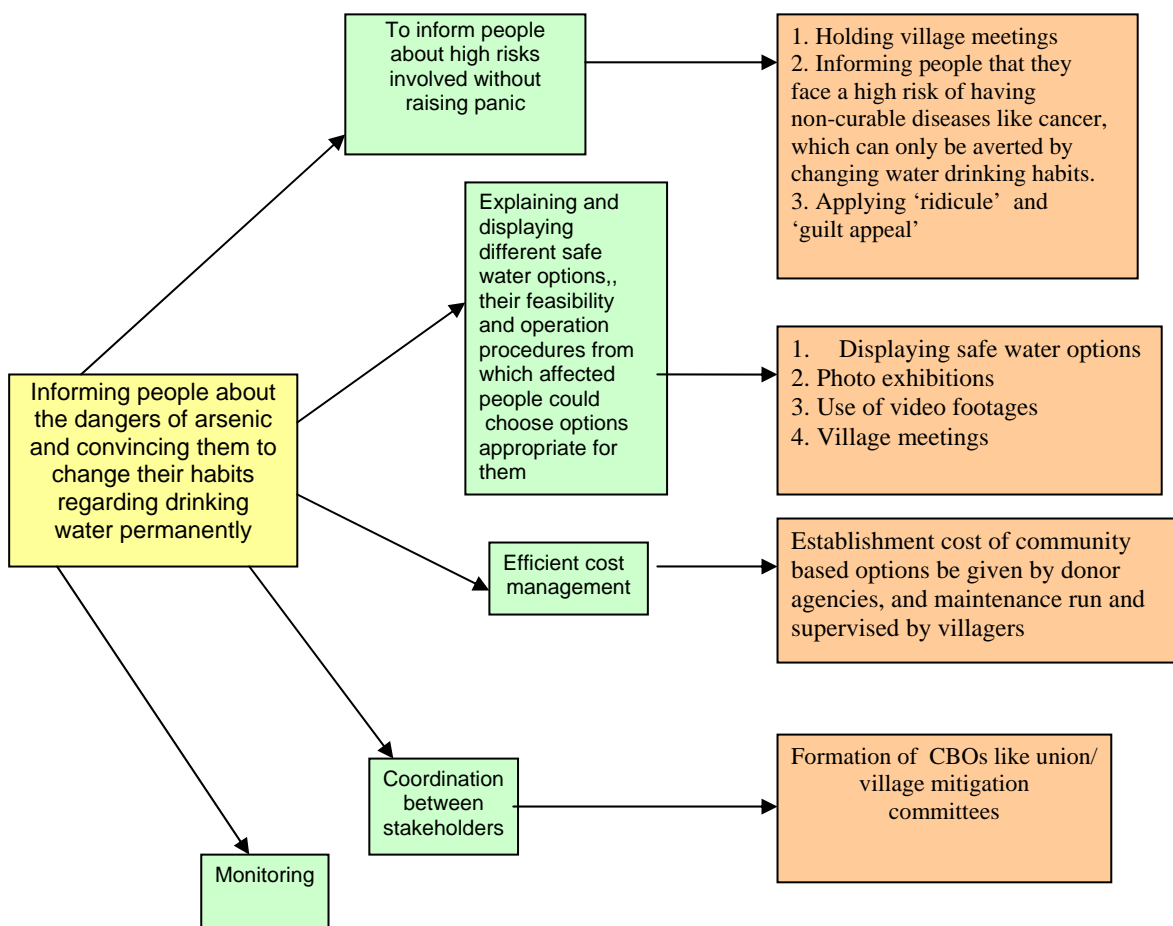


Figure 2: Ways to convince people to switch from contaminated sources to safe water options

Source: Modified from Khanum et al. (2003)

(5) *Formation of Village Committees:* Community based organizations (CBO) such as village committees are to be formed to coordinate the continuous process of mitigating the arsenic calamity at local levels (a combination of repeating awareness information and providing safe water options). Everyone in the committee should know what job they have to do and be responsible to the committee.

(6) *Demonstration of Functioning of the Safe Water Options:* Operation of each of the safe water options must be clearly demonstrated. Photo exhibitions, video footages could help the audience understand the process better. Provisions should be made to properly answer all the questions in the minds of the people.

(7) *Continuous Monitoring:* Regular monitoring has to be ensured by establishing a laboratory to test the arsenic in water samples (one laboratory enough for one district). High school/college students can be engaged in collecting water samples from drinking water sources and monitoring them not only for arsenic but also for Coliform bacteria, and other substances that are detrimental to human health.

(8) *Continued Motivational Communications:* Meanwhile, motivational communications must be continued through the media and through the trusted and influential personalities of the village. All items that need to be informed to the people to ensure the highest level of awareness must be

conveyed through these communication procedures. Although traditionally women in Bangladesh do the work of bringing necessary water for all the household members, both male and female members of household can share the job. Where feasible, employing villagers as water bearers could be an option. They could perform this job by collecting safe water in well-protected pots using a rickshaw van. In a nutshell, the whole process is shown in Figure 2.

### Conclusion

In this paper, factors that influence awareness level of the people have been discussed. Some possible ways in which people's awareness can be raised to the level that they actually drink from safe water sources have also been pointed out. We must remember that most people in Bangladesh, especially in the rural areas are poor with low level of education. Moreover, there is an established idea in the minds of the people that safe water is not something they should pay for—rather, it should be provided to them by the government and/or donor agencies free of cost, just the way they got the tube wells as safe water sources until 1993. After being used to the facility of tube wells within or very close to one's home compound, it is difficult to get accustomed to bringing water for everyone (it is assumed that per head water consumption for drinking and cooking is 5 litres) in the household. Policy planners must

consider these points in order to assure safe water supply to the arsenic affected people in Bangladesh. However, for the areas, which are very badly hit, it would be a good idea to provide the very badly hit areas with arsenic filters, preferably, Sono-filters.

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