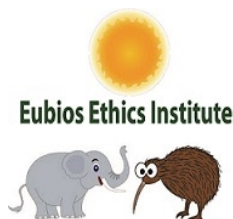


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### Editorial: New ABA Board

This issue includes 8 excellent papers, thanks to the authors, with some original data from public health studies, and bioethical reflection from disasters to compassion.

During the 15<sup>th</sup> Asian Bioethics Conference in Japan, 1-9 November 2014, we saw the election of the new Board of the Asian Bioethics Association, and also expressed thanks to the ABA Board members whose terms have ceased. The 16<sup>th</sup> Asian Bioethics Conference will be held in Boracay, the Philippines, 3-8 November 2015.

The new ABA Board is:

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Other key positions:

Publicity Committee Chair: Prof. Latifah Amin (Malaysia)  
Fund Raising Committee Chair: Prof. Nader Ghotbi (Japan/Iran)  
ABA Logo Development Committee Chair: Ms. Ananya Tritipthumrongchok (Thailand)  
2015 ABC16 Scientific Committee: Prof. Marlon Lofredo (the Philippines)

On this page there is the Asian Bioethics Association logo, which was chosen from over a dozen candidate logos, in a process that saw several rounds of voting and improvements. In appreciation of the logo design and as a reward for the competition – Mr. Faidh Hussein, Sr. Daphne Furtado, Mr. Muhammad Ziaul Huq and Prof. Marlon Lofredo – have been provided lifetime membership in the Asian Bioethics Association (ABA). We appreciate the efforts of Ms. Ananya Tritipthumrongchok for arranging the logo process, and Mr. Hasan Erbay, and others for their submissions and suggestions. We look forward to seeing many persons at ABC16 in 2015, and express appreciation to Prof. Nader Ghotbi, Prof. Takao Takahashi and Dr. Kayo Uejima for their efforts in holding a successful ABC15 in Japan.

- Darryl Macer

# Quality of life and palliative care needs of patients with Niigata Minamata disease: A complete survey after 50 years since the disaster

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## Abstract

**Background:** Minamata disease (MD) is caused by the ingestion of a large amount of fish or shellfish contaminated with MeHg included in industrial wastewater. In 1965, a number of cases were found along the Agano River in Niigata Prefecture in northern central Japan, which were collectively designated as “Niigata Minamata disease.” Patients with MD suffer from a set of complicated pains accompanied by various signs and symptoms. They also have mental and social pains, including loss of identity, stigmatization that leads to the refusal of friendship and marriage, and isolation in the local community. However, few studies have investigated the care and prevention measures required to relieve the symptoms of patients with MD.

**Aim:** The objective of this survey was to investigate the symptoms, pain, and suffering experienced by patients with Niigata Minamata disease as well as their QOL and coping strategies.

**Design and setting:** The survey was designed as a complete study of patients with MD accessible to the local government of Niigata Prefecture and that of Niigata City.

**Results:** The average score of the study subjects in the World Health Organization Quality of Life 26 (WHO/QOL-26) was considerably lower than that of the general population, while being female and having an occupation correlated with higher scores for some domains and/or overall QOL scores. The symptoms perceived by the subjects as distressing in their daily lives included numbness in the limbs, physical pain, disturbed sensory systems, limb dysfunctions, and fatigability. The measures commonly taken to relieve these symptoms included using medicines, taking a bath/going to springs, and maintaining warmth. The common emotional support included interpersonal relationships, emotional fulfillment, self-discipline in daily life, and bodily health. Those certified as having MD showed no significant difference in any domains and overall QOL.

**Conclusions:** Palliative care providers should extend their targets for non-cancer palliative care and develop approaches for MD-specific total pain.

**Key words:** Quality of life, palliative care, Niigata Minamata disease, bioethics, complete survey

## Introduction

Minamata disease (MD) was identified in the coast of Minamata Bay in Kumamoto Prefecture in southern Japan in 1956.<sup>1</sup> MD is caused by the ingestion of a large amount of fish or shellfish contaminated with MeHg included in industrial wastewater. In 1965, similar but relatively milder cases were found along the Agano River in Niigata Prefecture in northern central Japan, which were collectively designated as the “Second Minamata Disease” or “Niigata Minamata Disease.”<sup>2</sup> Patients with MD suffer from a set of complicated pains accompanied by various signs and symptoms, including

sensory disturbance in the distal parts of the extremities, ataxia, disequilibrium, bilateral concentric constriction of the visual fields, impaired gait and speech, muscle weakness, tremor, abnormal eye movement, and hearing impairment. Mental disorders and disturbed taste and smell also occur occasionally. Patients also have mental and social problems, including loss of identity as a worker or a fisherman, stigmatization that leads to the refusal of friendship and marriage, and isolation in the local community caused by a diffused prejudice that the disease is contagious.<sup>3</sup>

As of May 2013, 702 patients in the aggregate were officially certified as having MD in Niigata, whereas for 1,376, the application was turned down.<sup>4</sup> The strict criterion that requires the full set of symptoms to be present for certification as a patient with MD has generated a sense of unfairness among patients and caused divisions.<sup>5</sup> It has also been criticized by the Supreme Court, which ruled in 2004 that a person with a single symptom should also be recognized as a patient with MD.<sup>6</sup> The central government enacted a law (the Act on Special Measures for Compensation for Minamata Disease and Solutions to the Problems of Minamata Disease) in 2009, which aimed to “let those who should be given relief be given as much relief as possible.”<sup>7</sup> The stigmatization of patients also caused them to receive insufficient access to healthcare resources.<sup>8</sup> Patients who undergo discrimination are reluctant to visit medical or welfare facilities, whereas healthcare providers in their communities, including public health nurses and visiting nurses, have difficulties in treating patients because they have limited knowledge and experience regarding their complicated ailments. The marked characteristic of patients with MD in Niigata is that most of their neurological symptoms are not observed in their outward appearance. In addition, mental and social pains need to be assessed and managed carefully. However, few studies have investigated the care and prevention measures required to relieve the symptoms of patients with MD. Because no effective cure has been developed for MeHg poisoning and patients are inflicted with multifaceted symptoms or “total pain,”<sup>9</sup> the applicability of various palliative care approaches developed for other diseases should be considered to alleviate some of the patients’ widespread pain and distress as well as to improve their QOL.

The objective of this survey was to investigate the symptoms, pains, and sufferings experienced by patients with Niigata Minamata disease as well as their QOL and coping strategies.

## Methods

We adopted the QOL model<sup>10</sup> and the total pain model<sup>11</sup> for palliative care described previously as well as the International Classification of Functioning, Disability, and Health (ICF)<sup>12</sup> as a theoretical model. Patients with MD are prevented from living a healthy life because they have multiple chronic symptoms, age-related physical/mental hypofunction, and the agony of having the disease. Therefore, in the present study, we clarified the well-being of affected patients from the aspects of physical/mental function, society, spirituality, activities, social participation, as well as environmental and personal factors and examined the care necessary to improve their QOL.

## Recruitment of participants

The survey was designed as a complete study of patients with MD who were accessible to the local governments of Niigata Prefecture and Niigata City. This means that the subjects included those who had been officially recognized as patients with MD by *Niigata-ken Niigata-shi Kogai Kenko Higaisha Nintei Shinsa-kai* (Pollution Victim Certification Committee of Niigata Prefecture and Niigata City) and those

who had not been recognized by the Committee but had been issued a *techo* (health record book for medical and welfare records) by the governments to compensate for all or part of their medical and welfare fees. *Techo* was issued to those who were considered to have ingested a significant amount of fish and other foods polluted with MeMg in the Agano river before the end of 196 and who had some degree of sensory disturbance.<sup>13</sup>

Table 1: Patient demographics and clinical characteristics

Gender	N (%)
Female	272 (58.6%)
Male	187 (40.3%)
Not stated	5 (1.1%)
<b>Age</b>	
40's	6 (1.3%)
50's	25 (5.4%)
60's	66 (14.2%)
70's	214 (46.1%)
80's	129 (27.8%)
90's	15 (3.2%)
Not stated	9 (1.9%)
<b>Residential area</b>	
Niigata City	239 (51.5%)
Gosen City	14 (3.0%)
Agano City	176 (37.9%)
Aga Town	26 (5.6%)
Other	8 (1.7%)
Not stated	1 (0.2%)
<b>Living arrangements</b>	
Lives alone	31 (6.7%)
Co-habits with spouse only	92 (19.8%)
Co-habits with a non-spouse	18 (3.9%)
Co-habits with two persons	65 (14.0%)
Co-habits with three persons	66 (14.2%)
Co-habits with four persons	55 (11.9%)
Co-habits with five or more persons	112 (24.1%)
Not stated	25 (5.4%)
<b>Employed</b>	
Yes	59 (12.7%)
No	385 (83.0%)
Not stated	20 (4.3%)
<b>Certified as a patient with MD</b>	
Yes	128 (27.6%)
No	322 (69.4%)
Not stated	14 (3.0%)
<b>Authorized to require support or nursing care</b>	
Yes	69 (14.9%)
Require support level 1	7 (2.2%)
Require support level 2	10 (3.1%)
Require nursing care I	11 (3.4%)
Require nursing care II	12 (3.7%)
Require nursing care III	11 (3.4%)
Require nursing care VI	7 (2.2%)
Require nursing care V	5 (1.6%)
Not specified	6 (0.9%)
No	368 (79.3%)
Not stated	27 (5.8%)
<b>Currently treated diseases (multiple answers)</b>	
Hypertension	216 (46.6%)
Heart diseases	81 (17.5%)
Diabetes	67 (14.4%)
Malignant tumors	32 (6.9%)
Stroke	28 (6.0%)
Others	202 (43.5%)
Not stated	77 (16.6%)

The subjects were informed of the protocols used for data collection and analyses and then consented to inclusion in the study. A self-rating questionnaire was mailed to participants between November 2008 and March 2009. The questions

included items regarding the catchment areas, types of certification, demographic characteristics, symptoms perceived by the subjects as "distressing" rather than merely "experienced" in their daily lives and measures taken to prevent such symptoms, emotional support, and the World Health Organization Quality of Life 26 (WHO/QOL-26).<sup>14</sup> The WHO/QOL26 is a 26-item, self-reported measure designed to assess QOL. Twenty-four items measure four domains of QOL (physical, psychological, social, and environmental), and the other two items measure overall QOL and general health. The score for each question ranges from 1 to 5, and a higher score reflects a higher QOL. The present study used the Japanese version of the WHO/QOL26, which was created by Tasaki and Nakane in 1997.<sup>15</sup> We obtained permission to use this measure in our questionnaire from its publisher, Kanekoshobo. The data obtained from the survey were analyzed using IBM Statistical Package for the Social Sciences (SPSS) version 22.

### Ethical considerations

The study was conducted in careful consideration of the fact that the subjects were suffering from discrimination and prejudice in their communities that caused them considerable distress. The cover letter described the study objectives, methods, and duration as well as ethical considerations regarding the publication of the study results. Specifically, it stated the following: 1) participation in the study was not mandatory, 2) personal information and privacy would be protected, 3) the study would be conducted anonymously, 4) there were no advantages or disadvantages of participation or non-participation, and 5) the obtained data would not be used for purposes other than those described in the study objectives. The study was approved in advance by the Ethics Committee of the School of Medicine, Niigata University.

### Results

The questionnaire was distributed to 681 subjects, 464 of which responded (a 68% response rate). Of the study respondents 187 (40%) were male and 272 (59%) were female (Table 1). Most patients (77%) were aged  $\geq 70$  years, and a considerable proportion was aged  $\geq 80$  years (31%). More than half of the subjects ( $n = 239$ ; 52%) lived in Niigata City (an area downstream of the Agano River). In addition, 14 (3%) and 176 (38%) lived in Gosen City and Agano City (midstream areas of the river), respectively, and 26 (6%) lived in Aga Town (an area upstream of the river), in which the responsible companies were located. Most subjects ( $n = 408$ ; 88%) lived with one or more family members, and a small proportion ( $n = 31$ ; 7%) lived alone. Although most respondents (83%) were unemployed, 59 (13%) had jobs. Just over one quarter ( $n = 128$ , 28%) were certified as patients with MD. A smaller proportion of respondents (15%) were authorized to receive support or nursing care. The currently treated diseases of the study subjects were hypertension (47%), heart disease (18%), diabetes (14%), malignant tumors (7%), and stroke (6%).

The differences in the total and average scores in the WHO/QOL-26 were analyzed using *t*-tests to compare two groups (Table 2). The overall average score was 2.62 points, and the average scores of questions related to physical, psychological, environmental, and social relationship domains were 2.56, 2.59, 2.68, and 2.95 points, respectively. An approximately normal distribution was observed for all the scores. When comparisons were made between genders, no differences were noted in the scores for most domains or overall QOL, except that the social relationship domain scores were significantly higher in females than in males (3.08 vs. 2.81,  $P < 0.001$ ). Although there were no significant differences between age groups in overall QOL scores, the physical

domain scores were significantly higher in patients aged  $\leq 69$  years than in those aged  $\geq 70$  years (2.76 vs. 2.52,  $p = 0.001$ ). Employed individuals reported higher scores for the physical and psychological domains than unemployed ones (2.89 vs. 2.52,  $P < 0.001$  and 2.86 vs. 2.55,  $p = 0.001$ , respectively). This was also observed with regard to overall QOL (2.80 vs. 2.60,  $p = 0.006$ ). In contrast, there were no significant differences between individuals with and without emotional support in any scores. Individuals with an officially recognized requirement for nursing care had significantly lower scores in

the physical and psychological domains (2.12 vs. 2.66,  $P < 0.001$  and 2.22 vs. 2.67,  $P < 0.001$ , respectively) and overall QOL (2.37 vs. 2.67,  $P < 0.001$ ) than those without it. However, there were no significant differences in any score between individuals with and without certified MD. When comparisons were made between subjects with and without currently treated diseases (hypertension, diabetes, stroke, heart diseases, and malignant tumors), there were no significant differences between groups in any score.

**Table 2: Mean scores in the WHO/QOL-26**

	n	Domains									
		Physical	(SD)	Psychological	(SD)	Environmental	(SD)	Social-relationship	(SD)	Total	(SD)
<b>Overall average</b>											
Average	335	2.56	0.57	2.59	0.62	2.68	0.52	2.95	0.66	2.62	0.48
<b>Gender</b>											
Female	183	2.54	0.55	2.59	0.58	2.71	0.47	3.08	0.57	2.64	0.44
Male	147	2.60	0.59	2.61	0.66	2.63	0.58	2.81	0.71	2.60	0.52
p		.282		.832		.135		.000		.460	
<b>Age (years)</b>											
<70	78	2.76	0.55	2.68	0.64	2.62	0.50	2.85	0.65	2.67	0.47
70+	250	2.52	0.56	2.57	0.61	2.69	0.51	3.01	0.63	2.62	0.47
p		.001		.194		.262		.056		.341	
<b>Occupation</b>											
Yes	51	2.89	0.58	2.86	0.66	2.74	0.60	2.90	0.63	2.80	0.52
No	274	2.52	0.54	2.55	0.60	2.66	0.49	2.98	0.64	2.60	0.45
p		.000		.001		.343		.400		.006	
<b>Emotional support</b>											
Yes	155	2.59	0.58	2.60	0.63	2.73	0.56	3.00	0.68	2.65	0.49
No	132	2.58	0.56	2.63	0.62	2.63	0.48	2.93	0.61	2.63	0.45
p		.899		.626		.117		.302		.678	
<b>Authorized to require support or nursing care</b>											
Yes	49	2.12	0.55	2.22	0.56	2.60	0.49	2.93	0.67	2.37	0.46
No	272	2.66	0.53	2.67	0.61	2.68	0.51	2.98	0.61	2.67	0.46
p		.000		.000		.292		.621		.000	
<b>Certified as a patient with MD</b>											
Yes	85	2.56	0.58	2.54	0.66	2.75	0.55	2.91	0.63	2.63	0.5
No	242	2.57	0.57	2.60	0.61	2.65	0.51	2.97	0.67	2.62	0.47
p		.911		.395		.144		.414		.843	
<b>Currently treated diseases</b>											
Yes	283	2.54	0.56	2.58	0.61	2.67	0.51	2.96	0.66	2.61	0.46
No	52	2.68	0.59	2.63	0.70	2.70	0.57	2.92	0.63	2.68	0.53
p		.106		.562		.733		.721		.381	

Table 3 summarizes the "distressing symptoms" felt by the respondents in their daily lives. Of the 440 respondents, the most common sites of physical numbness and physical pain were the limbs (75%) and the knees and/or lower back (61%), respectively. A small proportion of respondents reported that they experienced numbness in their perioral area, back, and one side of the body, whereas some reported pain in their neck, shoulders, head, and back. More than one-third of respondents reported some sensory system disorders, including having difficulty with sight because of narrowing of the visual field (37%), ringing in the ears, dizziness, dysgeusia, and dysosmia. Fatigability (38%) and an increased likelihood of falling (33%) were similarly prevalent, and some patients experienced cramps in their limbs and calves, trembling in the limbs, weakness in the upper arms, forgetfulness, anxiety, depression, and poor concentration. These symptoms worsened more frequently when patients

moved their bodies, worked, did household chores, were tired, or the climate was cold or humid (Table 4). The symptoms commonly continued all day or occurred intermittently (particularly when getting up and at night). The effects of these symptoms on the patients' lives were divided into eight categories: hindered activities, mental distress, physical distress, having difficulty working and performing household chores, hindered activities and social participation, hindered safety, require support or nursing care, and financial worries. The measures and efforts taken to relieve the symptoms were separated into five categories: physical therapy, pharmacotherapy, making lifestyle changes, recreation, and developing care resources in daily settings (Table 5). The use of medications, particularly poultices, was the most common measure. Exercising, rehabilitation, taking a bath, going to springs, massages, acupuncture,

moxibustion, outpatient visits, and hospitalizations were also common measures taken.

Of all the study subjects, 211 (46%) had some emotional support, while 163 (35%) did not; 90 (19%) did not answer this question. Details regarding the subjects' emotional support were categorized into four groups (Table 6): interpersonal relationships (e.g., the presence of and interaction with people), emotional fulfillment (e.g., pleasure and the desire to live), autonomy in daily life (e.g., roles, responsibilities, and manufacturing), and bodily health (e.g., going to the springs, taking a bath, using medicines, and exercising). The most common emotional support was the presence of family; interactions with other people for emotional support were also common. Overall, various types of emotional support existed among the subjects: a desire to live (e.g., the growth of children, the well-being of the family, and praying), pleasure, kindness from family, learning about live, roles and responsibilities, manufacturing, support systems, going to springs, and exercising.

Table 3: "Distressing" symptoms felt by the subjects in their daily lives (n = 440, multiple answers)

Physical numbness (337)	N	%
Limbs	329	(74.8%)
Perioral area	4	(0.9%)
Back	2	(0.5%)
One side of the body	2	(0.5%)
<b>Physical pain (279)</b>		
Knees/lower back	266	(60.5%)
Neck/shoulders/head	36	(8.2%)
Back	7	(1.6%)
<b>Sensory-system disorders (222)</b>		
Difficulty seeing	161	(36.6%)
Ringing in the ears	29	(6.7%)
Dizziness	26	(5.9%)
Dysgeusia	4	(0.9%)
Dysosmia	2	(0.5%)
<b>Limb dysfunctions (169)</b>		
Likelihood to fall	143	(32.5%)
Cramp/tension/trembling in the limbs	24	(5.5%)
Difficulties in stoma management	1	(0.2%)
Weakness in the upper arms	1	(0.2%)
Fatigability (167)	167	(38.0%)
<b>Mental/cognitive dysfunction (13)</b>		
Forgetfulness	6	(1.4%)
Anxiety/depression	5	(1.1%)
Poor concentration	1	(0.2%)
Stammering	1	(0.2%)
<b>Sleep disorder (6)</b>	6	(1.4%)
<b>Cardiovascular symptoms (2)</b>	2	(0.5%)
<b>Excretory disorder (1)</b>		
Incontinence	1	(0.2%)
<b>Others (1)</b>		
Stomatitis	1	(0.2%)

## Discussion

The average score in the WHO/QOL-26 of the study subjects was 2.62, which is considerably lower than that of the general Japanese population (3.29) and comparable with that of patients with schizophrenia (2.69) and individuals with depression (2.81).<sup>16</sup> When comparisons were made with similarly aged populations, the scores of the subjects aged 60–79 years in the physical, psychological, social relationship, and environmental domains, which were 2.56, 2.58, 2.91, and 2.61, respectively, were much lower than were those of the general Japanese population in the same age range (3.53, 3.38, 3.25, and 3.27, respectively).<sup>17</sup> In addition, although the current subjects aged ≤69 years reported significantly higher scores for the physical domain than those aged ≥70 years, they did not report higher scores in the psychological, environmental, or social relationship

domain or overall QOL. These data suggest that the negative impact on patient QOL could not be completely explained by their age. The complexity of the factors that influence patient QOL is reflected in comparisons made according to gender, occupation, currently treated diseases, and emotional support. In particular, being female correlated with a higher score in the social relationship domain, being employed correlated with a higher score in overall QOL and physical and psychological domains, and having currently treated diseases or emotional support had no effect in any domain or overall QOL. The fact that 43.5% of the responders answered "others" when they were asked about currently treated diseases suggests that the subjects suffered from a wide variety of diseases; therefore, a more detailed survey would clarify this aspect.

Table 4: Factors that worsen symptoms and their influence on patients' lives

Predictors for symptom worsening (multiple answers)	N
<b>Activities (199)</b>	
Moving bodies	83
Working/doing household chores	39
Being tired	29
Staying in a similar position (sitting, driving)	19
Going out	19
Doing work with their hands (eating, taking medicine, putting on and taking off clothes)	10
<b>No predictors (137)</b>	
Continued all day	120
Occurred intermittently	17
<b>Time (95)</b>	
In the morning (when getting up)	49
At night	35
In the evening	11
<b>Seasonal conditions (temperature, humidity) (52)</b>	
In autumn/winter (coldness)	46
On rainy days (humidity)	6
<b>Mental conditions (1)</b>	
Haunted by future anxiety	1
<b>Influences on patients' lives (multiple answers)</b>	
<b>Hindered activities (196)</b>	
Difficulty in walking	55
Impaired mobility	48
Difficulty in the activities of daily living	50
<b>Mental distress (63)</b>	
Feel stressed, low morale, poor concentration, distress	22
Sleep disorder	16
Future anxiety	15
Family relations distress (concerns related to family burden or feeling alienated from family)	7
Poor concentration	3
<b>Physical distress (56)</b>	
Symptom-related distress	56
<b>Having difficulty working and doing household chores (55)</b>	
Having difficulty working and doing household chores	55
<b>Hindered activities and social participation (43)</b>	
Difficulty in activities/going out	29
Difficulty in communications	12
Difficulty in expecting others to understand	2
<b>Hindered safety (24)</b>	
Probability of accidents/incidents (burns and falls)	24
<b>Require support or nursing care (8)</b>	
Require support or nursing care	8
<b>Financial worries (3)</b>	
Financial worries	3
<b>No influence (5)</b>	
Worried about nothing	5

Table 5: Measures and efforts taken to relieve symptoms (n = 353, multiple answers)

Physical therapy (211)	N
Exercising/rehabilitation	61
Taking a bath/going to springs	57
Massage/acupuncture/moxibustion	49
Keep warm (using a kairo warmer)	28
Assistive technology and equipment	15
Foot bath	1
<b>Pharmacotherapy (168)</b>	
Using medicines	110
Outpatient visits/hospitalizations	58
<b>Making changes in the lifestyle (60)</b>	
Taking a rest	26
Balancing activity and rest	12
Acting slowly	9
Living cautiously	8
Using public care resources	5
<b>Recreation (27)</b>	
Refreshment of the spirit	13
Peace of mind	8
Meeting friends	6
<b>Developing care resources in daily settings (6)</b>	
Using daily equipment for care	5
Asking family members for care	1

The current study focused on the symptoms that the subjects perceived as distressing in their daily lives and suggested that some palliative care needs had been reported insufficiently. Numbness in the limbs and disturbances in the sensory systems such as vision, audition, and olfaction are well known symptoms in patients with MD; however, in the present study, physical pain (particularly knee and lower back pain), an increased likelihood of falls, and fatigability were also observed. These symptoms affected the patients' activities and social participation continuously in their daily lives and potentially accelerated their physical and mental dysfunction. In addition, difficulty walking, working, and performing household chores affected the fundamental daily life and interpersonal relationships of affected individuals. Although some symptoms were common in the general aged population, the prevalence of physical numbness suggests that these were associated with factors other than aging.

The measures commonly used to relieve these symptoms included taking medications, taking a bath or going to the springs, and staying warm. Many subjects made an effort to perform exercise and rehabilitation despite their bodily pain. One subject described the reason for his or her effort as "I'm sore and having a rough time, but I don't want to be unable to move." This suggests that symptoms can be eased by the deliberate provision of palliative care, including physical therapy and pharmacotherapy.

Approximately half of the subjects had emotional support, which was mostly derived from interpersonal relationships. Some of these subjects, both with and without certified MD, described their experiences of discrimination and prejudice because of their disease, and their spiritual distress was rooted in a sense of meaninglessness. Examples of patient quotes include "I can't express myself," "I can't make myself known as an MD patient," "why do I have to have this?," and "I can't find any meaning to live on with this body." Japanese individuals often have a firm sense of group identification.<sup>18</sup> MD impairs the interpersonal relationships between patients and their family, kinship, and local community.<sup>19</sup> Although many of the current subjects reported that they received emotional support from the people surrounding them, including family members, friends, and physicians, only a small number reported that they were estranged from family members and friends. This could be explained by the fact that the focus of this survey was the distress caused by the

symptoms of MD and not the distress caused by being a patient with MD. Because the present study was performed in a questionnaire format, it is necessary to hold thorough interviews to clarify specific details regarding the spiritual distress of patients.

Table 6: Emotional support (n = 211, multiple answers)

<b>Interpersonal relationships (122)</b>	
Presence of people (75)	
Family members	61
Friends	8
Physicians	6
Interactions with people (47)	
Interactions with family members	23
Interactions with friends	13
Interactions with people at a day center	6
Making friends	2
Visits from home care staff	2
Visits from volunteers	1
<b>Emotional fulfillment (43)</b>	
Desire to live (13)	
Growth of children/well-being of the family	8
Praying	5
Pleasures (11)	
Enjoying TV/radio	4
Going out with friends	2
Singing	2
Reading	2
Going out alone	1
Kindness from the family (10)	
Love from family members	7
Understanding/support from family members	3
Learning about life (9)	
Pursuit of the way of life	9
Presence of people (75)	
Family members	61
Friends	8
<b>Autonomy in daily life (32)</b>	
Roles/responsibilities (13)	
Taking care of family members	4
Doing jobs	6
Roles and obligations in society	2
Club/volunteer activities	1
Manufacturing (11)	
Manufacturing	11
Compensation system (8)	
For officially disclaimed victims	5
For officially recognized MD patients	3
<b>Bodily health (27)</b>	
Taking a bath/using medicines (18)	
Taking a bath/going to springs	12
Using medicines	6
Exercising (9)	
Exercise/rehabilitation	8
Preserving health	1

The present study clarified that one of the two official authorization criteria for health conditions predicts victims' QOL, while the other does not. Although individuals with a requirement for nursing care had significantly lower scores related to physical/psychological domains and overall QOL, there were no significant differences in the scores of any domains or QOL between subjects with and without certified MD. It is reasonable that subjects who required a higher level of support or nursing care had a lower evaluation of their QOL for the physical domain. However, evaluations related to the psychological domain and overall QOL were also lower among patients who required a higher level of support or nursing care. These results are important for devising appropriate care services and providing support to victims of the disaster, regardless of whether they are certified patients with MD.

While the palliative care needs of patients with Niigata Minamata disease revealed by our study had only been insufficiently known to healthcare providers, who are capable of intervening to sophisticate the measures taken by patients. Healthcare providers could extend their targets for non-cancer palliative care and develop MD-specific approaches, including symptom management for physical numbness and physical pain, psychosocial approaches for anxiety and depression, nursing service for hindered activities, and care for spiritual distress.

### Conclusions

The average score in the WHO/QOL-26 was considerably lower in the study subjects than in the general Japanese population. In addition, being female and employed correlated with higher scores for some domains and/or overall QOL.

The symptoms perceived by the subjects as distressing in their daily lives included numbness in the limbs, physical pain, disturbances in their sensory systems, limb dysfunctions, and fatigability.

The commonly taken measures to relieve these symptoms included the use of medications, taking a bath or going to the springs, and maintaining warmth.

The common emotional support included interpersonal relationships, emotional fulfillment, self-discipline in daily life, and bodily health.

Individuals with a requirement for nursing care reported significantly lower scores in the physical and psychological domains and overall QOL, whereas there was no significant difference in the scores reported by individuals with and without certified MD in any domains or overall QOL.

Palliative care providers could extend their targets for non-cancer palliative care and develop approaches for MD-specific total pain.

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## Pandemic Influenza Planning and Response in India, 1949-2009

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### Abstract

For last couple of years, the subcontinent of India has witnessed a number of influenza epidemic outbreaks. History reveals influenza epidemic to be a constant but neglected companion of India. Considering the repeated occurrences of the event on Indian soil, including influenza A H1N1 (2012-13) after 2009-10 pandemic event, a check to the planning measures has been done at national level. A literature survey on the initiative measures, planning accomplishments etc. reveals that it is only after the emergence of A H5N1 (2005), national health authorities have began planning efforts to mitigate and respond to influenza outbreaks. This paper outlines the evolution of Indian pandemic planning that can be traced in the research literature, summarize the accomplishments, and explain the importance of pandemic planning in India. Pandemic influenza (or influenza pandemic), as it is commonly known, emerges, evolves, attacks, and sways a large part of world declaring public health emergency in a short span. Several outbreak events such as SARS (2003), Avian influenza A H5N1 (2005), and H1N1 (2009) have demonstrated the need of international concern for public health emergency and had established the value of planning in advance. Preparedness planning in India is found to be at its nascent stage and it needs further improvement at multiple aspects to tackle the future public health crises, to rectify ethical failures.

**Key Words:** Pandemic Influenza, Planning, India

### Introduction

'Grip,' 'grippe,' or 'flu' as it is commonly known was first described by Hippocrates (412 BC)(1) but was nicknamed as 'influenza' in 1357(2). From 1650 onwards, mention of pandemic influenza can be found in literature (3). Since the

1890s, the pathogen of flu was mistakenly considered to be *bacillus* till 1933s, when the actual pathogen, the virus behind flu was identified (4). By then it has been recognized as a viral disease of mammals, specifically of humans, pigs, horses, as well as of a number of bird species (5). Among humans, it is a contagious lower respiratory tract disease characterized by some unique features; suddenness of arising, ease of spreading, short incubation period, high proportion of susceptible population, short duration of immunity etc.(6).

Its changing pattern and virulence has made it difficult to define and therefore continuous attempts have been made to define and redefine it through virological, epidemiological characteristics and also as public health disaster (7)(8)(9). As the effort to grasp its true nature continues all over the world, pandemic influenza also continued to have its recurring appearances in one or other part of the globe. The subcontinent of India is one such place, which had witnessed the repeated occurrences of pandemic and epidemic influenza through centuries. Even from January 2013 till 24 February 2013, India has witnessed 2267 positive cases, 254 deaths out of influenza A (H1N1)(10). In a month, such huge number of people falling ill, succumbing to the strain, along with the fact of circulation of strain A (H1N1) in epidemic form after pandemic A H1N1 (2009), implies that it is high time to contemplate about its planning initiatives and accomplishments. Therefore, an attempt has been made to check chronologically the planning efforts, measures, initiatives in India for a span of 60 years; 1949-2009, that is since its independence till 2009, when India got affected by A (H1N1) but first, a look into the pandemic and epidemic experiences of India.

### India and Its Experiences Out of Influenza

Before the twenty-first century, India suffered from influenza pandemics in 1781, 1830-3, 1889, 1918, 1957, 1968, of which the pandemics of 1830-3 and 1918 were ranked of the same status in terms of severity(11)(12). Of all these incidences, the first event of pandemic which attracted a pool of research literature is that of 1918 'Spanish Influenza'. Virulence was severe in young adults all over the world, India alone witnessed about 70 million deaths and the mortality rate was highest among adults between 20-40 years (13). It coincided with famine and caused extreme excess mortality in Central and United Indian provinces (for example, in Bombay Presidency, the urban death rate was 9.5% of population in comparison to rural death rate of 6.9%). Excess mortality was also found to be in females than in males in many provinces (such as in Bombay Presidency 7.4% women in the 15-40 age range died as compared to 5.7% men). In Bombay again, low caste Hindus had a death rate of 16.7% in contrast to Europeans (2.9%), Parsis (2.9%), Anglo-Indians (4.2%), Indian Christians (5.4%), high caste Hindus (5.3%), and Muslims (6.1%). Among the British Army in India, case mortality for white troops was 9.6%, while for Indian troops it was 21.9% (14, 15). The millworkers were also badly affected and outside the cities, indigenous people of hill and mountain region, the *Adivasis*, suffered in such a disproportionate proportion that their population in India as a whole fell from 9,593,695 to 9,072,024 (5.4%) between 1911 to 1921, while the overall population of India increased during the same period by 11.3% (16-20). The impact of the pandemic was so severe that it is mentioned '...in Bengal in December ... "rivers became clogged with corpses because firewood available was insufficient for the cremation of Hindus"' (21). In another description of this medical holocaust in India, it is described, "In Punjab trains were packed with dead and dying passengers, and streets and cemeteries were strewn with corpses. Altogether more people died in India during this

epidemic than during 20 years of cholera or during the four years of World War I." (22)

After this, pandemic influenza had its hold of Indian subcontinent again in 1957. Though it was mild in nature, India was worst hit (23). From 19 May 1957 to 8 February 1958, there were 445,178 reported cases with 1098 deaths. Bengal, with 7.2% of total population of the country at that time had lowest mortality rate (8.5/1000) during 1918 but highest in 1957, with 6.4% of all influenza cases and 40.5% of all influenza mortality. Along with the pandemic origin of type A virus, type B virus had simultaneously caused infection in several other states during this time. This influenza outbreak had affected mainly infants, children between 6-10 years (20.0%), young in between 21-25 years (20.8%). In some areas, specific occupational groups (medical and nursing personnel), and closed communities (European Residential School in Coonoor over three successive years of 1956 (62%), 1957 (39.2%), 1958 (57%)) were worst affected. As a whole, out of this influenza outbreak, mortality rate had increased by 19% in parts of India. As a precautionary measure, for the target production of 100,000 doses, the Pasteur Institute, Coonoor had managed to manufacture 35000 doses by 31 January 1958 but by the time the vaccine was in market, influenza had left the subcontinent.

After a long gap of 52 years, life in India was again disrupted by a highly transmissible but a low virulent pandemic influenza A (H1N1) in 2009. By 3 July 2011, it caused 2762 deaths with highest case-fatality in the age group of 20-39 years and next highest in under 5 years of age (24). Once it was even claimed that India topped the mortality chart (25). As a preventive measure, vaccines were imported initially but later on, indigenously developed vaccines were in market from mid 2010 for different groups of people (26).

Table 1: Circulation of Influenza Strains in India through the Centuries (28-37)

Year	Strain/s	Geographical Location
1950-57	A (H1N1), A (H2N2), A (H3N2)	Coonoor (South India)
1972-73	A (H3N2)	Dhoki and Thikol taluks (Ahmednagar District, Maharashtra), Hyderabad(Andhra Pradesh)
1976-2003	A (H1N1) and/or A (H3N2) and Type B	Pune (Maharashtra)
1981-1993	A (H3N2), A (H1N1), A (H2N2)	Calcutta (Kolkata, West Bengal)
1990-2000	A (H3N2)	Pune (Maharashtra)
1993	A (H3N2)	Delhi
2004(September) – 2008 (December)	A (H1N1), A(H3N2), Type B	Different parts of India
2007	A (H1N1) and Type B	In and around Delhi
2008	Type B	In and around Delhi
2009(First Half)	A (H3N2)	In and around Delhi
2009(Second Half)	Pandemic A(H1N1) and Type B	In and around Delhi
2010(First Half)	Type B	In and around Delhi
2010(August-September)	Type B subtype, pandemic A (H1N1)	In and around Delhi
2010(January-March)	A (H1N1) (2009), A (H3N2), Type B	Sri Nagar (Jammu and Kashmir)
2010	Seasonal A (H1N1), pandemic A (H1N1)	Eastern India, Greater Kolkata Metropolitan Area



Besides these major human influenza outbreaks, India regularly suffers from frequent occurrences of human seasonal influenza and Avian Influenza (2005-2011) (27). Table 1 above highlights the circulation of seasonal influenza strains in India through the centuries in chronological order.

The above mentioned influenza strains are found to be circulated among the human population in India. However, it is to be borne in mind that pandemics of influenza occur when an animal or bird influenza virus, to which humans have no or limited immunity acquires the ability, through genetic reassortment or mutation, to cause sustained human-to-human transmission leading to community-wide outbreaks. The recent outbreak of influenza A (H7N9) in China in 2013-2014, and past outbreaks of 1918, 1976, 1997, evidentially proved this direct transmission from animals or birds to humans. Keeping in mind this zoonotic nature of influenza virus and interspecies transmission capability of the influenza virus, a literature survey was also carried on the circulating bird flu strains in India. Bird or avian flu was first noticed in India in 2006. From then on, it continues to resurface in different parts of the country. Literature brings to notice that since 2006 to December 2012, A (H5N1), Avian flu strain has been found to be circulated in different states of the country (however, in West Bengal, different strains A (H9N2), A (H4N6) were also found to be circulated). Table 2 summarizes such incidences.

**Table 2. Avian Influenza Outbreaks in Different Parts of India, 2006-2012 (Source: DAHDR, Annual Report 2012-2013)(27)**

States of India	Year
Maharashtra, Gujarat, and Madhya Pradesh	February–April 2006
Manipur	July 2007
West Bengal	January- May 2008, December 2008- May 2009, January 2010, September 2011
Tripura	April 2008, February-March 2011, January, March, April 2012
Manipur	July 2007
Sikkim	January 2009
Assam	November-December 2008, September 2011
Orissa	January-February 2012
Meghalaya	January 2012
Karnataka	October 2012

The above mentioned events of influenza outbreaks, both in humans and bird population establishes that an influenza outbreak is not an event to be listed in the forgotten pages of Indian history. Rather it is a constant companion of India, visiting the country with pandemic potential at certain intervals. This implies a need of advanced awareness and better preparedness with the consideration of the experiential lessons from past events. Therefore, the primary purpose of this paper is to describe the evolution of Indian pandemic planning, starting from 1949 till 2009 when India got affected by pandemic influenza A (H1N1). For, the historical and policy context within which pandemic occurs help in assessing the implications of pandemic planning for responses to future pandemics and for ongoing infectious disease preparedness efforts. The next following section is an attempt to look into such awareness, initiatives, and planning measures of India.

#### Sources

For the purpose of this article, searches have been conducted of the key websites of Ministries of health, animal welfare etc. (e.g., [www.mohfw.co.in](http://www.mohfw.co.in)), peer-reviewed manuscripts, research articles, published governmental plans,

working group reports, reports of health committees, annual reports of the ministries, and other supporting documents relevant to pandemic planning in India.

#### Chronology of Indian Pandemic Planning Measures and Initiatives

Acknowledging the devastating impact of pandemic influenza of 1918-19 in India, the first health committee report of the country, Bhore Committee report (1946) recommended including influenza as a compulsory topic in the course of Public Health Engineering. Soon after independence, in response to the invitation from World Health Organization, a national influenza centre was set up in the Pasteur Institute, Coonoor, India under the guidance of late Dr. I.G.K. Menon (38). While the centre continued to isolate and identify virus and extended its support for international collaboration, in 1956-58, the country was shook by the deadly blow of another pandemic influenza, popularly known as "Asian Flu". The devastating impact of the influenza in the country provoked the then health committee members to give a serious thought on the pandemic mitigation measures. So, the next following health committee report, Mudaliar Committee report (1962) considered influenza pandemic as a global health problem and recommended the nation to initiate and deal with vaccine production strategies, public health implementation measures; especially quarantine, isolation, and supporting World Health Organization in its world influenza program through Pasteur Institute, Coonoor. It had also tried to draw attention to the need of research on influenza in India.

The next major events leading to the rethinking of pandemic influenza response measures in the country were "Avian flu" (A H5N1 2005), "Swine flu" (A H1N1 2009). Therefore, the working group's report on 12<sup>th</sup> Five year Plan (2011) and Annual Health Report 2010-11 (2011)(39) of Ministry of Health and Family Welfare (MoHFW), have acknowledged the burden of these two incidences of the then recent past and proposed implementing proper mitigation strategies to avert future pandemics. These outbreaks have also reminded that there is a need to have a comprehensive pandemic preparedness with a focus on institutional framework with proper planning and coordination, command and control, regulatory framework, surveillance and laboratory support, communication, public health measures, hospital system, and also planning for logistical distribution. Therefore, national pandemic planning committee was formed with the following members; Secretary (Ministry of Health and Family Welfare (MoHFW), Chairman), Secretaries of Department Animal Husbandry & Dairying, Director General of Health Services, Director General of Indian Council of Medical Research, Director of National Institute of Communicable Diseases, Animal Husbandry Commissioner, Department of Animal Husbandry, Dairy & Fishery, Joint Secretary (DM), Ministry of Home Affairs as members, and Additional Secretary (DG), MoHFW as Convener (40). Task Force and Joint Monitoring Group were also formed to check the outbreak at its source, to delay the entry of the infection in the country, and also to reduce the spread of the infection in the country. Pandemic plans (41) with focus on the country not being affected and affected and with an awareness and concern for all these mentioned components were also came into formation. However, the plans were either in draft form or disclosed as contingency plan. Moreover, they were found to give more attention to the scientific and logistic aspects of mitigation without revealing and acknowledging the impacts of past pandemics, epidemics as well as endemic influenza strains. Apart from these, some initiatives and measures were also undertaken through the centuries. An overview of the major initiatives of management of influenza outbreaks in

India is outlined in Table 3.

Table 3: Timeline of India's Major Initiatives to Manage Influenza Outbreaks in Birds and Humans (40, 42-48)

Year	Initiatives, Measures Undertaken	Action Followed
1950	India Influenza Centre, Connoor established in collaboration with World Health Organization	Virus was isolated for the first time in the country
1957	A committee under the chairmanship of the Director General of Health Services, New Delhi, was set up to consider the various problems concerned in the vaccine production and use	Production of vaccine initiated
1959 onwards	Isolations of virus carried out throughout the year by Pasteur Centre	Study the prevalence of influenza viruses in the surrounding area continued
1976-77	National Institute of Virology initiated influenza surveillance in Pune, Maharashtra	Surveillance extended
1986	Centre for Animal Disease Research And Diagnosis established in Indian Veterinary Research Institute (IVRI), Izatnagar	Made provision of healthcare and diagnosis of animal diseases in the whole country
1998	High Security Animal Disease Laboratory at Bhopal	Made provision for research, diagnosis and control of exotic and emerging animal diseases according to the need of the nation
1999	The disease investigation wing of the Institute of Animal Health and Veterinary Biologicals (IAH & VB), Hebbal, Bangalore, Karnataka has been recognized as Southern Regional Disease Diagnostic Laboratory (SRDDL), identified as a BSL III laboratory	Made provision for prompt and effective diagnostic services for identification of disease problems with an aim to eradicate them in the southern part of the country
2000	Fully functional bio-containment laboratory	Established awareness of containment, continuation of precautionary measures (Same reference)
2001-2003	No documents found	
2004	Multisite influenza surveillance, funded by ICMR-CDC, IDSP initiated, planning activities started Random collection of samples from poultry farms as per sero surveillance recommended	Continuation of precautionary measures
2005	A joint action group has been formed between the departments of health and animal husbandry. Action Plan (Draft) in respect of Avian Flu, Contingency Plan by DGHS, Department of Animal Husbandry, Dairying & Fisheries (DADF) MoHFW	Acknowledgement of the threat of global outbreak of Avian Influenza, apprehensions of a human pandemic Extension of testing laboratories of the animal husbandry department capable of H5N1 diagnosis to Bangalore, Pune, Kolkata, Jalandhar, Bareilly and Bhopal Formation of National Pandemic Planning Committee
2006	Action Plan updated	Enhanced biosecurity

		measures, specified requirements and protocol for vaccination in poultry
2007	Serum Institute of India received grants of US\$ 2-2.7 million to develop processes for production of inactivated or live attenuated seasonal and/or H5N1 influenza vaccines or for establishing filling facilities using imported antigens/ India	Initiated production of vaccine to strengthen capacity and to fill global shortage
2008	No documents found	
2009	World's apex body for animal health (OIE) recognized HSADL as OIE reference laboratory for avian influenza in May 2009 Draft plan for A H1N1 or any novel sub type focusing on phase 5 and 6 by DGHS, MoHFW	Led to the extension of services to neighboring countries  Led to action steps to mitigate human infection spread

### Evolution of the Pillars of Pandemic Preparedness

Table 3 clearly designates that, in India, the pandemic planning initiatives have always been restricted mainly to surveillance and vaccine development. However, more recently, with the advent of influenza A H5N1 (2005), A H1N1 (2009), communication and emergency service provision have been added as the foundation of disease mitigation strategies. The evolution of these components of pandemic planning is summarized below.

Surveillance, including isolation of virus, rapid detection of the disease has always been the foundation of Indian pandemic response strategy. With the outbreak of AH5N1 (2005), the concern to provide referral diagnostic services over and above the disease diagnostic laboratories mainly arose. As a result of that five Regional Diseases Diagnostic Laboratories and one central laboratory started working; Institute of Animal Health and Veterinary Biologicals, Kolkata (Eastern), Disease Investigation Laboratory, Pune (Western), Animal Health Institute, Jalandhar (Northern), Institute of Animal Health and Veterinary Biologicals, Bangalore (Southern) and Institute of Veterinary Biologicals, Khanapara, Guwahati (North-eastern) and the Centre for Animal Disease Research and Diagnosis (CADRAD) of IVRI, Izatnagar has been operational as the Central Disease Diagnostic Laboratory (49).

With the concern of human pandemic influenza, surveillance in India gained momentum soon after the emergence of novel pandemic strain of influenza virus A (H1N1) in Mexico and USA in 2009. The main objectives of the surveillance programme had been establishment of epidemiological and virological influenza surveillance network in different geographical areas of India, development of human resources through training and strengthening of infrastructure, expansion and strengthening of the surveillance in a phased manner, timely dissemination of information generated and improvement of awareness and contribution of the influenza strains and information generated to the global influenza surveillance. Department of Health and Human Services (DHHS)-CDC in collaboration with Indian Council of Medical Research (ICMR) had been involved in the intensive influenza surveillance programme and National Institute of Virology (NIV), Pune was identified as the referral center for the influenza surveillance programme in the country and its task remained to control all the regional centers. The regional centres were increased from 5 (in 2005-6) to 9 with the onset of AH1N1 (2009) in the country. These nine surveillance centers, funded by the Center for Disease

Control and Prevention, USA and Indian Council for Medical Research (ICMR), across the country were operational to study the epidemiology and disease burden due to influenza. The centers were distributed at different geographical sites; All India Institute of Medical Sciences, New Delhi; Vallabhbai Patel Chest Institute, Delhi; National Institute for Cholera and Enteric Diseases, Kolkata; King Institute of Preventive Medicine, Chennai; Regional Medical Research Center, Dibrugarh; Indira Gandhi Medical College, Nagpur; Christian Medical College and Hospitals, Vellore and Haffkine Institute, Mumbai (50). The expansion and extension of surveillance networks had improved the detection, identification facilities but whether they were sufficient to serve the need of the whole of country had remained an unanswered question.

Communication, another core component of planning were found to be very much disease outbreak oriented in India. With the global outbreak of A H1N1 (2009), the Government of India initiated a series of preventive actions approved by the Inter-Ministerial Task Force (IMTF). All health-care facilities in states under the country's Integrated Disease Surveillance Project (IDSP) and medical colleges were activated to report on influenza-like illnesses and pneumonia cases. The Government took the responsibility to communicate risks, personal protective measures and preventive guidelines through the mass media to the public. The Ministry of Health and Family Welfare had rolled out a structured media campaign on the prevention of flu infection (51). In spite of this development, timely dissemination of information to the citizens of the country was disputed during the A H1N1 (2009) incidence (52).

In order to meet the global shortage of pandemic AH1N1 (2009) vaccines and to strengthen the local capacity, three pharmaceutical companies; Serum Institute of India, Bharat Biotech, Hyderabad and Panacea Biotech, New Delhi worked on vaccine development (53). Indian Council of Agricultural Research (ICAR) had also developed bird flu vaccine to control the spread of the virus and also for vaccination in anticipation of an outbreak (54). However, no separate prioritization plan was recommended for the distribution of the vaccines and antiviral drugs with the recognition of the shortage of the supplies.

After the onset of influenza A H5N1 (2005), a special task force, rapid response team, and monitoring team were formed in India. After the incidence of A H1N1 (2009), special task forces were reset under the supervision of the Chief Medical Officers at each district to spread information about the disease and to monitor all suspicious cases of influenza. However, as pandemic influenza mitigation involves an all sector approach, a coordination strategy also needs to be build with emergency response staff such as water, fire, telephone, etc.

These steps, taken as the measure to mitigate the pandemic AH1N1 (2009), reflect the planning process and initiatives that had been continued through the years in the country. And it highlights some noticeable considerations as stated below.

## Conclusion

Pandemic and epidemic influenza outbreak planning initiatives and measures undertaken through the centuries had a direct impact on the mitigation and response measures during 2009 pandemic event in the country. The response and mitigation measures of human pandemic preparation as part of public health obligation, in India, has been found to be at very nascent stage, outbreak oriented, and reactive in nature with a lack of constant and continuous efforts to plan in a complete and adequate manner.

The subsequent absence of pandemic influenza in national health policy documents and a lack of experiential

learning from past events, not only weaken national influenza control and mitigation measures but also highlight moral lapses in providing due protection from sudden invasive, acute communicable infectious diseases such as pandemic influenza. It also reflects overlooking the facts of foreseen and avoidable consequences and highlights the acts of omission and commission. To prevent such happenings, this paper suggests; (a) to ascribe a constant public health importance to influenza pandemic and epidemic by giving them a due place in national health policy and program documents, (b) to acknowledge past pandemic, epidemic as well as endemic influenza events with facts and figures in pandemic preparedness and response plan, (c) to commit to continuous and proactive planning, exercising, refining, and improving the measures. For by doing that, (a) country can show its responsibility, accountability to be a part of global influenza pandemic preparedness program following International Health Regulations (2005)(55), and also that of World Health Organization (2005, 2007, 2009)(56), (b) At national level, such acknowledgement can strengthen influenza prevention and preparedness programs, (c) can at least lead to continuous commitment and effort to develop and revise the strategies, (d) will also reflect a greater concern of protecting a large number of lives which come to stake with a single blow of pandemic, and last but not least, (e) can also help in identifying the challenges, the barriers to preparation and response measures.

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## Animal rights and the need for a universal ethics

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As human beings, could we be happy if we are aware that others are suffering or in pain? Many philosophers would give a firm negative answer to this question.

In this article, we try to discuss the same moral question for other living beings, namely animals. So, could we be equally happy if we inflict suffering on animals? Consequently, the question is one that deals with the moral behavior of human beings. However, no serious thinker would expect that human beings could suppress suffering in the whole living world. So what remains ethically legitimate is the question on suffering that is caused by us on animals.

For a start, I will consider the traditional ethics, be it deontological (Kantian), utilitarian or based on virtues. In most cases, all involve mainly human beings. For them, moral principles are set by human beings for human beings. I would like to suggest here that it is not exactly relevant. First of all, animals are able to develop cultural traits, including what could be called "proto-morals". Secondly, it is not true that human beings can attribute moral rights only to their fellow human beings.

### Animals and (proto)cultures

Many animals demonstrate evidence of behavioral traits which can be considered as "cultural". A cultural trait can be defined as a behavioral trait which can be transmitted, usually within a family or a society, by channels not involving the biological (genetic) transmission (Marler and Hamilton, 1968). These channels can be learning from the parents or just spontaneous learning by imitation from other members of the same species. The more efficient the brain is, the more likely, cultural traits will be more complex. Animal cultures are especially developed among mammals and birds. To distinguish these cultures from human cultures, which often reach a level of language that has a much higher degree of complexity, I classify these animal cultures as "proto-cultures", though the "purists" would prefer to refer to them as "cultures". It is implied here that, in many instances, animals have less complex cultures than human beings, but this does not of course contradict the Darwinian belief that any living being is equivalent in its aptitude to live: bacteria and plants are, at least, as adapted as we are. Referring to "proto-cultures" simply suggests that, in the field in which mankind highly performs (that is complexity of thought, linked to a powerful cerebral cortex), and only in this field, animals show, to a certain extent, less complex behavior than us.

Animals use tools, cognitive rules, communication processes (referring to stimuli present in their environment), (rarely) languages (referring to stimuli no more present in their environment) and manifest occasional aesthetic choices for some colors, some shapes or some rhythms during their songs (Chapouthier, 2009; Lestel, 2001). As far as ethical choice is concerned, some traits observed in animals can be considered as "proto-ethics, as defined earlier.

Human ethics provide several examples of "roots" originated in these animal proto-ethical choices. We dislike torture and condemn it, but we are usually more emotionally shocked by the torture of a young child than by the torture of an adult. This is the consequence of a deep Darwinian rule that animals rearing their offspring must emphasize their specific protection. Another example can be given in the taboo of incest. Human beings behave as monkeys or apes do. All of them have a tendency to avoid incest. If we would be like mice or cats, then, for us, incest would not be a taboo. This shows the existence of animal roots in our ethical behavior, even if we, humans, develop from these roots, specific abstract and discursive moral systems.

The most extensive study of proto-ethics was made by Frans de Waal in chimpanzees (De Waal, 1989). Observing troops of chimpanzees, Frans de Waal found in them may behavioral traits that we, human beings, would consider as "moral", such as: sympathy, attachment, care for the young, help to disabled subjects, punishments, negotiations, cooperations, reconciliations... For example, forgiving is not... a mysterious and sublime idea that we owe to several millenniums of judeo-christianity, noticed De Waal. The mere fact that monkeys, apes and men all show reconciliation behavior means that the ability to forgive is probably more than thirty millions years old.

If ethical choices find their roots in animal behavior and proto-cultures, human beings could however be defined and distinguished as "moral rulers".

### Human beings as moral rulers

If we accept the existence of proto-ethical processes in animals, we should however consider that human beings are still the only ethical rulers. By "ethical rulers", I mean that only humans would use the exceptional language ability to create abstract and discursive systems, which belong to the three main kinds of moral we mentioned earlier: deontological, utilitarian or based on virtues.

Human beings owe to their powerful brain the ability to transfer the biological roots of morals into these complex systems based on language. Human beings are ahead of (other) animals in their understanding of nature (science), in their imaginary world (art) as well as in their sense of duration, although all these abilities also find also their roots in animal behavior. Higher animals have knowledge of their environment, dream as we do at night and can anticipate certain events, such as a migration or a coming winter. But it is clear that these traits when developed by human beings are more complex in science, art or duration, to the point that human beings can be considered as "obsessed" by duration and future.

However, despite this powerful brain, human ethical behavior is practically a disaster, taking into account the crimes, tortures, wars or atrocities committed by mankind throughout history.

The question that ensued is how can the human species improve morals (ethics), which, despite the traditional ethical stances, has remained so low? My view point is that human morals could be improved by establishing a more global universal ethical stance that includes care for animals and for the environment. This ethical stance would indeed be

proposed by human beings who are 'ethical rulers', but it should grant rights to other, non human entities.

This is already evident. Already abstract and legal entities, such as "corporate bodies", have rights without being human beings. Take the port of Pireaus, near Athens in Greece, as an example. As a corporate body, the port of Pireaus has rights, but it cannot claim to be a human being! I advocate that similar rights should be granted by mankind to animals as "sentient beings".

### The Universal Declaration of Animal Rights

Respect for animals can be considered in two different ways. Schopenhauer (2000) proposed to base it on "compassion" and this position is quite similar to religious oriental stances, such as the ones derived from Hinduism, Buddhism or Jainism. Since the occidental tradition is more formal and expresses itself in "rights", it is this notion of rights which I will expound. Other authors have already emphasized, in several ways, the idea to grant rights to animals (Regan, 1983). But the position I will defend here is the one expressed by the Universal Declaration of Animal Rights, proclaimed at UNESCO in Paris (but not by UNESCO) in 1978, and usefully revised in 1989 (Chapouthier and Nouët, 1998). My arguments broach the text of 1989.

This declaration is similar in project with the « Declarations on Human Rights ». Its basis is that animals being sentient beings should, as formerly suggested by Bentham (Bentham, 1970) be protected against suffering. As a set of formal principles, this declaration is basically Kantian. However, though this idea of rights for animals is clearly modern, it can also be interpreted as an extension towards universalism in the Aristotelian tradition, thus adhering to the ideas of modern Aristotelian views (Chapouthier, 2008; Khroutski, 2010). Rights here are not conceived in the philosophical stance as "natural rights", but clearly as rights granted to animals by human beings in their role as ethical rulers. Such granted philosophical rights could then be transformed into laws.

The declaration comprises a preamble based on «unity of life», possession of a «nervous system», that allows the occurrence of suffering, and finally a « unity of ethics ». The first article states that: «All animals have equal right to exists within the context of biological equilibrium – This equality of rights does not overshadow the diversity of species and of individuals» Thus this first article clearly includes an ecological perspective and an opening on biodiversity. The following articles relate to general respect for animals, treatment of wild animals, domestic animals and animal species, to experiments on animals, to necessary modification of the laws, and to the important need for education of the young. Additions to the text deal with "The spirit of the Universal Declaration of Animal Rights" and with "The biological foundation of the Universal Declaration of Animal Rights".

The important facts are that rights for the animals do not exclude however the specific characteristics of each animal species (a spider cannot have the same rights as a dog) and that human beings cannot rule nature (human beings should respect conflicts in nature and not take sides, for example, between a predator and a prey). Another important feature of this declaration is that, when there is a conflict involving a human being, Human Rights should be considered first. As any other animal species, human beings should not be deprived of the privilege of defending their own survival first. By "Human Rights", it should be understood that they are the fundamental rights to live, to eat, to improve medicine, and not, of course, the rights to hunt for fun or to see bullfights.

Usually Human rights are in accordance with Animal rights. Several examples of it can be given. When inspectors visit

families where there is suspicion of ill treatments of children, they often discover ill treatment to animals as well. In Europe, many owners of dogs or cats abandon their pets at the approach of vacation time. At the same time, there is an increase in the abandonment of elderly parents at hospitals. In Europe also, the geographic areas where bulls are tortured in bullfights are the same as those where fights of gladiators once took place. The major punishment during the French revolution was decapitation. But before the use of the guillotine, manual decapitations were practiced following the work... of a butcher, who knew how to cut easily the head of animals. A last example could be given in the wars of the last centuries, where animals such as horses, were injured or killed in the same way as soldiers.

If Human rights and Animal rights are usually in accordance with each other, there are still some exceptions. Obvious ones are, for example, when a human being is attacked by a predator. In this case the fundamental (human) rights of our fellow man to live should be preserved first. The same argument is valid for animal experiments, where animal rights should come after the (human) rights to biological and medical knowledge. But these are exceptional cases. Conflicts between Human and Animal Rights, are relatively rare.

Better care for animals could also greatly contribute to the moral behavior of human beings among themselves. This is what is mentioned in the preamble of the declaration: "Considering that the respect of animals by humans is inseparable from the respect of men for each other". The final request of the declaration is not far away from oriental stances such as the ones of Hinduism, Jainism or Buddhism...But, in the declaration, the emphasis is non-religious, as it is merely based on rational (scientific) grounds. Thus the declaration could be adapted to (or adopted by) human beings, regardless of their religious convictions.

Finally, a universal ethics, extended to animals should also take care of the environment. Indeed the declaration includes the care for "species" and "natural equilibrium", which implies an ecological point of view. But a further extension to plants or to "natural beauties" or "scenic environment" should follow.

### Conclusion

An extended or universal ethics, including care for animals and also, to a certain extent, care for other environmental entities, would probably lead to an improvement in the community life and this will finally foster a better and more harmonious way of life for humankind as well as for animals.

Thus animal rights, not conceived in the philosophical stance as "natural rights", but clearly as rights granted to animals by human beings as ethical rulers, could then be transferred into law and eventually extended to environmental values, and so open the way to universal ethics. This will possibly allow humankind to adopt a more ethical behavior, a behavior in better adequacy with human's powerful brain than the succession of atrocities we committed during history. And this could be a proper way to happiness.

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## Implications of African Conception of Personhood for Bioethics: Reply To Godfrey Tangwa

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### Abstract

The question of what constitutes personhood is controversial in Western bioethical literature especially in relation to its implications for healthcare. Godfrey Tangwa explores the traditional African perspective of a person and maintains that it is different totally from the Western perception(s) as there is no dichotomy between a person and a human being in the African context. He defends a conception of personhood as a moral agent rather than a moral patient, which the Western view focuses on. The basic justification he offers in support of his position is the eco-bio-communitarian worldview. This paper seeks to respond to Tangwa by arguing that his positions on person are not only metaphysically superfluous; they are also ethically incoherent. This paper argues that Tangwa's theses on "the traditional African perception of a person" are inaccurate representations and misapprehension of the common notion of personhood in sub-Saharan Africa. In reconstructing an African concept of personhood, this paper explores its plausible (but limited) implications for global clinical bioethics relevance.

### Introduction

The concept of personhood is one of the most contested concepts with diverse interpretations in Western bioethical discourse. The debate on personhood is important for two basic related reasons. One is its connection with understanding the value of life. For instance, the unprecedented advancements in biomedical technologies have continued to challenge traditional understanding of life and death. According to Thomasma, Weisstub and Herve (2001: 3), "*The concept of personhood has become intimately connected with fundamental ethical questions about the value of life.... [and] has come to be a means by which medical care is excluded from some (e.g., human embryos, fetuses, anencephalic infants)*". In consonance with them, the concept of personhood has become a central concern in the emerging dilemmas posed by the biotechnological advances in today's world. In consequence, such advances have continued to question traditional definitions of personhood as inadequate for coping with today's reality not only in biomedical context, but also in social human existence.

Related to the above reason on why the debate on personhood is important is that it is pivotal to the resolution of some moral problems such as those concerning "the

*beginning and end of life; abortion and withholding or terminating life support in a range of cases involving neurological damage, dementing illness and comatose states"* (Macklin 1983: 36-7). Given the growing importance of personhood conception in health care, it deserves mentioning in consonance with Thomasma et al. (2001: 3) that "*bioethics ought to be enlarged to incorporate into its framework an anthropological understanding of person.*" As Corrado Viafora (2014) observes, anthropological presuppositions do precede every ethical theory, and philosophical anthropology of respect of person and human dignity should serve as the foundations for any system of principles and rules in bioethics. As a consequence of the importance of concept of personhood generally, and in particular, in biomedical decisions in healthcare, it is therefore pertinent having cogent understanding of personhood irrespective of the provenance of the idea.

Perhaps it is in the light of the foregoing that Godfrey Tangwa, a foremost African bioethicist, attempted providing a discussion of the notion of personhood from the African viewpoint. While the bioethical discussions on personhood started in, and have mainly been conducted within Western context, Tangwa's article, "*The Traditional African Perception of a Person: Some Implications for Bioethics,*" is a pioneering attempt to contribute to the discourse on personhood from the African viewpoint. His central theses in the paper are: (i) "the African concept of personhood is totally different from what is found in the West" (Tangwa, 2000: 42); (ii) in traditional African thought, there is no dichotomy between a person and a human being (Tangwa, 2000: 39); (iii) eco-bio-communitarianism is the justification of the African perception of the person (Tangwa, 2000: 42); and (iv) "it is ideal to combine the efficacy of Western science and technology with the moral sensibilities of traditional Africa" (Tangwa, 2000: 43).

This paper is a critique of Tangwa's thesis on what he claims as "the traditional African" notion of person and its supposed implications for bioethics. This attempt becomes pertinent, at least, because there seems to be no evidence in the literature of a critical evaluation of Tangwa's position on personhood. Moreover, it is essential in order to avoid a putative spurious branding of "the traditional African perception of person" when indeed, there is no such generic conception of person in Africa. There are many different views, as there are in Asia, for example. The first part of this article provides a conspectus of Tangwa's positions. The second part of this paper challenges Tangwa's four-prong theses as inaccurate representations of the African understanding of personhood. In avoiding the conceptual error, which his article is fraught with, this paper provides rigorous analysis of an African concept of personhood by drawing on the common understanding of it in sub-Saharan ethical literature. Beyond the culturally sensitive notion of personhood, which for the most part, has little significance and implications for bioethics, the third part of this paper attempts a reconstruction of an African conception of personhood that is contributory to the existing bioethical discourse on the theme. The critical inquisition here bothers on understanding the extent to which the anthropological presuppositions that implicitly or explicitly shape sub-Saharan African understanding of moral principles may offer reasonable insights on the extensively researched themes of personhood and dignity in international bioethics discourse. The concluding part of the paper indicates some suggestions for future research.

### On the Traditional African Perception of Personhood

Tangwa describes the perception, attitudes and understanding of the Nso-African on personhood. The Nso'

are an ethnic group that speak Lamnso language and substantially occupy the Bamenda Grassfields, Northwest province, Cameroon. As Nso' native, Tangwa discusses the Nso's understanding of personhood, which he contrasted with a popular notion of personhood in the West. According to him, in Nso traditional culture, personhood is generally captured in the saying "*Wir dze wir*," literally translated as a "human being is a human being simply by being a human" (Tangwa, 2000: 39). Quick to disprove any objection of tautology in the translation of *wir dze wir*, Tangwa said within the Lamnso language, the supposed tautology is absent as the phrase connotes "*the reverential respect with which anything human is approached*" (Tangwa, 2000: 39). In the saying "*wir dze wir*," the keyword – *wir*, "stands indiscriminately for both human being and human person" (Tangwa, 2000: 39). In the same vein, the word – *wan*, is used for neonate, infant, child and baby without discrimination of individuating features. *Wan* (baby human being), therefore, biologically leads to *wir* (adult human being).

Though the Nso' view recognizes differences in developmental stages of a being as well as variation in social stratification typified by age, experiences and hierarchy in society; yet, as Tangwa (2000: 39) notes, "such categorizations do not carry any moral significance." This is because moral worth is indiscriminately due to all human beings, and remains constant and unchanging throughout developmental stages and lifetime, regardless of any individuating characteristics, possible health conditions, or social rank. Therefore, for Tangwa (2000: 39), the African (Nso) traditional perception of personhood does not participate in the dichotomy between human beings and human persons, which is apparent in the West.

One basic justification for the linguistic and descriptive perception of personhood in the Nso' view identified by Tangwa is the eco-bio-communitarian thesis. As he writes: "*the actual justification for how the African perception of the person is applied has to do with the African worldview*" (Tangwa, 2000: 42), which he calls eco-bio-communitarianism. The idea of eco-bio-communitarianism is that there is strong ontological interdependence and inter-relations not only among human beings, but also among human beings, nonhuman animals, superhuman spirits, plants and inanimate things. The implication of this idea highly held among Africans is that things are generally and reverentially respected because "*a human being can conceivably transform or be transformed (with or without knowledge or consent) into any other ontological entities in this life or in the life after death...*" (Tangwa, 2000: 42).

On the above premise, Tangwa argues that the Nso' view of person is different from Western moral philosophy on the ground that while the latter is driven by the attempt to sharply distinguish persons from the rest of the cosmos, and then to identify the ways in which persons must be treated, the former does not draw such distinction. Critical to Tangwa's sketch of the differences between African views and Western views on person, he cited Tristram Englehardt as exemplifying the Western viewpoint. Englehardt defines persons as "*entities who are self-conscious, rational, free to choose, and in possession of a sense of moral concern*" (Engelhardt 1996: 136) and concludes that human "*fetuses, infants, the profoundly mentally retarded, and the hopelessly comatose*" are nonpersons, having no "*standing in the secular moral community*" and falling "*outside of the inner sanctum of secular morality*" (Engelhardt 1996: 139). According to Tangwa, the reverence to person in Nso' African thought is however different from Englehardt.

Besides Englehardt, philosophers such as Peter Singer, Joseph Fletcher, Mary Warren among others have also put forward different criteria for the identification of personhood.

While our interest in the main is not to delve into details of their views, it is important to state that their criteria of personhood range from rationality, freedom of choice, recollection of the past, future awareness, minimum intelligence, sentience to capacity for autonomy. Consequently, the emphasis on these criteria in the discourse of personhood exempts the neonate, children, irrational, severely physically or mentally challenged from moral consideration. By contrast, the African (Nso') traditional perception of personhood applies to humans in all the developmental stages and to all possible conditions. Implicitly, the Nso' do not acknowledge wealth, power, rationality, autonomy, rights and responsibilities etc., as criteria for moral consideration in their understanding of personhood. It is on this account that Tangwa makes this distinction between the African and Western notions of personhood thus:

*"If the African perception of a person differs from the Western perception, this is not because it does not recognize the various developmental stages of a human being or qualitative differences based on the degree of attainment of positive human attributes or capacities, but rather because it does not draw from these facts the same conclusions as are drawn in Western ethical theory. In particular, the differences between, say, a mentally retarded individual or an infant and a fully self-conscious, mature, rational and free individual do not entail, in the African perception, that such a being falls outside the "inner sanctum of secular morality" and can or should thus be treated with less moral consideration. But since the Western preoccupation with personhood would seem to be dictated precisely by the need to draw such a consequence, it ought also to be said that the African concept of personhood is totally different from what is found in the West"* (Tangwa, 2000: 42).

Pushing this comparative thought further, Tangwa argues that: "*The Western conception of a human person, as a category or subset of human being, is appropriate only for the ascription of moral responsibility, liability, and culpability rather than for the ascription of moral worth, desert, eligibility, or acceptability into the moral community made up, as it necessarily is, of both moral agents and patients. By contrast, the African or Nso' perception of a human being, which applies to the elusive entity underlying all categories, stages, and modalities of a human being, although conceptually less neat and analytically less firm, seems to accord better with our ordinary moral intuitions and sensibilities and is thus more appropriate for nondiscriminatory morality in general.*" (Tangwa, 2000: 42-43)

Besides the distinction between personhood as a moral patient (in the West) and personhood as a moral agent (in African thought), Tangwa warns against following the motivations behind the constant rethinking of moral categories of person in the Western world, which he identified to be science, technology and commerce. The Nso-African view of person, though reverentially respectful and ritualistic, it is driven by the "*deep-seated attitude of live and let live, be and let be*" (Tangwa 2000: 42). He suggests therefore that "*it would be ideal to combine the efficiency of Western science and technology with the moral sensibilities of traditional Africa*" (Tangwa 2000: 43) in order for Western technological culture to be humanized by African culture. In achieving this, he recommends alienating Western technology from "*its entire value system, assumptions, expectations, propaganda, and evangelical spirit surrounding it*" (Tangwa, 2000: 43).

Given the foregoing general textual overview of what Tangwa considered to be "the traditional African perception of personhood" what then are the strengths and flaws in his discourse?



### A Critique of Tangwa's account of Personhood

The title of Tangwa's article, "The Traditional African Perception of a Person: Some Implications for Bioethics," presupposes that there is a generic "African perception of a person" that is generally agreeable to among Africans. However, in reality, there is none. Africa is heterogeneously diverse in worldviews, ideals and perceptions of a person. At best, there can be found a commonly dominant view on what constitute personhood; but Tangwa seems not inclined to this. Rather, he prefers advancing the Nso' perception and proceeding from a particular instance to representatively generalize as the traditional African perception of a person. On this assumption, Tangwa is quick in judging the African perception as better over the divergent conceptions in Western discourse. Where there is dichotomy between human being and human person in Western bioethical discourse, there is no such dichotomy in "the African or Nso' perception of a human being" as the latter is applicable to all stages and categories of human being in any possible condition. On this supposedly difference, Tangwa rated the African view as more cogent because it accords "better with our ordinary moral intuitions and sensibilities and is thus more appropriate for nondiscriminatory morality in general" (Tangwa, 2000:43).

While it is unconvincing that there is hardly such a consensus about our ordinary moral intuitions, Tangwa's central thesis is questionable on many fronts. He premised his claim that there is no distinction between a person and a human being among the Nso' on linguistic fact. The word- *wir*, is a referent without apparent differences between human being and human person. Critically, this claim is suspect. The absence of the 'word' person in Nso' language is perhaps a situation indicative of some linguistic non-fecundity and defects requiring no semantic celebration as Tangwa does. He has mistakenly taken language as a necessitating basis for drawing inferences about understanding of moral status. While language may be an inclining cultural resource, it should not necessitate reasoning at a fundamental moral level, such as on what qualifies one to have moral status.

A central claim in Tangwa's account of the African notion of personhood holds that for the Africans, personhood is construed in terms of moral agent (one who is expected to give others the moral recognition they are owed) and not a moral patient (one owed moral recognition, independently on her own accord), which is Western oriented. While the concern of the former is to attribute "moral worth, desert, eligibility or acceptability into the moral community," the latter concern is that of assigning "moral responsibility, liability and culpability" (Tangwa, 2000: 42-3) to some humans than to others. This position means that personhood should be understood simply as biological beings of intrinsic moral agency without any different moral status. There are some implications of this position. For one, it may be thought that it "would have the effect of making the bioethical conception of personhood far less contentious" (Behrens, 2011: 113-4). But this perhaps is not the case as the view itself is entangled in more questionable assumptions.

One of the difficulties of such a view defended by Tangwa is the eco-communitarian metaphysical foundation on which he based the argument of the African concept of personhood. A second difficulty is the normative inability of such a conception to command higher moral priority to the most vulnerable. A third difficulty that has no clear explanation in Tangwa's discourse is accounting for why human beings and animals have different moral status when they both share the same internal life force that allows for transmigration of one being into the other. It is pertinent discussing each of these possible critiques of Tangwa's African account of person.

On the first point, Tangwa claims that "*the line separating human beings from the other ontological entities that populate the world, in the African world view, is neither hard nor straight.*" This is because of the African belief in transmigration of the soul and reincarnation. The idea of soul transmigration makes it difficult to make sharp distinctions between human beings and the rest of the cosmos as all nature's constituents are interdependent and interrelated. Besides the point that the idea of transmigration of the soul in African thought is a controversial issue and largely disputed in many quarters as a myth without any evidential merit, Tangwa's (2000: 42) justification of it is more problematic. He argues that the "*the actual justification for how the African perception of the person is applied has to do with the African world view,*" that is eco-bio-communitarianism. Epistemologically, to justify a belief as such, an internal referent to eco-bio-communitarian African worldview cannot suffice. It is only an external justification that can allow for an unsympathetic appraisal of the deficiency, flaws and possible strengths of the African view of person.

We now turn to the normative ground of objecting to Tangwa's claim on every being, irrespective of state of vulnerability such as infant, dementia, the aged, and other physically challenged, has the same moral status as human beings with capacities. Contra Tangwa, the problem with this position is that the most vulnerable ought to be treated differently with greater compassion and care consideration, and doing this requires the recognition that such beings have different moral status (Behrens, 2011). Tangwa's (2000: 39) claim on *Wir dze wir*, "a human being is a human being is a human being simply by being a human) does not sufficiently warrant such special moral protection. A position as this does not allow for degrees of moral status, which sometimes is justifiable on equitable grounds to promote the best interests of the most vulnerable.

Related to the above is the question of divergence between the moral status and agency of human beings and animals, when they share the same internal property of life force, which makes possible the idea of transmigration from one being to the other. Nso' morality, writes Tangwa (2000: 39), "*is human-centered in the sense that only human beings are deemed to be moral agents, with moral obligations and responsibilities, but not in the sense that moral consideration and concern are limited to human beings.*" In this sense, human beings only have asymmetrical obligations and duties towards nonhuman animals and other things in nature while they do not have same in return towards human beings. Yet, Tangwa insistence on the possibility of "transmigration, transformation, and transmutation within and across species" is premised on the supposition of common life force that both living species and inanimate things in nature share. The truth of this claim lies in providing clear explanation of what is ontologically responsible for difference in moral status and agency. Alternatively, the truth of the claim would require normative explanations detailing why human beings in general are directly owed duties as opposed to the indirect duties reverentially owed other animate and inanimate things in nature.

Though without a concrete outline or exploration of the implications of the traditional African perception of a person for bioethics, Tangwa's optimism of using the African notion of moral agency to humanize what he called the "morally blind" economic driven proclivity of Western science and technology is unwavering. A way of achieving this synthesis is his recommendation that "*the kernel of Western science and technology*" should be separated from its "Western package" by which he meant the Western "entire value system" (Tangwa 2000: 43). Neither is this conceptually and practically possible and desirable because technology is

intractably linked to culture. Nor is his recommendation that “Western science and technology be put to different and more humane uses in other cultures [when received] without the socio-political-economic and metaphysico-religious conceptual structures that accompany them in the West” (Tangwa 2000: 43) feasible in my opinion. It is more rational to encourage local cultures in the non-Western world to develop their own technologies in realization of the interconnectedness and diversities of the human race than the divisive strategies being reinforced by Tangwa.

From the foregoing, a critical view of Tangwa’s perception of the African-Nso idea of personhood shows that it is not only metaphysically superfluous; it is also ethically incoherent. Such a view is a misapprehension and a reductionist conflation of person with human being and not in any way representative of the common notion of personhood in sub-Saharan Africa. His purported African notion of personhood, as Behrens (2011: 116) unambiguously notes, “does not lead to highly contentious moral conclusions in quite the same way that the bioethical notion does.” Importantly, it is limited in its possible contributions towards understanding and illuminating many bioethical problems plaguing our contemporary world. If ideas from Africa are to be substantially useful for global bioethics, the original views latent in the people’s worldview would have to be reconstructed and not left at the first-order of latent worldview as surreptitiously done by Tangwa.

### Reconstructing an African Concept of Personhood

Contra Tangwa, the concept of personhood whether in African thought or Western is distinguished from human beings as biological species. While the question of what exactly constitutes personhood has been central to many philosophical debates in the Western world both at ontological and normative levels, especially in the field of bioethics; in the African context, the controversies surrounding it have remained purely in the area of African normative ethics, descriptive sociology, anthropology and metaphysics (Menkiti 1984; Wiredu 1992b; Gyekye 1997; Ikenobe 2006; Metz 2007, 2011a, 2011b; Fayemi 2009; Comaroff and Comaroff 2001; Behrens 2011; Iroegbu 2012).

As a moral philosophical construct, personhood, be it in Western theorizing or African articulation, is “used to denote some morally relevant status attributed to those who might be identified as persons” (Behrens 2011: 107). A cross-section analysis of personhood in African philosophical literature suggests that it is a constructive ensemble of virtues of relations of both potential and capable beings in the community. The concept of personhood as a bioethical category has not gained much attention in the African discourse.<sup>1</sup> However, it is important to state that from the existing African philosophical-anthropological scholarship, some differences can be delineated between the common Western understanding and the prominent African view of personhood.

Thadeus Metz (2011a: 11), an American native of African scholarly orientation, brilliantly articulates, broadly speaking, the core difference between the African and Western notions of personhood: “In a sub-Saharan context, ‘personhood’ most often indicates virtue or human excellence, a quality that varies from individual to individual based on her attitudes and decisions. In contrast, Anglo-American bioethicists use the

same term to pick out moral status or standing, a feature that is often thought to be invariant among individuals (or at most to vary based on differential capacities, rather than actualizations of them).”

It is in line with the above that D.A. Masolo (2010: 13), writing on the African conception of personhood states that we are “...born humans but [strive to] become persons ... [as] the project of becoming a person is always incomplete.” Understood in this sense, personhood is an unending process of becoming more of a humane person, acquiring virtuous attributes “through associating with others with whom we share a mutual dependence” (Behrens 2011: 110). By implication, personhood in the words of Behrens is an ideal we strive to “attain than a status we either possess or do not possess.” It is a social process of self-construction in a relational framework of diverse long-live daily activities. While the process is inseparable from the product, the product remains an ideal. As an ideal, Wiredu (1992b: 104-5) notes, it “may or may not be realized and to which one may approximate in varying degrees.” Menkiti, the renowned Nigerian philosopher, is famous for writing that: “As far as African societies are concerned, personhood is something at which individuals could fail, at which they could be competent or ineffective, better or worse. Hence, the African emphasized the rituals of incorporation and the overarching necessity of learning the social rules by which the community lives, so that what was initially biologically given can come to attain social self-hood, i.e., become a person with all the inbuilt excellences implied by the term” (Menkiti 1984: 173).

The above position is similar but not the same with that of Tangwa. For both Menkiti and Tangwa, personhood in African thought focuses on status of persons as moral agents, and not moral patients. While in Menkiti it is about normatively developing virtues of the moral agent, in Tangwa it is about ontological constituents or force that connects human beings, superhuman spirits, nonhuman animals, plants and inanimate objects in mutually reinforcing and interdependent relationship. For Tangwa, personhood qua humanhood is therefore not a matter of degree and one cannot be a ‘lesser person;’ personhood is simply a human being as a moral agent.

Tangwa’s position is related but not the same with that of Kwame Gyekye (1992), the Ghanaian philosopher, who holds that a person is endowed with certain attributes which are prior to community formation. Unlike Tangwa that uses metaphysical category in blurring the distinction between human being and person, for Gyekye, he normatively argues that while personhood is partly determined by communal values, fundamentally, there are other things apart from the community which make a human being enjoy the attribute of personhood. Gyekye (1992: 111) identifies attributes such as, “rationality, the capacity for virtue, ability to make moral judgments and to choose as those conferring personhood on the individual.” However for both Tangwa and Gyekye, personhood cannot be achieved or acquired because one automatically becomes a person at birth.

Whether in Gyekye, Metz, Tangwa, Menkiti, Masolo, Wiredu or Behrens, the normative conceptions of personhood in many sub-Saharan thinking has to do with the moral status of an agent with profound social significance. To quote Metz (2012: 391), “in typical African reflection, talk of ‘personhood’ ... is inherently moralized, such that to be a person is to be virtuous or to exhibit good character. That is, one can be more or less of a person, self or human being, where the more one is, the better.” At the level of social significance, “a person is social not only because he or she lives in a community (the only context in which full, human development is possible), but also because, by internal constitution, a human being is part of a social whole” (Wiredu,

<sup>1</sup> An exception is the works of Metz (2012) who have engaged in a serious discussion of the bioethical implications of a constructed African theory of moral status and dignity. Though the sub-title of Tangwa’s paper has the caption “some implications for bioethics,” a content analysis of the article reveals no clearly cut-out intimation and implication for bioethics.

1992a: 84). The communal and social identity of a being is believed to be present even before birth in sub-Saharan African culture. Every being is “*essentially the center of a thick set of concentric circles of obligations and responsibilities matched by rights and privileges revolving around levels of relationships*” (Wiredu, 1992a: 87) starting from household kinship through lineage and clan to the larger community.

Wiredu also shares the ‘becoming’ conception of personhood in African thought, which has link with the social relational constitution of a person. In consequence of the social characteristic of a person, Wiredu (1992a: 87) holds that life is “*a continual striving after personhood in ever increasing dimensions.*” This view allows the possibility of loss specter of personhood, especially, when there is habitual default in duties and responsibilities of a being. However, becoming less of a person does not imply not being worthy of basic respect and sympathy as a human being. Every human being is entitled of respect by the virtue of simply being human but being respectable is associated with personhood. As an ideal worth striving for, Wiredu (1992a: 87) defines personhood as “*the concept of an individual who through mature reflection and steady motivation is able to carve out a reasonably ample livelihood for self, ‘family,’ and a potentially wide group of kin-dependents while also making substantial contributions to the well-being of the larger society.*”

In the sub-Saharan anthropological conception of the person, there is what Wiredu (1992a) calls “*an acute sense of an essential dependency of the human condition.*” While the idea of self-determination is understood by the Africans, “*its very possibility is predicated on the residue of human dependency. Human beings, therefore, at all times, in one way or another, directly or indirectly, need the help of their kind*” (Wiredu 1992a: 89). The awareness that human dependency cannot be completely eliminated irrespective of one’s abilities acquired overtime, makes pivotal, the consensual approach in decision making among the Africans. Just as Wiredu (1992a: 92) notes, “*A communalistic orientation will naturally prize social harmony.*” The greater a being demonstrates capacity for being part of harmonious relationship, the greater the being’s moral status. The level of a being’s personhood is therefore associated with the degree to which the person conforms to the ideal standard of human actions. Actions are considered right in so far as they connect people together and “*what separates people is wrong*” (Verhoef and Michel, 1997: 397). The African way of pursuing such an ideal is through decision making by consensus rather than individuated exclusion position or majority opinion.

In striving for such an ideal, cultivation of virtues of excellences such as wisdom, politeness, generosity, care, friendliness, harmony, fellowship and hard work is important. In addition, values such as solidarity, consensus, dependency, relationality, care, proper participation in the rituals of bereavement are “*contributory proof[s] of real personhood*” (Wiredu, 1992a: 92) in African culture. The normative constituents and criteria of personhood among the sub-Saharan Africans are therefore, largely, about self-regarding duties to others which among other things aim at harmony of interests and caring for the ‘other-self.’

#### **African Relational Conception of Personhood: Any Global Bioethical Relevance?**

From the foregoing, it might be asked whether the sub-Saharan African conception of personhood, by implication, necessarily excludes certain group of vulnerable beings from the ideal of personhood be it potentially or permanently and are the rationale of such exclusions different from the common explanations in the West. Put differently, what can

the sub-Saharan African anthropological understanding of personhood as status of moral agent add to the subsisting international bioethical debate? The sub-Saharan notion of personhood can enrich global bioethical discourse with its intimation towards developing moral sensitivities, virtues and obligations of the agent in relationship to others. It is useful, in a way, in the sense of fostering relationships either between healthcare providers and care receivers or between researchers and research participants.

In addition, in the light of the dominant sub-Saharan understanding of personhood as moral agents, such view leads one to the conclusion that infants and some non-achieving adults fall short of personhood. This view is articulated by Wiredu when he states that “*Neonates, infants are not persons because they are “still in preparation for that status”* (Wiredu, 1992b: 107). While adults who are not considered persons lack virtues of excellences and are considered with opprobrium, severely vulnerable beings, the demented aged for example, are still respectable of personhood based on their past outstanding contributions to their lineage and community, respectively. Considerations of past actions are, therefore, relevant in partly determining how people ought to be treated in the present (Metz 2011b). But in the absence of such evidential moral uprightness, integrity, communal affection and good human fellowship, the elderly demented remains just at the level of a human being. The most fundamental problem with this relational and communal conception of personhood is that “*if one is not part of a community of the relevant sort, then one counter-intuitively lacks a moral status*” (Metz 2012: 393).

The above limitation notwithstanding, the conclusion to be drawn from the common African conception of personhood is that it is useful only in the sense of ‘moral agent’ and not ‘moral patient’ to use Tangwa’s phraseology. However, it is possible to argue that the African anthropological understanding of personhood can be revealing as well for the moral status of moral patient. Metz’s construction of an African relational theory of moral status is apt in this regard. For him, the capacity of a being to be “*part of a communal relationship of a certain kind*” determines personhood in degrees. Communal relationship is understood here as “*relationships in which people identify with each other [by sharing a way of life] and exhibit solidarity with one another [by caring for one another’s quality of life]*” (Metz 2007). In such a relationship, a being can either be a subject or object. To quote Metz at length on this point: “*... a being that is capable of being both the subject and object of such a relationship has full moral status, whereas a being that is capable of being merely the object of such behaviour has partial moral status. Being a subject involves identifying with others and exhibiting solidarity with them oneself. A being can be a subject of the relevant communal relationship insofar as it can think of himself as a “we”, seek out shared ends, sympathize with others and act for their sake. In contrast, a being can be the object of a friendly relationship insofar as characteristic human beings could think of it as part of a “we”, share its goals, sympathize with it and harm or benefit it. Note that having the capacity to be an object of such a relationship does not imply that a being would or even could respond to any friendly engagement by another*” (Metz, 2012: 394).

The above construction of personhood is based on a modal relational view that emphasizes in principle, capacity of being part of a relationship either as a subject or an object. The differences in degrees of ability to be either a subject or an object of a communal relationship constitute differences in moral status. The greater the capacity is the greater the degree of personhood. This view has some direct implications for grading the personhood of moral patients such as people in vegetative state, the severely mentally incapacitated,

psychopaths, infants, who are capable of objects of communal relationship. Whether this constructed interpretation of personhood in African thought as consisting of both moral patients and agents is plausible than the exclusive popular African understanding of personhood as moral agent remains a controversial issue not of immediate concern.

Irrespective of the African conception of personhood one holds dearer, it has implications for bioethics, though at different degrees. For instance, the idea that personhood consists in virtuous activities of a moral agent such as fellowship, caring for the 'other-self,' and sharing a way of life through mutual aid are important for improving others' quality of life and well-being, especially in end-of-life discussions in the health care setting. Such a conception of personhood that recognizes the dependency, vulnerability, relationality, insufficiency of human beings, and "sharing a way of life with others is an important relational ethical perspective" (Metz, 2013: 89) that can complement the care ethics orientation in Western bioethics.

The African notion of personhood as 'other-regarding' has implications for clinical practice, especially as it concerns consent, information disclosure and proxy-representation. The element of family-determination (as opposed to self-determination) in African health care practice has anthropological foundation in the African understandings of the nature of personhood and familyhood. Rather than disclosing information and obtaining formal consent from the individual patient directly, a patient's family representative(s) takes charge. Without necessarily isolating the patient, the active involvement of the family in the diagnosis, treatment and reconciliatory trajectory is that "a sick person should not sustain the burden with directly signing a consent form" (Fan 1997: 195). In such process, there is a broader consultation involving not only the family-representative, the patient (where necessary) but also the other family members, maternal and paternal.

The decisions usually made by family members are usually in harmony with the patient's interest and wishes and not necessarily patient's consent. Given the sometimes metaphysical conception of the source of an illness common in African beliefs, the consent of a patient cannot be achieved because of the supposed transcendental element or cause obstructing the consciousness of the patient. In such situations, family members act in the best interest of the patients even without consent. However, in situations of natural etiology, decisions of family representatives are usually in consonance with the patient's wishes and consent. Where there are disagreements, either between the patient and the rest of the family or among the members of the family, it is expected that the family head resolves that before such consent authorizes the physician's course of action.

It is important to critically point that this family-embedded autonomy in decision making may perhaps be imprudent in emergency situation, especially in cases of intra-family conflicts, which sometimes creates some moral distress for physicians. More fundamentally, it is epistemologically questionable, the extent to which family-embedded autonomy and representation are truly representative without questionable interests.

## Conclusion

This paper has attempted a critical evaluation of Tangwa's conception of personhood from an African perspective. As problematic as his views are, this paper establishes that his narration of Nso's perception of personhood is not in tandem with what common views in the African literature. However, the critical evaluation of Tangwa's view attempted in this work should not undermine his significant contribution to the

discourse on personhood from an African viewpoint. While this paper provides some insights on the common strand of thought on personhood in sub-Saharan African philosophical discourse, it shows the possible inferences that can be drawn from the emphasis on personhood as moral agency for bioethics. The paper establishes that the possible contributions of the African notion of personhood, though different from the emphasis on moral status in the Western discourse, are however incapacitated for robust bioethics discourse.

The limited contributions of the common African understanding of personhood to bioethics is not unconnected to the fact that theorizing on personhood itself is more of a first-order activity relying heavily on the cultural worldview. A second-order theory of personhood that would valuably constitute a resonant anthropological frame for bioethics anywhere at least, needs to "rest on the best scientific [and genetic] data ... available about human beings ... along with the [ontological, sociological and moral] values we associate with persons" (Thomasma, Weisstub and Herve: 2001: 8).

Metz (2012) has attempted doing this with his constructed African modal-relational theory of moral status. Though an illuminating work both on moral agency and moral status from an African perspective with well-outlined implications for bioethics debates, it is apt to say, contra Metz, that the identity label of 'African' in his theory, would by implication not be claim of uniqueness of thought or commonality of sub-Saharan experiences. Rather, it will only be claim of point of origin of the author. As an American, it perhaps remains to be seen how his view qualifies as African despite his defense to the contrary. While it is beyond the scope of this research to attempt constructing a theory of personhood in African thought, or replying Metz in particular, the point is that the moral agent conception of personhood in Africa can complement existing understanding of personhood as status of moral patient in the Western tradition. This is important in serving as an integrative basis for justifying bioethical judgment in our pluralistic society.

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## Compassionate Care by Clinicians: Insights from the Judeo-Christian and Buddhist Traditions

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Hospitals in modern industrialized countries have a culture that is significantly shaped—some would say dominated—by rationality, the scientific paradigm, and the technology of diagnosis and treatment. Though it is widely acknowledged that both cure and care are important, there are a significant number of healthcare practitioners who are competent in relation to the technologies of cure but who have little facility with the human dimension in medical practice. Others see the value in compassionate care, but in the midst of the pressures and demands of their profession lose sight of the vision to an extent. With this in mind, some writers in the field of healthcare have felt the need to highlight the vital importance of care and compassion (Brien & Lewith 2001; Coulehan 1995; Dougherty & Purtilo 1995; Graber 2004; Pellegrino 1979; Pellegrino & Thomasma 1997; Pembroke 2007; Rhodes 1995; Stevenson 2002; Sulmasy 1997; Thomasma & Kushner 1995). There are slight variations in the way the term *compassion* is understood in these texts. I take it to mean opening oneself to the suffering of a person, being moved by it, and feeling a strong desire to do all in one's power to alleviate it.

The aim in this essay is to make a contribution to the existing body of work by focusing on certain insights that are provided by the Judeo-Christian and Buddhist traditions. The writing on compassion in these traditions is of course

extensive. In order to keep the task within manageable bounds and maintain a sharp focus, just three of the many possible facets of the topic covered in the relevant spiritual writings have been selected for attention. From the Jewish and Christian traditions, the notion of receptivity to the suffering of the other is highlighted. In the biblical perspective, the compassionate person is viewed as someone who takes the suffering of others into her womb or heart. It is suggested that the tenderness and kindness expressed by these metaphors presents an ideal in compassionate care by clinicians. Further, the insights of the Christian philosopher, Gabriel Marcel, on overcoming a lack of compassion will be employed. Marcel contends that breaking through hardness of heart requires a sudden submersion in the inner reality of the other and being compelled to see things through her eyes.

In turning to Buddhism, use is made of the notion of compassion with equanimity. The Buddhist ideal is opening oneself to the pain of the other while maintaining calmness or stillness of mind. This is particularly appropriate in the context of healthcare. The healthcare professional needs to be able to share the suffering of her patients without becoming overwhelmed by it.

### In Conversation with the Judeo-Christian Tradition

Bergant (1996) observes that in the cluster of Hebrew words for compassion, *rhm* is the most prominent. It has the primary meaning of "cherishing," "soothing," or "a gentle attitude of mind." It refers to a tender parental love. The word *rehem*, meaning womb, is also derived from this root. Hence, Bergant (1996) concludes that this Hebrew word-group indicates a bond like that between a mother and the child of her womb.

Leon-Dufour (1988) describes the Hebrew notion of compassion, as one might expect, in a very similar way. He suggests that *rhm* "expresses the instinctive attachment of one person for another" (p. 351). Leon-Dufour (1988) observes that this feeling has its seat in the maternal bosom or in the bowels (or, as we would prefer to say, heart) of the father. It is a tenderness which drives a person to action on behalf of those in distress.

The New Testament writers often use *éleos* (mercy) when speaking of compassion (Bergant 1996). A form of the verb *oiktiro* (connoting sympathy) also appears. However, when reference is made to the compassion of Jesus, *splánchnon* is always used. Köster (1985) provides a convenient summary of this Greek word's derivation and its employment in the sacred texts. In early Greek usage, the word denotes the "inward parts" of a sacrifice. Later, it was used to refer to the "inward parts of the body," and finally to the womb. We also find the noun form used in the *Testaments of the Twelve Patriarchs*. There it denotes "the center of feelings" or "noble feelings." On one occasion the verb is used to indicate mere emotion, but it generally refers to the inner disposition which generates acts of mercy. The adjective, *eúsplanchnos* (tender-hearted), denotes human virtue and the disposition of "pity."

The noun appears in three of Jesus' parables: the Good Samaritan, the Prodigal Son and the Unmerciful Servant. Of particular interest for our discussion is the way Paul describes compassion. Only the noun occurs in his writings. He uses *splánchna* not merely to express natural emotions but as "a very forceful term to signify an expression of the total personality at the deepest level" (Köster 1985, p. 1068). It occurs twice in Philemon (vv. 7, 20); reference is made to the refreshing of the *splánchna*. In v. 12 of that letter, Paul says that in Onesimus he is, in effect, coming in person with a claim for Philemon's love. Phil. 1:8 contains a unique phrase. Paul declares that "God can testify how I long for all of you with the affection (*splánchna*) of Jesus Christ." The reference

is to “the love or affection which, gripping or moving the whole personality, is possible only in Christ...” (Köster 1985, p. 1068).

In these various uses of the word *compassion* by the biblical authors, there are a number of key features. First, the idea of tenderness comes out in a number of places. Second, compassion is associated with an instinctive, intimate relationship: it is like the loving, soothing action of a mother or father. Finally, it refers (most clearly in Paul’s usage) not just to an emotion, but to the deepest part of the personality. This depth dimension is indicated by the cluster of inner parts identifying the seat of the emotion—namely, the womb, the bowels, and the heart.

In the Bible, then, we have a picture of compassion according to which a person is in such deep solidarity with the pain of another that she takes that pain into herself. She receives the other in her suffering and distress in her innermost space (the heart or the womb). This notion of compassion-as-receptivity is developed by the French Christian philosopher, Gabriel Marcel.

Marcel (1964) establishes the link between receptivity and disposability (*disponibilité*) using the metaphor of “in-cohesion.” To exist with others, he observes, is to be exposed to influences. It is not possible to be human without to some extent being permeable to those influences. Permeability, in its broadest sense, is associated with a certain lack of cohesion or density. Thus, the fact of being exposed to external influences is linked with a kind of *in-cohesion*. I am “porous,” open to a reality which seeks to communicate with me. Marcel (1964) puts it this way: “I must somehow make room for the other in myself; if I am completely absorbed in myself, concentrated on my sensations, feelings, anxieties, it will obviously be impossible for me to receive, to incorporate in myself, the message of the other. What I called incohesion a moment ago here assumes the form of disposability...” (p. 88).

Disposability, then, is closely associated with receptivity. As we saw above, receptivity involves a readiness to make available your personal center, your innermost domain (recall the metaphors of the womb and the heart). Marcel (1964) uses a different metaphor to capture this phenomenon; he refers to inviting others to be *chez soi* (at home). He observes that we receive others in a room, in a house, or in a garden, but not on unknown ground or in the woods. Receptivity means that I invite the other to “be at home” with me. A home receives the imprint of an individual’s personality; something of myself is infused into the way my home-space is constructed. Contrast this with “the nameless sadness” associated with a hotel room; this is no-one’s home. To share one’s home-space is disposability or availability because “[t]o provide hospitality is truly to communicate something of oneself to the other” (Marcel 1964, p. 91).

The meaning of hospitality can also be broadened to include receiving into the self the appeal of another for understanding and compassion. When I open myself to the call of the other to be with her in her pain and confusion, I am able to spontaneously feel with her. The intonation of my words, my posture, and my facial expressions say to her that I am with her in her suffering. Contrasted to this responsiveness, however, there is an indisposability which Marcel refers to as an “inner inertia” or “spiritual asthenia” (Marcel 1964, p. 50). The distress of the other is experienced as something alien; I simply cannot receive it into my innermost sphere. To illustrate this fundamental lack of responsiveness, Marcel (1964) contrasts the mundane scenario of a person asking for information which is not at one’s disposal with the case of a person appealing to one’s sympathy. In the first case, I must respond to a concrete question such as: What is the population of Rome? I go

through my “file” of information and find that there is nothing available in relation to this question. Marcel (1964) then moves to the appeal from the other for understanding of her personal distress. In response, I can “utter certain formulas” from my repertory of sympathetic responses, but this is “only reading something out of a catalogue” (pp. 50-51); it is not feeling-with her. The only way to break out of this “self-obsession,” according to Marcel (1964), is by “submerging oneself suddenly in the life of another person and being forced to see things through his eyes” (p. 51). A person cannot break out of this “inner inertia” relying only on her own personal resources; it is through the presence of another person that this “miracle” is accomplished.

It is worth noting that what Marcel is talking about here is sympathetic rather than empathetic engagement. Empathy and sympathy are not interchangeable terms (Chismar 1988; Wispé 1986). The form of the substitution in the two is different. “In empathy, we substitute ourselves for others. In sympathy, we substitute others for ourselves. To know what it would be like if I were the other person is empathy. To know what it would be like to be that other person is sympathy” (Wispé 1986, p. 318; emphasis in the original). Marcel is suggesting that to move from cohesion to in-cohesion, to become porous to the other’s suffering, requires imagining what it would be like to be the other person. The clinician who lacks compassion needs to substitute the other for him- or herself. He or she needs to grasp what it is to be this person—someone who is suffering pain and discomfort, disorientation, loss of independence, and anxiety.

#### In Conversation with the Buddhist Tradition

We saw above that in both the Hebrew Scriptures and the New Testament compassion is viewed essentially as taking the pain and distress of the other “to heart.” Buddhists have a similar notion (Dalai Lama 1999; Salzberg 1995). The Pali and Sanskrit word *karuṇā*, “compassion,” literally means “experiencing a trembling or quivering of the heart in response to a being’s pain” (Salzberg 1995, p. 104).

In the texts of early Buddhism, the term often refers to a mental state to be radiated out to all sentient beings (cf. Aronson 1980; Harris 1997). This is usually taken to be its primary reference. In the meditation on compassion, a phrase such as “May you be free of your pain and sorrow” is used (Salzberg 1995). The one meditating first directs the blessing toward a person who is experiencing great physical or mental suffering. He or she then directs the benevolent wish toward a series of other select individuals. Included in the list is him- or herself, a benefactor, a friend, a neutral person (someone about whom the mediating person has neither positive nor negative feelings) and a difficult person. Finally, the blessing is radiated out to all sentient beings.

It is held that compassion and loving-kindness are (potentially at least) fundamental characteristics of all human beings<sup>2</sup> (Dalai Lama 2002; Dreyfus 2002; Master Sheng-Yen 1998). But the compassion that exists naturally in human beings is not particularly strong and neither is it universal; it needs to be developed. While persons naturally feel compassion toward those that they like, the situation may be quite different in relation to strangers. Certainly, it is not often the case that a person responds with compassion to the suffering of an enemy. In contrast, the Buddha held up the ideal of compassion for all sentient beings.

What is required of the person on the path to enlightenment is a state of equanimity. Equanimity (*upekkhā*) is along with compassion one of the four *brahma-vihāras* or sublime attitudes (the other two are loving-kindness—*mettā*, and

<sup>2</sup> Actually, Buddhists believe that this is true of all sentient beings.

sympathetic joy—*muditā*). *Upekkhā* is even-mindedness or impartiality. It should not be confused with feeling equanimity—a stance that will become important for us below. The former attitude refers to extending your compassion impartially and therefore to all sentient beings; the latter indicates “the experience of neither pain nor pleasure...and it can arise in wholesome, unwholesome, and neutral states of mind” (Aronson 1980, p. 81). Importantly, the stance of feeling equanimity should not be equated with the absence of feeling or emotion.

In the Māhāyana tradition, the bodhisattva is one who has “the great compassion” (*māhā karuṇā*). Though the primary reference to compassion is the meditative practice, it is also closely linked to liberative action. Out of compassion for the suffering of sentient beings, bodhisattvas commit themselves to helping others on the path to enlightenment. They postpone complete enlightenment and attainment of *nirvana* in order to make themselves available for this service.

A distinction is made between bodhisattvas who are beginners and those who are advanced. Both types are intensive and impartial in their expression of compassion, but only the beginning bodhisattvas are overwhelmed by compassion. They are deeply moved by the suffering of other beings and sometimes weep in their distress. Those who are advanced, on the other hand, develop equanimity (i.e., feeling equanimity). Their compassion is even stronger than that of the beginners, and it is more balanced in the sense that it does not result in emotional outbursts.

The cultivation of compassion with equanimity is considered to be vitally important as it ensures that encounters with suffering by those on the path will not lead to emotional turmoil. The Buddhist ideal is calmness or stillness of mind combined with a heart of loving-kindness and compassion. “Equanimity allows one to feel compassion for the suffering of others without becoming overwhelmed by or neglecting it... This completely open mental atmosphere depends on achieving a state of emotional nonattachment in which perception is not directed by our self-ascribed interests” (Friedland 1999, p. 39).

The Buddha taught that associated with all experiences in life are three feeling states—namely, pleasure, pain, and neutrality. The aim of those on the path is the cultivation of a nonreactive stance in relation to the various states. In order to do this, they must counteract their natural tendencies. When experiencing something that is pleasant, a person naturally wants it to continue; she clings to it. Here she is encountering a fundamental cause of *dukkha*—suffering or, better, disquietude or unsatisfactoriness. That cause is attachment. When a person suffers a painful experience, she views it as negative and she instinctively wants to push it away. Another basic cause of *dukkha* surfaces here—namely aversion. If the experience is neutral in tonality, a person habitually falls into inattention; the lack of stimulation means that she is unable to stay interested and focused. A third fundamental cause of *dukkha* is unveiled here, and that is delusion. The way of the Buddha is balanced response or non-reactivity to the differently toned experiences that make up our lives. It may seem that equanimity indicates an unfeeling stance—and some scholars of Buddhism have argued this (see, for example, Spiro 1970)—but this is not the case. In the Pāli scriptures, it is clearly indicated that the abandonment of the negative emotions of attachment, hatred, and delusion does not mean the destruction of *all* emotion (cf. Aronson 1980, p. 95). Those who have chosen the way of non-attachment may experience a rich and fulfilling emotional life. Salzberg (1995) expresses the situation well, “*Meditation does not turn us into gray, vegetative blobs with all feelings washed out. The Buddha taught that we can feel pleasure fully, yet without craving or clinging, without defining it as our ultimate*

*happiness. We can feel pain fully without condemning or hating it. And we can experience neutral events by being fully present... This non-reactivity is the state of equanimity, and it leads us into freedom in each moment*” (p. 144)

In sum, compassion in the Buddhist tradition is construed as opening to the suffering of others while maintaining a stance of non-attachment. Non-attachment should not be interpreted, however, as indicating a lack of emotion or feeling. It is held that it is possible to sorrow with those who are sorrowing, while maintaining a calm, balanced state of mind.

One can easily see how this insight from the Buddhist tradition can be profitably applied in the healthcare context. The caring clinician needs to open herself to the suffering of her patients without becoming overwhelmed by it. I hasten to point out that this stance of compassion with equanimity is different from the detached approach that has sometimes been advocated in the past. In his Valedictory Address delivered at the University of Pennsylvania in 1889, Sir William Osler exhorted the Medical School graduates to cultivate equanimity or imperturbability. This essential quality “*means coolness and presence of mind under all circumstances, calmness amid storm, clearness of judgment in moments of grave peril, immobility, impassiveness...*” (Osler, 1963, p. 27). Osler (1963) recognizes the value in sensitivity, but only on the condition that it does not interfere with calmness and control. In fact, in order to ensure that the physician operates with an optimal level of composure, he should cultivate “*a judicious measure of obtuseness*” (Osler, 1963, p. 28). Aring (1958) echoes the views of Osler. He advocates a “*reflective commitment*” to the patient’s problem while at the same time maintaining equanimity. In order to carry out his or her clinical duties with maximum effectiveness, the physician identifies to an extent with the patient’s situation, while at the same time standing apart from “*the enervating morass*” (Aring, 1958, p. 440).

What the Buddhist tradition indicates vis-à-vis clinical work is quite different. Buddhist masters would feel very uncomfortable with expressions such as “a judicious measure of obtuseness” and standing apart from “the enervating morass.” These clinical approaches connote detachment rather than the non-attachment or non-grasping advocated by Buddhist teachers. These teachers claim that it is possible to maintain inner calm and freedom of spirit while opening oneself to the suffering of others.

## Conclusion

The biblical view of compassion as receiving the suffering of the other in one’s innermost space (the “womb,” the “heart”) takes us to the center of what is involved in this vitally important human quality. It establishes an ideal for compassionate clinical work. The clinician who acts with compassion opens herself to the suffering of her patients. To use Marcel’s metaphor, she is porous in their presence. She facilitates a humanized engagement in which connection with the lived experience of the illness is accorded the same attention as skilled diagnosis and treatment.

Of course not all clinicians have a capacity for compassionate care; they suffer in their work from “spiritual asthenia.” The only way for them to move past this, according to Marcel, is to break through the wall that has been erected and enter into the experience of the patient. That is, they need to imagine what it is to be this person—to be someone who is experiencing pain and discomfort, disorientation, fear, and uncertainty. In the absence of any attempt to reach across the interpersonal space, there is simply no possibility of growing into compassion.

The danger in opening oneself to the suffering of others is that one may be overwhelmed by it. The Buddhist ideal is most helpful at this point. The Buddha taught opening oneself

to the distress of the other while maintaining calmness or stillness of mind. This is particularly appropriate in the context of healthcare. The healthcare professional needs to be able to adopt a compassionate stance to the suffering of her patients without becoming burdened and distressed by it.

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## Ethical Issues of Wireless Sensor Network in Health Care Applications

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### Introduction

Advances in medicine and reduction in morbidity rates are leading to an aging populations of human beings. Especially in developed countries there is a tendency towards gentrification of the population. It is speculated that in 2060, 30% of the human population in EU countries will be at or above 65 years old. Similar situation would be found in Japan, USA and Canada. Hence efficient and effective aged care will become an important issue. Hospitals, care providers and nursing homes may not have enough facilities to look after the aged people. When people become older they feel a decline in their cognitive, sensory and motor functions. Hence even simple tasks become difficult for them and they cannot look after them safely. Hence they have to be shifted to institutional care facilities or retired homes. In this context, Ambient Assisted living gains importance in which WSNs will assist and monitor the aged or patients assuring a better quality of life.

### Applications

The health care applications of WSNs include monitoring temperature, respiration, heart rates, pulse, blood pressure and blood glucose levels of the patient. The medical sensors can closely monitor the patient's physiological conditions. After sensing the vital body signs, they can be transmitted after returning home becomes feasible. WSNs are very useful for people affected by Alzheimer's disease as they experience progressive neurological disorder. They can be helped by WSNs in carrying and their routine activities.

### Components of WSN

The key components of WSN include sensor coverage area, sensor mode, sink node and WSN manager. The geographical region covered by the WSN is the sensor coverage area and the sensor node is the actual sensor device. The sink node is provided with the additional networking capacity like WiFi, 3G or internet connection.



WSN manager helps in managing WSN with the software hosted on fixed workstation. The components of sensor node are Transceiver, power, processing and sensing units. The power unit comprises of several alkaline or lithium batteries or solar power units. The processing unit has a microcontroller and flash memory. The transceiver unit looks after the communication with the other nodes while the sensing unit will generate an analogue signal, convert it to digital and transfer it to the processing units.

### Ethical issues

There are ethical issues related to the applications of Wireless Sensor Networks. Most of them involve privacy of the users. There are also concerns about the security of information. WSNs are vulnerable to security attacks.

### Privacy issues

In health care applications, the medical data transmitted should remain confidential. But WSNs are prone to attacks and may be accessible to others. The threats can come from passive attacks like listening into data or active attacks like manipulation of the data. According to NCVHS (National Committee for Vital and Health Statistics) of the United States Department of Health and Human Services "*Health information privacy is an individual's right to control the acquisition, uses or disclosures of his/her identifiable health data.*" Individuals have to share their data with doctors, sports team trainers, relatives, friends, family members or insurance companies. Unauthorized collection of data or its leakage may harm the patient. If an intruder alters the medical data of a patient, it may pose life-threatening risks. Misuse of medical information, leakage of prescriptions and eavesdropping on medical data are some of the privacy issues on health care applications of WSNs. When the patient's data flows in the WSN, it is prone to wireless threats like eavesdropping and snooping. Leakage of medical prescriptions can be a big source of privacy violations. Data eavesdropping may cause damage to the patient as his data can be used for illegal purposes, which will breach his privacy. If the privacy issues are not addressed properly, it may lead to public mistrust and the benefits of WSN technology cannot be reaped. There are privacy issues like who can have permission to own the data, what type of data, how much and the place of collection of data and who can inspect the data. Normally the medical data of particular patient has to be accessed by the physician, nurses and clinical staff. Hence there should be firm guidelines and defined regulations about the uses of medical data for privacy to be maintained. In emergency situations there can be flexibility in other people having access to such data. At the same time, the data should not be accessible to persons with malicious intent. Hence to avoid such issues the information sensual through WSNs can be encrypted and awareness about the importance of keeping privacy can be created among the public.

### Security issues

Security involves the maintenance of protection that ensure a state of inviolability from hostile influences. As the communications in WSNs are wireless in nature, there are more possibilities of threats and attacks to security. They may be of system security and information security. The attackers may change the destination of packed data or steal the data by eavesdropping. The sensor devices have little external security measures and hence are prone to physical damage. During transmission of data through networks, vital data may be stolen by eavesdropping. According to Kargl *et al.* (2008) the attacks include, eavesdropping and modification of medical data, forging to alarms on medical data, denial of

service, location and activity tracking of users, physical tampering with devices and jamming attacks. Wireless media are more vulnerable than wired media to attacks and threats.

In selective forwarding threat, malicious nodes can refuse to forward certain messages like patient's data and it may not be broadcast further. In sinkhole threat, the attacker can attract all neighbouring nodes to form routes through a malicious node.

A compromised node may prevent multiple false identities to other neighbouring nodes in the network resulting in Sybil attack. As wireless rely nodes are unguarded, a rogue rely node may provide unrestricted access to an attacker who can cause a masquerade. In certain cases false alarms can be created which will result in the rescue operations of the emergency team futile. Masquerading nodes are very dangerous in health care applications as they can apply denial of service attacks disrupting the application operation. If such a node capture the medical data of a patient, these captured messages can pose replay threats, when the medical treatment relies on fresh messages from the medical sensors, masquerade nodes replay the old messages which may lead to mistreatment and over treatment.

WSNs help patient mobility and his location can be traced with system based on radio frequency, ultrasound, or received signal strength indicator or geopositioning. If such signals are intercepted by an adversary, it could directly infringe a person's privacy. If an athlete is monitored, the adversary can modify his health data which may lead to suspicion in doping tests and spoiling of his sports career.

Denial-of-Service (DoS) attacks can be on physical, link, network and routing, transport and application layers through jamming, node tampering, collision, exhaustion, neglect and greed, homing, misdirection, spoofing, replaying, routing-control traffic or clustering messages, flood and de-synchronization, overwhelming sensors and reprogramming attack. These attacks may cause damage to the WSNs and lend to the loss of the patient's life in health care applications.

Ashraf *et al.* (2009) suggested that safety should accompany the availability, scalability, efficiency and the quality parameters of inter-node communication. For having system security safety measures have to be undertaken at administrative, physical and technical levels.

Keeping valuable and personal information in network devices leaves the data at serious risk to theft, sabotage, exploitation and manipulation. Hence for achieving information security, data encryption, data integrity, authentication and freshness protection can be incorporated.

### Security mechanisms

These mechanism help to detect, prevent and recover from security attacks. As sensitive information is handled by WSNs, strong cryptographic functions like encryption, authentication and integrity can be adopted to prevent malicious attacks. Key management protocols can be applied to distribute different types of cryptographic keys. They include trusted server, key pre-distribution and self enforcing protocols. Secure routing protocols have to be designed to avoid security vulnerabilities.

### Conclusion

WSNs make the life of people more comfortable and provide viable solutions for health care applications. As there are several security and privacy issues in WSN application, they need to be addressed at the starting point of design, deployment and implementation of any application. Thus a fool-proof security mechanism must be designed for the successful deployment of WSN application. People will trust it, if the technology is safe.

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# Sinking of ethics with MV Sewol

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## Abstract

The 2014 sinking of Korean ferry MV Sewol leaves many victims and social problems behind. It also raises many ethical problems. This paper reviews its occurrence and ethical dimensions in business and governmental ethics, media reporting ethics and seafarers' ethics. The ethical study on this accident will clarify the problems surround the disaster and can prevent further tragedy from occurring.

## Introduction

The tragic sinking of Korean ferry MV Sewol occurred on 16 April 2014. Two hundred and ninety five bodies were found dead and nine are still missing. Most of the victims were Danwon high school students on a field trip to Jeju island. The sinking was real-time and televised, without any proper

passenger rescue operation, and thus became a great shock to the Korean people.

The ferry that should have been discarded but illegally modified for overloading lost balance after the sharp turn by novice crew members at maenggol channel notorious for its strong underwater current. The improperly secured cargo fell to one side of the ship and the Sewol lost restoring force. and The ferry became tilt and began to take on water. While the authorities The Sewol sank within two and a half hours. The captain announced the passengers should stay calm and not to leave the current position. Only the passengers who disobeyed this announcement saved their lives. A few passengers who reached the deck or jumped into the water were rescued by fishing boats and other commercial vessels that arrived at the scene. More lives could have been saved if Coast Guard and Navy carried out more proper rescue operation. They did not get into the sinking ship to get any passenger out. Coast Guard even prevented Navy divers from participating while waiting for divers from Undine, a private underseas rescue operation company. Japan Coast Guard offered support, but Korea Coast Guard declined this offer. The Navy disapproved of an American warship and helicopters searching for missing passengers. The other governmental authorities such as Counter Disaster Headquarters failed to control the whole emergency situation. As the public began to condemn the government, the presidential office even denied their responsibility as a control tower.

It caused furious political reactions. Victims' families ask to investigate the reasons why 304 innocent passengers came to death being televised by mobile phone messages and youtube video clips. And they request the person in charge of this man-made disaster to be prosecuted.

Besides, there are many efforts to bring the truth of Sewol into light. Musicians play the music "A thousand winds", writers wrote the book "Nation of the blind", journalists made the documentary film "The truth shall not sink with Sewol" and the activists are on hunger strikes and advertise Sewol tragedy in foreign newspapers.

It can also become an ethical issue. The behavior of many actors involved can be judged ethically. This paper considers bleaching of business and governmental ethics, media reporting ethics and seafarers' ethics surrounding this disaster.

## Bleaching of business and governmental ethics

Chunghaejin marine bought the Japanese ship ferry Naminoue over the average life span of 15 years and illegally added a 240 passenger cabin under the patronage of Korea Register of Shipping. on the last voyage They reduced the ballast water to hide the overloaded cargo; these in a whole resulted in a balance problem. Chunghaejin Marine and Korea Register of Shipping bleached business ethics to make more profit at the sacrifice of passengers' safety.

They did not train the crew properly. The 25-year old third mate only had one year of experience in steering a ship and an additional five months of experience on the Sewol. Helmsman had only 6 month of experience on the Sewol. At the moment of accident, the captain (employed on a one year contract) was absent from the bridge and they were in control of steering the ship. There appears to have been a deficiency in training relating to emergency planning. This is an ethical issue since emergencies can happen at any time. Staff training is essential and should always include emergency training (1). And risk can be managed by following the precautionary principle. There seems to be suspicious connections among the ship owner, ship register office, navy and coast guard. These ethical bleaching and corruption altogether make simple accident into horrible disaster.

### Bleaching of media reporting ethics

The Korean media did not show enough level of professional ethics violating a set ethical guidelines on reporting disasters and major accidents provided by Journalist Association of Korea. Some reports were not correct; at first, MBC reported that all passengers have been rescued. This news was re-reported by other news media. If it were not any reports that almost all of the passengers were saved in the first few hours, the rescue operation could be more efficient. Other reports were blamed for their sensationality; the reporters desperately in need of the news materials contacted survivors and victims families and friends from the sinking ship (2).

During the capsizing, it was thought that passengers made calls and sent messages. But later some of the survivors' messages inside the capsizing ship were found fake.

Some intentionally posted the malicious hoax messages. Other who believed these messages true shared these messages. The problem worsened immeasurably when conventional media disseminated these messages to the public. Intentional or unintentional spreading of these messages may have retarded the rescue. The problem worsens immeasurably when trusted conventional media streams are utilized (3).

### Bleaching of Seafarers' ethics

Above all, the ship crews, especially the captain should be blamed not to meet ethical standards. They abandoned the sinking ship first, left many passengers on board without giving any proper information for evacuation.

It seems that we cannot blame the coast guard for not getting into the sinking ship to risk their lives but at minimum on the rule of beneficence we can blame the captain and crews members for abandoning the ship and not giving passengers information for evacuation.

The captain's ethical responsibility can be simply expressed in a phrase "the captain goes down with the ship." The captain did not make any efforts to rescue passengers under condition of minimal risk. Rule of beneficence argue that a person P has an obligation of beneficence to help another whenever the other is at risk of significant loss of or damage to some basic interest; P's action is necessary (singly or collaboratively) to prevent this loss or damages; P's action (singly or collaboratively) is likely to prevent the loss or damage; and P's action does not present significant risks, costs, or burdens to P while the benefit that the other person can be expected to gain outweigh any burden that P is likely to incur. Some legal punishments for failure by the rule of beneficence may be justified (4).

At now there is no specific international regulation on violating captain's professional ethics. While United States law does not require a captain to stay on the ship (5), Korean Seafarer Act Article 10 says "The captain must check passenger's safety and should remain on the ship during a disaster." Article 11 also says that, "The captain should try his/her best to save the passengers' lives, ship and cargoes," and Article 106 says, "Any captain who violates Article 11 shall be subjected to an imprisonment under 5 years."

In other countries such as Taiwan, the law also requires it. Taiwanese Seafarers Act Article 73 says "1. If a ship is in imminent danger, the master shall endeavor to adopt any measures to save the human lives, ship and cargoes. 2. No matter what danger occurs during navigation, the master shall not abandon the ship unless has consulted with other seafarers. Nevertheless, the master has the right to make final decision. When the ship shall be abandoned, the master shall endeavor to rescue the passengers, seamen, ship documents, mails, moneys and precious articles. 3. The

master, if violate the regulation stipulated in Paragraph 1 and 2 shall be responsible for the measures adopted by him/her." And Article 76 says, "any master who commits the provisions of Paragraph 3 of Article 73, shall be subject to an imprisonment under seven years, and subject to imprisonment from 3 to 10 years for causing death to another."

### Conclusion

The tragic sinking of MV Sewol is yet to be solved. The captain and other crews who abandoned MV Sewol are being indicted on charges of murder and abandoning the ship, but legal punishment alone is not sufficient. If we try our best to clarify the issues in many dimensions including ethical dimension, we can prevent further tragedy. If we fail, it can happen again and it will cost many lives of innocent people. It is one of ethicists' duty to consider the ethical dimension of the tragedy, mostly can be neglected.

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## Bioscience Ethics Education Challenges Learning Across the Generations

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### Abstract

There is an urgent need to reduce the gap in translating newly acquired knowledge from the bench to the classroom. With no secure, long-term solutions towards protecting our 'global' natural and cultural heritages, we must empower future generations to become sufficiently knowledgeable to best provide them with a safety net for survival. This proposal depicts a workable framework incorporating more fully ethical elements into existing educational programs as taught in science, medicine, law and economics. To facilitate reform, a commitment to update education and to expand the pool of individuals concerned about 'Global' ethics would, of necessity, facilitate path-breaking discoveries and creative opportunities for social advancement. I am convinced that newly created Education Department will enhance the pleasure of learning whilst increasing community accessibility to much needed ethics education. By working together to improve the available resources for learning, we will promote understanding and further endorse relevant themes crucial to modern bioethics. UNESCO can be a powerful and neutral platform where stakeholders with diverse backgrounds from

all over the world get together to incorporate updated education materials and create adaptive change.

## Introduction

One of the activities undertaken to disseminate information concerning the Universal Declaration on Bioethics and Human Rights, adopted in 2005 by UNESCO, is the Ethics Education Program. This program maps existing teaching material in the area of ethics in the Member States of UNESCO. Different programs are described, discussed in expert meetings, and made available on the Global Ethics Observatory website <http://www.unesco.org/shs/ethics/geobs>. Experiences concerning the contents, passion, methods and materials of existing programs are therefore publicly accessible and can be exchanged among experts. Teachers who want to research and initiate ethics teaching can find suggestions and ideas in the database.

The quality of ethics teaching programs, however, depends substantially on the quality of the teachers. Ethics teaching can be made much more influential and attractive for students if it is presented by a highly qualified, stimulating and inspiring teacher. The present proposal is an all-purpose guide highlighting possible ethical dimensions of science and is divided into two parts – general background and specifics identifying skills where I may possibly be useful in facilitating a flexible series of interconnected workshops and educational tools in bioscience ethics. The specific themes, as identified in Part 2, can readily be up-graded or adapted for team teaching and integrated as required within the overall curriculum of our fledgling UNESCO Education and Research Departments. Bioscience ethics facilitates free and accurate information transfer from applied science to applied bioethics. Its major elements are increased understanding of biological systems, responsible use of technology, and curtailment of ethnocentric debates to be more in tune with new scientific insights. Pioneered by me in 1990s, bioscience ethics has become an internationally recognized discipline interfacing science and bioethics within professional perspectives such as medicine, law, bioengineering and economics. The fundamental feature of the discipline is its breadth; thus, facilitating streamlining of significant aspects across future learning/teaching requirements while, at the same time, provide individual student/teacher choice of topic or field of endeavour.

Validating science into the teaching and practice of ethics is important because science plays a crucial role in the learning of ethical behaviour. Overlooking such critical aspects of learning must, inevitably, diminish a student's comprehension of the true natures of science and of ethics. Scientists and the population at large are frequently forced to make difficult value-laden ethical choices which may include choices between pure and often more lucrative applied research projects. Critical choices such as whether to work on military or non-military projects, whether to generate power from depleting energy sources or from renewable energy, by what means should climate change be managed are crucial to our future wellbeing. Increasingly, potential conflict between industrial developments and the ecological health needs of the planet force us to select from a variety of possible alternatives – especially since a sizable fraction of current scientific research is funded by big business or the military which, predictably, imposes restricted information access on corporate, security or other grounds. Scientists, because of their specialized training, have distinct social responsibilities to ensure that society is sufficiently knowledgeable to assist their communities make informed choices about the uses and potential abuses of science. The introduction of bioscience-bioethical themes in all education curricula should be a definite requirement since all students will need to participate,

as future citizens, in making ethically informed choices about the 'doing' of science.

## Part 1: General Background: Active Approach to Learning and Teaching

The delivery of effective education can be through face-to-face delivery, multimedia, video and online conferencing tools, podcasting lectures and 'online only' courses. When designed effectively, e-Learning has been recognised for its potential to enhance learning and to increase student accessibility to higher education. Online-based teaching programs, at their best, promote flexibility in which students listen to their i-Lectures in private and do their 'homework' in the classroom with their educators and colleagues. Typically, the focus is on the topic's most difficult aspects or on widening the concept through deliberating broader implications – all promoting valuable learning interactions.

Active learning is about learning by doing – it involves a student-focused approach and requires students to research meaningful learning activities and think about what they are doing. Active learning demands that students become co-creators of their learning; that is, teaching and learning activities and the assessment tasks require students to participate in their learning. This challenges the more passive forms of direct instruction since active learning techniques are far-reaching and may well require students to design their own activities and assessments, team learn or use group design. For example, students may choose to modify or upgrade a task, set new standards for the outcomes of the task, or mark each other's work, give feedback, and reflect on the learning research that was developed. In essence, group work provides a thought-provoking range of opportunities to engage in a wide variety of skills such as resourcefulness, critical thinking, group interaction and communication, time management, logical and succinct delivery of outcomes, leadership negotiation, conflict management and much more.

The main principle behind active learning is to directly engage and to challenge students in activities that activate both mental and physical skills and to question their own level of understanding.

### Traditional Teaching

Instructor is a knowledge transmitter.  
Students are passive learners.

Students apply acquired knowledge in tests.  
Learning is content-based, subject focused.

### Active Learning

Instructor is a problem setter and coach.  
Students actively formulate their own learning.  
Students develop cognitive learning strategies.  
Learning focus is on problem solving.

Active learning techniques are designed to harness the power of collective intelligence and network effects.

### Active Learning: Example Case Studies

1: Ask your students to choose one slide from a particular PowerPoint lecture presentation which piqued their interest and then expand on the content by providing a couple of extra slides. In this way students are actively engaged in research and acquire practical experience in delivering course materials.

2: Ask your students to write a newsprint article, or produce a video or audio news report, based on published bio-scientific research, or having the students re-write or edit a problematic newspaper article to be more accurate, more ethically balanced. This could include reference to additional media resources that clarify science-based and ethical perspectives or clarify the original data where it is available to the public.

3: Group work is where the group is responsible for delivery of a project outcome or analysis of real-world case studies and

dilemmas. Specifics might be to critically appraise the ethics of a science-based article. Students gain experience in active rather than passive reading and the critical evaluation of possible biases, or prejudices, of scientific material as presented to the general public. Another related technique is to directly engage students in the design and execution of original research, in this case both as researchers and subjects. This advanced scheme allows the educators to work alongside the students as peers rather than sitting above them as judges. A good idea is to ask each student to take on a rotating role of Presenter, Manager and Recorder in addition to a Reflector role. Leadership roles are then experienced by all members of a particular group.

We may well remind ourselves that the word 'assess' is derived from the Latin word *assidere* which means 'to sit beside' emphasizing that teachers and students sit beside each other as partners with common educational objectives. In this sense, assessment is not simply a testing and judging (ranking) instrument, but also a nurturing and mentoring tool in the learning and teaching processes.

4: Problem-based learning (PBL) is a popular technique in medical schools where rather than presenting content as in traditional classroom teaching, the teacher poses a problem for the students to solve, usually in groups. The main characteristics of PBL are:

1. Students explore real world, open-ended problems.
2. Learning is largely self-directed, including planning, implementation and evaluation.
3. The activities are usually conducted in small groups.
4. Teachers take the role of facilitators.
5. Learning outcomes emphasize not only content knowledge but also process and learning attitudes.

5: Discovery-based learning (DBL) is similar in concept to problem-based learning. The main difference is that DBL is structured around practical learning environments such as science labs. Students are required to design and construct their own investigations in order to discover fundamental principles within a particular domain; i.e., putting theory into practice.

6: Concept Maps are instructional rubrics that show students how to make a map with clear routes to their destination – they provide information and direction within the whole picture (see selected example on page 7). Using concept rubrics in education is far beyond routine learning as it is about engaging students in collaborative, active learning within a framework of social evaluation.

## Part 2: Existing Skills and Materials Available to Education or Research Departments

During the last two decades there has been a considerable increase in science information followed by rapid development of new techniques and varied applications. Applying new knowledge raises new challenges – not least the challenge of interpreting the ethical significance of any new scientific application. Despite this, and at a time when student demand for ethics education is increasing, ethics is not currently a significant part of the senior high school or university curriculum. Thus it is clear that a greater focus on science-ethics education is essential. We need to examine in greater detail the ethical questions arising out of simple everyday life events, discuss ethical dilemmas and interrogate and explore new ways of being.

It must be emphasized that children begin to develop enduring ethical standards at an early age and that these standards are realized through experiences of early childhood. The junior and senior high school years are crucial transitional years where students are most susceptible to both

negative and positive experiences. Consequently, there is a need for targeted educational programs dealing with lifestyle choices, health and wellbeing ratings, sexual experience, fertility and responsible reproduction. Long before young adults consider parenthood a desirable option, they need the opportunity to acquire adaptive biological, technological and ethical knowledge. Contemporary subjects dealing with issues as identified above should be incorporated into the school curriculum at an appropriate time that correlates with the students' biological age rather than with their chronological age.

There are many reasons for my proposal to review existing high school curricula. For instance, statistics from differing international sources (Australia, Canada and the United Kingdom, among others) have shown that girls reach puberty at a younger age and undergo menarche (first menstruation) years earlier than did girls in the middle of the last Century. This accelerated development is thought to be predominantly due to improvements in nutrition and socio-environmental change while other theories range from rising rates of obesity to endocrine-disrupting chemical ubiquitously present in our environment. The onset of puberty signals, in both sexes, a complex period of development experienced as a changing kaleidoscope of physical, cognitive, emotional and social capacities that climax in sexual maturity and full reproductive potential. Indeed, adolescence ushers in profound changes in patterns of risk taking relating to health.

Reports originating from many countries have established that adolescent sexual experience and heightened substance use are significantly interrelated. Notably, high school students are well acquainted with sexuality and have, on the whole, had experience with one or more partners before age 17. They also have ready access to tobacco, alcohol and a variety of other recreational substances. Girls, who have gone through puberty early, are twice as likely to have been pregnant or aborted a pregnancy at the age of eighteen, compared with their peers – a serious statistic impacting on the health of the present and subsequent generations. Whether the fall in the age of puberty is based on our evolutionary response to improved health and nutrition or not, we still have an ethical obligation to see that communities focus on preparing young kids for sexual maturity with all its attendant vulnerabilities whenever it might arrive. Educational guidelines for teaching sexuality should promote that all children need to know about puberty before it happens but for a growing number of primary schoolers this is not the case.

In summary, the above demographics highlight the necessity for the introduction of a coordinated course, or series of team taught programs, made available and implemented by UNESCO's Education Program, aimed at increasing reproductive understanding at a stage when the emotional ability to make serious, informed decisions is not yet fully developed. Across Australian public schools, for instance, education regarding safe sex practices is not taught in the classroom until students reach the senior years and, for early maturing girls, this may not be in time for their first sexual experience. Even lessons on reproductive biology, minus sexuality, are generally not taught until later years, making holistic understanding fragmented and uncoordinated. Conceiving and bringing up a child is the most important responsibility any adult can have and there is much to learn about interacting genetic and epigenetic variables affecting biological systems and behavioural consequences. Learning needs to be in tune with present-day reality and insights.

The present proposal aims to build a secular multifaceted course, or series of programs, informing students and their educators about important physiological changes that go on in young bodies and which may, depending on circumstance, have positive or negative effects across societies and

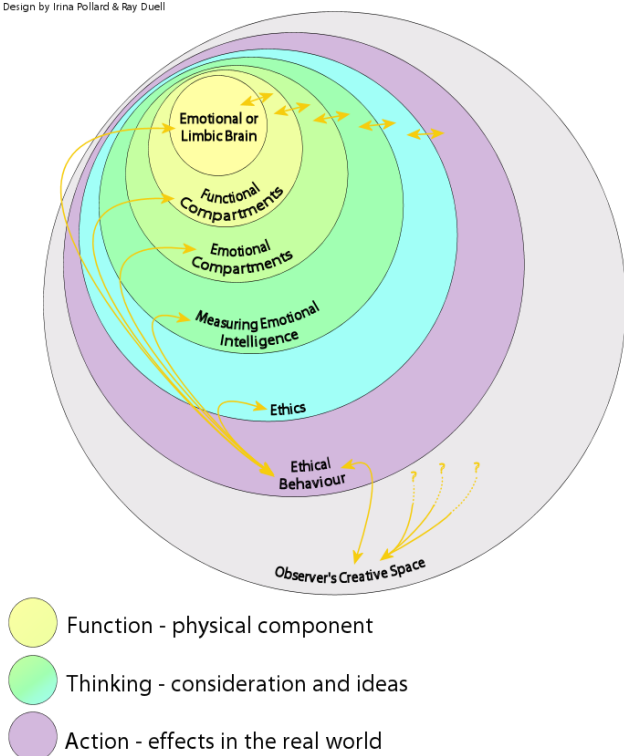
generations. The proposed programs (see 'Lecture Descriptions and Links') do not follow or impose a particular model or specific view of ethics. Rather they articulate a series of transdisciplinary topics that reflect and integrate current bioscience-bioethical theories and principles as they relate to human reproduction.

Access to additional potential projects can be found in my student text book 'Bioscience Ethics' CUP, 2009 or from my education web portal freely accessible at <http://www.bioscience-bioethics.org/>. However, in order to incorporate effective tools and innovative ideas into the classroom teacher guidance has to be provided to ensure that learning sessions are culturally appropriate. A related issue concerns assistance provided in the translation of workshop subject matters and their realization within individual schools i.e. ethics from workshop to classroom. Importantly, educational realizations need to appropriately respect adaptive local norms and diversity while also protecting secular stewardship and international rights. Some communities are also well covered by stewardship of secular ethics as expressed in mission statements or statements such as the UNESCO charter.

**Figure 1: Emotional Intelligence & Ethics – facets**

## Emotional Intelligence & Ethics

Design by Irina Pollard & Ray Duell



**Emotional or Limbic Brain** – interconnects with all outer rings and also connects exclusively with the sub-compartments via Functional Compartments (i.e. connected to = thalamus, hippocampus, amygdala, hypothalamus, pituitary gland).

**Functional Compartments** – connected to = thalamus, hippocampus, amygdala, hypothalamus, pituitary gland.

**Emotional Compartments** – connected to = perceiving emotions, reasoning with emotions, understanding emotions, managing emotions.

**Measuring Emotional Intelligence** – connect to = self-awareness, assertiveness, independence.

**Ethics** – connected to = innate, self-taught, learned, improved.

**Ethical Behaviour** – connected to = social awareness, self-management, relationships management.

**Observer's Creative Space** – connected to = newly built construction.

## Bioscience Ethics Education: Downloadable Notes and Teaching Materials

The following tools maybe used to initiate faculty undergraduate/postgraduate discussion workshops relating to possible ways of incorporating within their institutions formal bioscience-bioethics programs that supplement the mandatory curriculum.

### A: Concept Map

A concept map is a diagram, or graphical tool, showing possible relationships and is useful in the organization of particular ideas and knowledge. For example, the concept map depicted here refers to the plasticity of the human mind. The central theme or focus of this diagram is education. To this end the map provides a set of interconnecting relationships, ideas, and terms where each layer (ranging from the innermost to the outermost) can be readily linked back to its original focus. Students are invited to respond in three parts by providing links between EQ and ethics according to individual choice:

a) Consider the list of facets provided with each layer. These are suggestions rather than exhaustive lists, and you are welcome to use any of these in any combination in your essay, or devise your own (based on these examples).

b) State in your essay what you would title your outer ring (where it currently says "Observer's Creative Space"). This should be at least referred to in the title of your essay or it may even be used as your essay title. Make a number of connections between your new outer layer and the other layers, based on how you consider they interact.

c) Write an essay on how your chosen topic (the new title of your outermost ring) interacts through the connection(s) you have chosen from the Map (making sure to state what the connections are in the introduction of your essay).

### B: Downloadable i-Lecture and DVDs

Subjects covered in this lecture series promote increased awareness of self within the environment. Modules 1-3 provide an overview of topics such as the treatment and causes of infertility, growth and maturation, parental behaviour and neonate biology and examines the effects of procreational biology on the foundation of human social structure. Modules 4-6 deal with reproduction as it relates to health and social issues and reinforces the role of biotechnology in the rapid advancement of human achievements in medicine and veterinary science. Topics include stress physiology, fertility control, teratogens, human dominated ecosystems and responsible global stewardship. Other topics emphasize lifestyle and health, immune regulation, and the state of wellbeing. To facilitate learning each module is separated by a series of questions or problems that the students are expected to discuss by participating on the discussion board. Discussion's intention is to encourage thinking about what has been learned – the deeper the engagement, studies show, the better the retention. The overall gain is the opportunity to flexibly integrate and embed digital learning into the fabric of the entire curriculum.

### Selected Lectures, DVDs & Links

#### Module 1: Introduction to Bioscience Ethics & Reproduction

L1.1: [Bioscience](#) [Ethics](#) & [Reproduction](#)

The role of ethics in science and technology are explored using practical applications of reproductive functions in medicine.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=HIMFQAEKwbo>

#### L1.2: Human Origins, Natural Selection & Evolution of Ethics

Traces the evolution of ethical consciousness and relates how ethics impacts on modern science and its applications.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=SVqkVuGPJc>

### **Module 2: Human Reproduction and Development**

#### L2.1: Fertilization and the Initiation of Development

Provides an overview of human reproduction taking particular note of lifestyles, fertility and the ethics of preconceptional care.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=TW1YGbjVC4Q>

#### L2.2: Development and Placentation: Maternal-Fetal Communication

Traces the evolution of bonding, the establishment of pregnancy, placentation and epigenetic gene regulation heritable down the generations.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=MAImCoVWh4s>

#### L2.3: Patterns of Human Growth

Traces life cycle as defined by biological characteristics such as critical periods during development and factors contributing to intrauterine growth restriction and preterm births.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=D7b83yIZOdM>

#### L2.4: Sex Determination, Brain Sex & Postnatal Personality Development

Traces the foundation of adult sexuality in fetal life and explores the genetics of regular and 'hidden genders'.

YouTube link is as follows:  
[http://www.youtube.com/watch?v=hcAFMrBDF\\_U](http://www.youtube.com/watch?v=hcAFMrBDF_U)

#### L2.5: Assisted Reproduction: At the Intersection of Ethics and Social Determination

Experience a realistic simulation of routine medical assisted treatments available to couples seeking fertility assistance at an IVF clinic.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=bW0iFX7rTq0>

### **Module 3: Gender, Sexuality and Social Aspects**

#### L3.1: GL1: Transgendered: A Personal Perspective – Katherine Cummings

Introduces the evolution and wide-ranging bases of the transgendered as lived by an XY woman.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=OPSdQRUNP6E>

#### L3.2: GL2: Gender Diversity – Gina Wilson and Katherine Cummings

Traces current political activism supporting Intersex Rights and acceptance of sexual diversity.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=AyWtTaZe0eo>

#### L3.3: Human Sexuality: Behaviour & Pheromones

Describes the chemistry of attachment, desire, kinship laws and incest.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=sMSSHu9r7YI>

#### L3.4: Sociobiology

Describes the biological basis of social behaviour and fitness enhancing strategies such as sexual triggers and body image.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=fpAou13S4c0>

### **Module 4: Considerations of Effective and Ethical Reproduction**

#### L4.1: Principles of Toxicology & Teratology

Establishes a better understanding of the science of toxicology with special reference to human reproduction.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=IM268WpvA18>

#### L4.2: Substance Abuse & Parenthood

Describes the physiochemical characteristics of drugs, the neuroendocrinology of addiction and socio-political responsibilities.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=z8uUnEBOHYg>

#### L4.3: Fertility Awareness & the Aging Gamete

Causes of human congenital anomalies at birth are investigated from the biological, behavioural and bioethical perspectives.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=nsK2ySJBPMs>

#### L4.4: Parental Behaviour & the Neonate

Early developmental patterns and physiological adaptation to extrauterine life are discussed.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=gDHY6zwnwBU>

#### L4.5 Stress and Adaption: Neuroscience & Neuroethics

The biology of stress from the perspectives of sickness and health, happiness and depression, advances in neuroscience and neuroethics are examined.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=dbzzNI8ckw4>

### **Module 5: Sustainable Ethics**

#### 5.1: Social Discrimination and Health Disparity Across Generations

Challenges social discrimination and health disparity in general and in contemporary Australia.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=LU1xMSP41LY>

#### L5.2: Population Growth and Economic Dynamics

Provides an overview of economic dynamics, sustainable population growth and modern approaches to fertility regulation.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=4gpgqXBDGFGo>

#### L5.3: Human Dominated Ecosystems

Environmental priorities are re-evaluated and the effectiveness of multiple-entry bookkeeping, stewardship of Earth and the Gaia theory are assessed.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=uwkRu9mj7LA>

#### L5.4: Sustainable Peace for a Sustainable Future

Self-sustaining characteristics of the ecology of violence are challenged and whether modern warfare is fitness enhancing or a losing evolutionary strategy is questioned.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=DJT4QDRSHAY>

### **Module 6: Ethics in Society**

#### L6.1: GL3: Policy Papers: The Politics & the Ethics – Jenny Burchmore

Examines the ethical and political dimensions of policy development using case studies in fisheries and water management policy.

YouTube link is as follows:  
<http://www.youtube.com/watch?v=TLwjQq-b7ml>

#### L6.2: GL4: Sustainability Indicators – Morgan Pollard

Reviews the bioethical basis of global limits, ecological economics and UN Millennium development Goals.

YouTube link is as follows:  
[http://www.youtube.com/watch?v=f\\_7CzmohBmU](http://www.youtube.com/watch?v=f_7CzmohBmU)

#### L6.3: GL5: Ethics of Doing Science – Roger Hiller

Provides an integrated view of academic science, industrial science and military science to promote a better understanding of the ethical implications of scientific and technological developments.

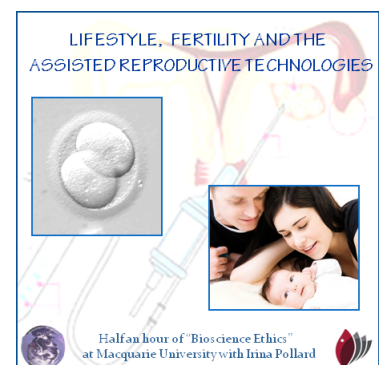
YouTube link is as follows:  
<http://www.youtube.com/watch?v=7iARiSPcTDI>

### **Lecture Associated Movies and Other Resources**

Below are two free-to-air public education movies of interest.

#### “Lifestyle, Fertility and the Assisted Reproductive Technologies”

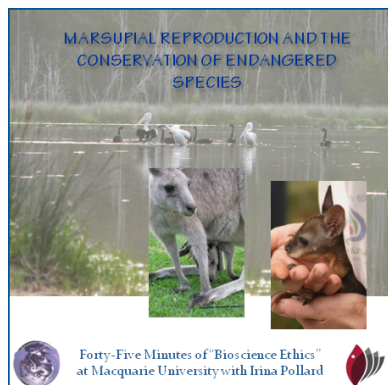
describes how our life choices and reproductive health interrelate across the generations. YouTube link is as follows:



<http://www.youtube.com/watch?v=PE69Wmmw8nU>

“**Marsupial Reproduction and the Conservation of Endangered Species**” challenges human-dominated ecosystems, portrays kangaroos in the wild and presents examples of endangered species and captive breeding programs.

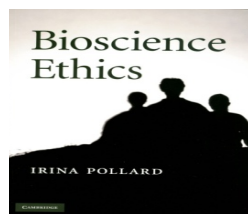
YouTube link is as follows:  
<http://www.youtube.com/watch?v=Bq0xxq49C6Q>



**The Bioscience – Bioethics Friendship Co-operative Portal** <http://www.bioscience-bioethics.org/> provides access to educational materials and other useful links for those interested in Bioscience and Bioethics.



**Student text ‘Bioscience Ethics’ by Irina Pollard** (Cambridge University Press, 2009).



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