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## **Editorial: Bioethics in East Asia**

Four of the five papers in this issue are from East Asia, so I thought it would be timely to make some comments on the development of East Asian bioethics twenty years on from the first conference of the Asian Bioethics Association, which was held in Beijing, China

in 1995, to launch the East Asian Association of Bioethics. A number of editorial board members were there, as that year also saw the launch of the full Journal (EJAIB), developing from the Eubios Ethics Institute Newsletter. In 2015 the Asian Bioethics Association will hold its 15<sup>th</sup> Conference, in Japan. There will be a further transition of ABA President, from many who have served the ABA since the inception with Professors Hyakudai Sakamoto, Renzong Qiu and Sang-yong Song, who were the founding fathers of the association. There were many other conferences held in the 1990s, and Professor Norio Fujiki and myself worked on a series of conferences in Fukui, Japan. Many of the publications of Eubios Ethics Institute document the process, a process which also assisted the development of bioethics in all regions of the world.

In this issue Dr. Kanayama presents a dialogue on listening to others, central for all relationships. Prof. Asai and Prof. Lai's papers come from the Seventh Kumamoto University International Bioethics Roundtable, that Prof. Takahashi and myself have worked hard to continue the spirit of dialogue in East Asia and develop methods for analysis. Lai looks at organ donation in Hong Kong, and then goes on to consider the much wider implications of modern medical technology. Asia looks at the future of end of life care in East Asia with a comparative study also.

Dr. Swazo explores ethics of infectious disease in a discussion of MERS, with the implications in Saudi Arabia and beyond. Prof. Wang explores stem cell debates in China. The global implications of technology and public health are clear to all readers of EJAIB, and something that the debates in East Asia can interchange with the rest of the world.

American University of Sovereign Nations (AUSN) launching our MPH and Masters in Bioethics and Global Public Health on 21 April 2014 when approved as University. I look forward to meeting many readers at conferences across the world, and the new campus and environment. Many of the issues to attempt to promote dialogue on identity and research are similar in indigenous bioethics as in Asian bioethics, and it is a journey that must be continued and developed at every step. Please follow the website. - Darryl Macer

## Naming and being named, listening and being listened to: Opening one's heart to others - Thoughts from days spent with friends from L'Arche<sup>1</sup>

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### Introduction

To think together is to walk together as "colleagues," as people who share the same hardships, while showing solidarity with the very real difficulties experienced by others. I get the sense that one of the potentials inherent in the relationship of listening is the notion of "becoming weak together." In other words, the act of listening is a process of "descending together" to face the difficult realities experienced by another.<sup>2</sup>

It was while Jesus was having dinner at Levi's house (Mark 2:15):<sup>3</sup> "Have 'I' been invited to eat at Levi's table? Or have the 'many' who have gathered at this table invited 'me'? Where is the 'I' in this scene? On whose side does it rest?"

Levi is named as a tax collector, and the many gathered at his table are named as sinners. Who defines these people as tax collectors or sinners? At first glance, "tax collector" might seem an objective name for a politico-economic or sociocultural occupation. The issue here is the social and cultural judgments imposed on the job title of tax collector;<sup>4</sup> it is the definition of sinner that plainly expresses these judgments. There are no subalterns.<sup>5</sup> Likewise, there are no people called tax collectors or sinners. These designations are nothing more than "all that he is as a material being, a being that can be spied on, defined, predicted apart from its own will, 'at second hand'."<sup>6</sup> However, those who have been abandoned in circumstances and called subalterns exist as real living people, as do those named and judged as tax collectors or sinners. However, who defines people as sinners and from what perspective? In such situations, is the "I" the one that defines or the one that is defined?

Those who name the people present at Levi's table as tax collectors or sinners are not substantial concepts, let alone relational concepts. Rather, when all is said

and done, they are nothing more than exploitative concepts indicating the power structure of those who name and those who are named. This is because the sociocultural definitions of tax collectors and sinners—in other words, "name equals judgment"—are identified as the personality of the person being defined by those who define. In addition, with regard to the definition of sinner, those who are defined as such fabricate uniformity by sharing the same name, leading to concealment of the identity and an inner hierarchy of uniformity among individuals defined as sinners.

Furthermore, the problem is not limited to the stigmatization of definitions. As Paul Freire points out, definitions are internalized by those who are defined and become adopted as identity. "Excuse us, we ought to keep quiet and let you talk. You are the one who knows, we don't know anything."<sup>7</sup> Or, another example is the "good patients/bad patients" highlighted by Judy Chamberlin: "So I gritted my teeth and told the staff what they wanted to hear. ...In short, I lied."<sup>8</sup> The "I" discussed here is dependent on the word being defined in the sense of "You are..." Those who are defined are compelled to live "forced lives." This is why, "to be oppressed means to be disenabled not only from grasping an "identity," but also from reclaiming it,"<sup>9</sup> and "being oppressed means the absence of choice."<sup>10</sup> Sayako Nobuta describes this situation as follows, "To name such conditions, to sometimes prohibit the naming of these conditions, and to prohibit all other definitions: this is what we call power. In other words, power is the right to define conditions."<sup>11</sup>

If "I" were the one being named as a tax collector or sinner, how would my voice/pain reject those who define me in order to reclaim the right to define conditions? If "I" were the one defining others as tax collectors or sinners, how would I overcome my judgment? For example, a rabbi asks, "Why is that person eating at the same table as tax collectors and sinners?" How can I listen to their voices/pain? "Who speaks? Who listens? And Why?"<sup>12</sup>

For those being defined, definitions confront the subject (Sujet) of "I" as something that should render service (sujet).<sup>13</sup> Names and definitions are things that

<sup>7</sup> P. Freire, 1996(1970), *Pedagogy of the oppressed*, M. B. Ramos,(trans.), Penguin, p 45.

<sup>8</sup> J. Chamberlin, 2013, *Confessions of a non-compliant patient*, National Empowerment Center Articles, (Retrieved January 5, 2014) <http://www.power2u.org/articles/recovery/confessions.html>

<sup>9</sup> N. Alarcon, 1991, "The Theoretical Subject(s) of This Bridge Called My Back and Anglo-American Feminism," in H. Calderon(eds.) & G. Anazaldua(eds.), *Criticism in the Borderlands. Studies in Chicano Literature, Culture, and Ideology*, Duke University Press Books, p 37.

<sup>10</sup> B. Hooks, 1984, *Feminist Theory : from Margin to Center*, South End Press, p5.

<sup>11</sup> S. Shinoda, H.Kamioka& S,Campbell, 2004, *A Labyrinth Named Abuse*, Syunjyū -sya, p.122. ; Reference of, S. Shinoda, 2003, *When the family who loves too much breaks*, Iwanami-Shoten, pp 152-153.

<sup>12</sup> B. Hooks, 1994, *Teaching to Transgress: Education as the Practice of Freedom*, Routledge, p 40.

<sup>13</sup> M. Foucault, 1976 , *Histoire de la sexualité1 : La volonté de savoir*, Gallimard, pp 111-112.

<sup>1</sup> Thoughts from days spent with "friends" from Gunma L'Arche : [http://www.larche.org/en/welcome\\_to\\_larche\\_international](http://www.larche.org/en/welcome_to_larche_international)

<sup>2</sup> I. Mukaiyachi, 2009, *Technique previously*, Igaku-Shoin, p 116

<sup>3</sup> Refer to the NIV for the Bible.

<sup>4</sup> H, Mizushima, 2010, *Facing the reality of trauma*, Iwasaki-Gakujyutu-Pr , pp 7-8. Please refer to the item about the distinction p 20. in the "judgment" and "assessment".

<sup>5</sup> G. C. Spivak, 2010, "Can the Subaltern Speak?", R. C. Morris(ed.), *Reflections on the History of an Idea*, Columbia Univ Pr, p 21.

<sup>6</sup> M. M. Bakhtin, 1984, *Problems of Dostoevsky's Poetics*, C. Emerson(trans. ed.), Univ of Minnesota Pr, p 59.

consume “I” from the foundations. The fact that this discrepancy exists in names relating to oneself, between the inner and outer “I,” is a source of great anxiety to me.

Irrespective of whether “I” only allows discussions of words permitted by the things that define me, it is possible to redefine one’s circumstances through other methods. However, the existing circumstances mean that there are no words which enable those who have been forcibly defined to salvage their own experiences.<sup>14</sup> In this case, what should be done to recapture one’s letters and words? How can a person reclaim his or her words? How should one narrate one’s own experiences?

For Jun Hozumi, words were not merely tools for self-expression or communication, let alone for recreation or signs. “Words are food for living, recuperation, and growth; having words determines our very way of life. The discovery of words made it possible to subvert our insalubrious selves and our worlds, and it was through the discovery of words that we were able to build new worlds and selves.”<sup>15</sup> Thus, words existed as a means of supporting life. At the same time, as Nobuta points out, the discovery of words is also a process of “becoming”<sup>16</sup> a person.

It was the discovery of the words “I am a victim” that proved to be the biggest turning point in my life. For me, who had thought of myself as an accomplice, the word “victim” was a revelation.<sup>17</sup>

The use of words such as domestic violence, abuse, victim, and perpetrator redefines the definitions of circumstances that had hitherto been taken for granted. While empowerment tends to be viewed as giving power to another party, the usage of the word in fact shows that a redefinition has already begun.<sup>18</sup> As such, it is the generation of awareness of the dominant story<sup>19</sup> that defines the conditions for survival. “The story changes through the discovery and naming (of this).”<sup>20</sup> The voices/pain of those who have been named are now being heard, but how?

As Freire points out, the solution is “to transform that structure so that they can become ‘being for themselves’.”<sup>21</sup> To unilaterally define circumstances is to enforce the values of those defining the circumstances. However, for the oppressed, it means that “their ideal is to be men; but for them, to be men is to be oppressors”<sup>22</sup> and that “the oppressed...are at the same time themselves and the oppressor whose image

they have internalized.”<sup>23</sup> This led to Hozumi’s discovery of the word victim, and it also forms the experiences of those who continue to be robbed of the right to define situations encountered by Nobuta.

How can people forced into such difficult circumstances become aware of the circumstances that make their lives so difficult without internalizing them? They need “to find one’s own voice and to orient it among other voices, to combine it with some and to oppose it to others, to separate one’s voice from another voice with which it has inseparably merged.”<sup>24</sup> “Their own language, which, emerging from and returning upon their reality, sketches out the conjectures, the designs, the anticipations of their new world.”<sup>25</sup> Freire proposes the manner of living through a problem-posing education. This gives rise to the perspective that “if it is in speaking their word that people, by naming the world, transform it, dialogue imposes itself as the way by which they achieve significance as human beings.”<sup>26</sup> “Here no one teaches another, nor is anyone self-taught. People teach each other, mediated by the world,”<sup>27</sup> and “problem-posing education affirms men and women as being in the process of becoming.”<sup>28</sup> Within issue-based education (practice), the generated themes and codes are selected from real circumstances for those who have been defined. “In the process of decoding, they began to see how they have been acting in the past, thus reaching a ‘perception of their previous perception’. By achieving this awareness, they come to perceive reality differently.”<sup>29</sup> Eventually, attempting to solve each respective situation is the basis for a realistic resolution of differences between the respective situations as well as the various biases and prejudices that these entail.

What is proposed here is that the coexistence of talking, listening, and teaching equals mutual learning in other mutual self-help groups; further, underlying both talking and listening is a single narrative community<sup>30</sup> built upon the method of living known as “do by oneself together.”<sup>31</sup> What these methods have in common is the recapture of (subject [word] = subject [as an entity]) in the form of “I.” “Stop thinking only of others and start ‘living for myself’; “change the subject to ‘I’ when thinking, talking, and acting”; and “make a clear distinction between myself and others.”<sup>32</sup> Doing such things will lead to a transition to “the ability to say ‘I will’”<sup>33</sup> and from “your message” to “my message.”<sup>34</sup>

<sup>23</sup> Ibid, p 43.

<sup>24</sup> M. M. Bakhtin, 1984, *Problems of Dostoevsky’s Poetics*, C. Emerson. (trans. ed. ), Univ of Minnesota Pr, p 239.

<sup>25</sup> P. Freire, 1996 (1970), *Pedagogy of the oppressed*, M. B. Ramos, (trans.), Penguin, p 60.

<sup>26</sup> Ibid, p 69.

<sup>27</sup> Ibid, p 61.

<sup>28</sup> Ibid, p 88.

<sup>29</sup> Ibid, pp 140-141.

<sup>30</sup> Y. Noguchi, 2002, *Care as a narrative*, Igaku-shoin, pp 178-180.

<sup>31</sup> The house of Bethel, 2005, *The party study by “The House of Bethel”*, Igaku-Shoin, p 45.

<sup>32</sup> S. Shinoda, 1998, *Rule named love*, Kairyu-Sya, p43.

<sup>33</sup> H. Kamioka, H. Oshima, 2010, *Then challenged*, Igaku-Shoin, p55.

<sup>34</sup> M. Saito, 2010, *Wish I do not cure*, Misuzu-Shobo, p159.

<sup>14</sup> T. Kanai, 1989, *Postmodern feminism*, Keiso Shobo, p 111.

<sup>15</sup> J. Hozumi, 2004, *Soul extension*, Kobunken, p 102.

<sup>16</sup> S. Shinoda, 2003, *When the family who loves too much breaks*, Iwanami-Shoten, pp 165-166.

<sup>17</sup> J. Hozumi, 2004, *Soul extension*, Kobunken, pp102-103.

<sup>18</sup> S. Shinoda, H. Kamioka, & S. Campbell, 2004, *A labyrinth called abuse*, Syunjyū-sya, p 125.

<sup>19</sup> S. Shinoda, 2003, *When the family who loves too much breaks*, Iwanami-Shoten, p 154.

<sup>20</sup> S. Shinoda, 2003, *DV and abuse*, Iwanami-shoten, p102, p 155.

<sup>21</sup> P. Freire, 1996(1970), *Pedagogy of the oppressed*, M. B. Ramos, (trans.), Penguin, p 55.

<sup>22</sup> Ibid, p 27.

On the other hand, for those who have chosen self-harm as a means of survival, it involves having them change their words when discussing their acts of self-harm from "I cut myself" to "I was forced to cut myself."<sup>35</sup> At first glance, this appears to surrender the status of (subject [word] = subject [as an entity]); however, "once people step back into the perspective of an observer and divorce themselves from reality, reality comes back to oneself during the course of examining things with other members of the group. ...As an experience of human affairs, one reconstructs and reclaims oneself once...and then accepts this is who they are."<sup>36</sup> In other words, this is talking and listening as the paradoxical event of "do by oneself together" and "active acceptance," while changing the subject of one's utterances and receiving support from fellow self-help group members. "I cannot think for others or without others, nor can others think for me."<sup>37</sup> "Dialogue, as the encounter among men to 'name' the world, is a fundamental precondition for their true humanization."<sup>38</sup>

Thus, while accompanying the recovery of (subject [word] = subject [as an entity]) and engaging in the joint task of supporting fellow group members, changing one's words, and talking about or listening to new words, the "I" that had its right to define circumstances stolen and that lived through the words of the "stronger person" provides a redefinition of the circumstances and a sense of "I" through the new word "we." However, no matter how much support is received from fellow members, talking about oneself is very painful and exhausting for those forced to live through words resulting from enforced definitions amidst defined circumstances. "Talking is tough. Whenever I talk, invisible blood begins to spurt from my body. This is because talking is essential for reclaiming one's life."<sup>39</sup>

2. "I have told you already and you did not listen. Why do you want to hear it again?" (John 9:27)<sup>40</sup>

For those who define, "listening" should not merely be about listening to the other person's words. It is about accepting those who utter words within conditions and creating places where it is possible to listen, which in turn should lead to transformations in the nature of the "I" that strives to listen. Insights that Akihisa Teramoto gained in the course of his involvement in activities with people with intellectual disabilities provide hints regarding the nature of power structures surrounding listening.

The mentally deficient behaviors of people with intellectual disabilities are in fact not due to "disabilities" but are "learned" behaviors. Many of their so-called

disabilities are "created" as a result of having been placed in unnatural environments divorced from normality. They are at a social disadvantage because they lack the requisite services. But are they really "incapable"? Is it not that they are being "rendered incapable" rather than genuinely incapable?<sup>41</sup>

It is the non-handicapped rather than the handicapped who should be the subject of scrutiny. The structure of being questioned about capability becomes an issue of management or control in a workfare context. "How can I 'support' them so that they can do it? How can I make them understand?" As Nobuta argues, "trying to change another person is to control that person."<sup>42</sup> In trying to change another person or to escape from relationships of dominance, "it is perfectly possible for the person providing support to understand the person they are dealing with and to change."<sup>43</sup> The subject of continual questioning through contact and being with the other person is not the nature of the other but that of the "I."

By nature, empowerment education refers to struggling to make "those who lack competence" reach a level of intellectual ability on par with "those in power." As such, it results in the type of society that while superficially multicultural, is in fact a form of multiculturalism that retains the privileges of those in power. Here, we see an attempt to avoid becoming vulnerable on the part of those in power.<sup>44</sup>

Dealing with people as individuals with a name and face rather than individuals in the category of "handicapped" will lead to generating words that the "I" does not expect. Can people realize that the denigration of these unexpected words as "abnormal" or "deviations" is nothing but violence? Rather than treating the people one encounters as "the other," it is the sensitivity to the "otherness" that the other person momentarily reveals. It is to face existences of a kind that transcend imagination, with "the other as the other."

Those involved in medical and healthcare settings are known as helpers. Regardless of whether they are aware of this, those in the position of helper seek to truly become helpers. This also merely reflects acting out the asymmetrical relationship of "user." It is this asymmetrical relationship that leads to the imposition of values in the form of "you must do this," "you should do this," or "I want you to do this" under labels of "individual support" and "help." The act of helping gradually paralyzes the self from the recipients of help, abandoning them in a state of thoughtlessness in which they are uncritical toward the outside world. This is not how it should be; Mr. A should depict Mr. A's own life story. Even considering things that for helpers seem to be "mistakes," they should embrace Mr. A's own life story. They should listen to different life stories and the

<sup>35</sup> I.Mukaiyachi, 2009, *Technique previously*, Igaku-Shoin, p58-59.

<sup>36</sup> I.Mukaiyachi, Y.Nanb & M.Higuchi.2012, *Wrist Slash: Expert three-man talks*, Psychiatric Mental Health Nursing, Volume.15, No.5, p61.

<sup>37</sup> P. Freire, 1996(1970), *Pedagogy of the oppressed*, M. B. Ramos, (trans.), Penguin, p89.

<sup>38</sup> Ibid, p118.

<sup>39</sup> J.Hozumi, 1994, *The reviving soul*. Kobunken, p.274.

<sup>40</sup> Refer to the NIV for the Bible. NIV(*The New International Version of the Bible*), Zondervan, 2012.

<sup>41</sup> S.Shinoda, 2003, *DV and abuse*, Iwanami Shoten, p27.

<sup>42</sup> S.Shinoda, 2003, *When the family who loves too much breaks*, Iwanami Shoten, p66.

<sup>43</sup> S.Iwahashi, A.Teramoto & H.Suenaga 2008, *About good support?*, Seikatsu-Shoin, p133.

<sup>44</sup> Tanaka, N, 2000, *Beyond the Japanese education*, Alk, P370.



associated (social) values that have been internalized. In other words, one should stand firm in the presence of “negative things.”

“Solving without solving” is one means of escaping from such power structures.<sup>45</sup> This is to move away from the power structure of “Who? Whose? What? And How?” inherent in the stance of solving to an interactive structure of “For whom? What seems to be the problem? And how can we change our perspective?”<sup>46</sup> However, Hiroshi Matsunaga warns against asking the person concerned.<sup>47</sup> He points out that questions always hide the intentions of the person asking, and they result in verbalizing that person’s intentions to the one being questioned. Rather than asking, Matsunaga suggests that it is important to watch a person’s expressions and gestures. In this sense, “listening” does not refer to understanding but to “I” standing beside “you” and being together; this is the method of continuing to watch your overall appearance.<sup>48</sup>

However, helpers are located within internalized circumstances. This is because the gaze aimed at each individual and the manners facing them are all defined through circumstances that they reproduce. In the course of encountering their voices/pain and appearance, one should welcome their words, gaze, and thoughts in and of themselves as well as leave incomprehensible things as incomprehensible and things that are hard to accept as hard to accept. However, how does one go about this?

To begin with, stop questioning things without first abandoning the power structure of being named. As Nobuta points out, in power relations, “if a person strives to take a neutral stand, they will definitely stand on the side of the stronger party,” and “there is a need to clarify one’s position—whose side to take and who to align with.”<sup>49</sup> In other words, to clothe oneself in the guise of neutrality and then not reflect on one’s own position is to hide behind the right to define conditions that some exercise. Therefore, the following is required: to “shelve the words”<sup>50</sup> that you have internalized, to abandon the words that define conditions, not possessing the other person through one’s own words, and returning to a position of not understanding the other person through words. In other words, accept a range of voices/pain as they are and accept each individual’s voices/pain as their own. No matter how small or delicate the voice, strive to listen to it. Welcome each and every voice/pain, irrespective of your own preferences. Listen to a range of voices/pain and enable the creation of places where these voices/pain can be heard.

3. The one who receives instruction in the word should share all good things with their instructor. (Galatians 6:6)<sup>51</sup>

The fact that there are those who have the right to define conditions and steal others’ right to define conditions means that an asymmetry exists between voices. Here, voices/pain from a range of individuals are erased by the voices of the powerful or a single voice. This is not how things should be; there is a need to transcend such conditions and enable a range of voices to be heard that have thus far remained internalized, such as the unique voices of individuals who have been named and the unexpected voices of those who name. Even intensely provocative words and voices would be welcome, as would “faltering broken words, or words that cannot be formed when tried—the moments of drawing breath or the tears that well up when trying to voice such words.”<sup>52</sup>

Narratives are always addressed to someone. “To ask someone to listen is an all-out call from one subject to another; to ask someone to listen is to invite someone to come into contact with your being and know your existence.”<sup>53</sup> To answer this call, we pose this question: are not this and the act of listening, in which the listener attempts to accept the pain, suffering, and sorrow of the person talking through that person’s narrative, both things that should be done?

For Mikhail Bakhtin, voices are “social events of communication”<sup>54</sup> or “a moment in the continuous process of verbal communication.”<sup>55</sup> Put another way, all words are expressions and products of social interaction among speakers (producers), listeners (readers), and subjects of discussion (third parties), and “when discourse is torn from reality, it is fatal for the word itself as well.”<sup>56</sup> Therefore, words are encounters between ranges of individual voices and are sociocultural, socioeconomic, and historic events. These many individual voices/pain are also “a plurality of independent and unmerged voices and consciousnesses,”<sup>57</sup> “but [are] as a whole formed by the interaction of several consciousnesses, none of which entirely becomes an object for the other.”<sup>58</sup> They are events of encountering or failing to encounter voices/pain as such things. “The word is born in a dialogue as a living rejoinder within it; the word is shaped in dialogic interaction with an alien word that is already in the object. A word forms a concept of its own

<sup>51</sup> Refer to the NIV for the Bible. NIV (*The New International Version of the Bible*), Zondervan, 2012.

<sup>52</sup> N.Tanaka, 2000, *On that direction of Japanese language education*, Alk, pp 43-44.

<sup>53</sup> R.Barthes, 1984, *L'obvie et l'obtus*, Editions du Seuil, p. 220.

<sup>54</sup> M. M. Bakhtin & V. N. Vloskin, 1986, *Marxism and the Philosophy of Language*, L. Matejka (trans.) & I. R. Titunik(trans.), Harvard University Press, p 47.

<sup>55</sup> Ibid, p95.

<sup>56</sup> M. M. Bakhtin, 1996(1981), “DISCOURSE IN THE NOVEL”, M. Holquist,(ed. trans.) & C. Emerson, (trans.) , *The Dialogic Imagination: Four Essays*, University of Texas Press, p353.

<sup>57</sup> M. M. Bakhtin, 1984, *Problems of Dostoevsky's Poetics*, C. Emerson,( ed. trans.), Univ of Minnesota Pr, p6.

<sup>58</sup> Ibid. p18.

<sup>45</sup> Noguchi.Y, 2002, *Care as a narrative*, Igaku-Shoin, p. 94.

<sup>46</sup> The house of Bethel. 2002, *The non-helping theory of the house of Bethel*, Igaku-Shoin, p. 182.

<sup>47</sup> H.Suenaga, S.Iwahashi & A.Teramoto, 2008, *About good support?*, Seikatsu-Shoin, pp. 200-201.

<sup>48</sup> S.Sato, 2011, *Power which produces care*, Tajima Shoten, pp 111-112.

<sup>49</sup> S.Shinoda, 2003, *DV and abuse*, Iwanami Shoten, p 98, pp158-159.

<sup>50</sup> S.Matsumoto,(1999), About "sympathy", S.Ozaki.(Ed), *Power of swinging*, Seishin Syobo, p 80.

object in a dialogic way.”<sup>59</sup> Therefore, the events of talking and listening emerge as events in sociocultural, socioeconomic, and historic contexts, as multiple events in line with the plurality of voices/pain and as the voices uttered by each individual.

Encounters with these events are what Bakhtin indicates as dialogue. “*One can only relate to them dialogically. To think about them means to talk with them; otherwise they immediately turn to us their objectified side.*”<sup>60</sup> Only joint dialogical work makes enables both talking about and listening to each individual’s voice.

Only a dialogic and participatory orientation takes another person’s discourse seriously, and is capable of approaching it both as a semantic position and as another point of view. Only through such an inner dialogic orientation can my discourse find itself in intimate contact with someone else’s discourse, and yet at the same time not fuse with it, not swallow it up, not dissolve in itself the other’s power to mean; that is, only thus can it retain fully its independence as a discourse.<sup>61</sup>

The form of dialogue proposed here “does so with someone about something.”<sup>62</sup> Problems, troubles, and crises are understood and shouldered together; through love, people become involved with the concerns of others. There is a rewriting of each other’s words, a loving encounter between people in order to understand, explain, and transform reality to a deeper level or to encounter new words and discover new meanings.<sup>63</sup> In other words, as we have seen, through retrieval of the right to define a situation, this creates an event where one delivers his/her voice/pain to “I.” That is, these are events in which multiple “Is” listen to each other without integrating (forcing to integrate) the voice of the stronger party as things between “I” and individuals who present their voices through the recapture of their right to define conditions, as well as events as transformations created with them. Therefore, the event of dialogue is an extremely political inquiry.

When viewed in this manner, the event of dialogue in which one encounters or fails to encounter individuals’ voices/pain is an invitation to unlearn,<sup>64</sup> unteach, and self-disempower<sup>65</sup> them, guided by these individuals, who present their voices/pain to “I.” Within this world’s

dominant narratives, for those who have been able to weave their own narratives in line with these systems, what is the nature of these dominant narratives? Have they harmed others along with themselves? It is through the voices of those who have been defined that one’s own ways of living are re-apprehended in a critical light or as “the given and the created in a speech utterance.”<sup>66</sup> To those who have obtained a certain degree of status within these dominant narratives,<sup>67</sup> this must seem far removed from the dominant narratives. Is this possible? It is through their voices/pain that the circumstances through which I live are problematized. In other words, the ways of living in which one tries to listen to their voices/pain are taught through these events. One is thus repositioned to being taught by the voices/pain of others.<sup>68</sup>

Paradoxically, this does not mean that I interpret their voices/pain as objects but can accept them in and of themselves. Instead, these are events through which we encounter each other by descending together from these dominant narratives; however, in all cases, to be accepted also means failing to be accepted. Therefore, this is something that continues to change during the process of as well as en route to understanding.<sup>69</sup>

To be means to communicate dialogically. When dialogue ends, everything ends. Thus dialogue, by its very essence, cannot and must not come to an end.<sup>70</sup>

The end of dialogue means that a range of voices/pain are exploited, misappropriated, and shrouded by the voices of those in positions of power. Or, “if something occurs with the ability to construct subjectively comprehensible narratives, the ‘eventness’<sup>71</sup> of events—in other words, the event of dialogue itself—disappears. It is precisely for this reason that dialogue must come to an end. “*As long as a person is alive he lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word,*”<sup>72</sup> and “*human beings constantly create and recreate their knowledge, in that they are inconclusive, historical beings engaged in a permanent act of discovery,*”<sup>73</sup> and “*unfinished, uncompleted beings in and with a likewise unfinished reality.*”<sup>74</sup> It is precisely

<sup>66</sup> M. M. Bakhtin, 2013(1986), “The Problem of the Text”, V. W. McGee,(Trans.) , M. Holquist,(eds) & C. Emerson, (eds), *Speech Genres and Other Late Essays*, University of Texas Press. p119.

<sup>67</sup> The house of Bethel. 2002, *The non-helping theory of the house of Bethel*, Igaku- Shoin, p40.

<sup>68</sup> H.anderson & H.Goolishisn, “The Client is the Expert. ”, S. McNamee (eds)& K,Gergen (eds),1992, *Therapy as Social Construction: Inquiries in Social Construction series*, SAGE Publications Ltd, pp32-33.

<sup>69</sup> Ibid, p29.

<sup>70</sup> M. M. Bakhtin, 1984, C. Emerson,(trans.ed.), *Problems of Dostoevsky’s Poetics*, Univ of Minnesota Pr, p252.

<sup>71</sup> N.Tanaka, 2000, *On that direction of Japanese language education*, Alk, pp. 44-45.

<sup>72</sup> M. M. Bakhtin, 1984, C. Emerson,(trans.ed.), *Problems of Dostoevsky’s Poetics*, Univ of Minnesota Pr, p. 59.

<sup>73</sup> P. Freire, 2008, (1974), “Extension or communication”, L.Bigwood & M.Marshall,(trans.), *Education for Critical Consciousness*, p. 107.

<sup>74</sup> P. Freire, 1996(1970), *Pedagogy of the oppressed*, M. B. Ramos,(trans.), Penguin, p. 65.

<sup>59</sup> M. M. Bakhtin, 1996(1981) ,”DISCOURSE IN THE NOVEL” .M. Holquist,(ed. trans.) & C. Emerson,(trans.) , *The Dialogic Imagination: Four Essays*, University of Texas Press, p279.

<sup>60</sup> M. M. Bakhtin,1984, *Problems of Dostoevsky’s Poetics*, C. Emerson,( trans. ed.), Univ of Minnesota Pr, p68.

<sup>61</sup> Ibid, p64.

<sup>62</sup> P.Freire, 2008(1974),“Education as the practice of Freedom”, M. B. Ramos ( trans. ed.), *Education for Critical Consciousness*, Continuum, p41.

<sup>63</sup> T.Anderson, ”Reflections on Reflecting with Families.”S.McNamee(eds) & K,Gergen (eds),1992, *Therapy as Social Construction: Inquiries in Social Construction series*, SAGE Publications Ltd, pp58-59.

<sup>64</sup> S.Turumi, 1999, *The trial to educational redefinition*, Iwanami Shoten, p107.

<sup>65</sup> N.Tanaka, 2000, *On that direction of Japanese language education*, Alk, p289, p345, p372.

because of this that dialogue does not end. The untested feasibility<sup>75</sup> of dialogue continues to resound with the voices/pain of being together at the sites where individuals' voices/pain issue forth. As a result, it continues to transform the conditions. However, as long as the other person does not know how the listener receives what they say, it is equivalent to being unheard. But how can they know?

Lived words are engraved deeply with pain, suffering, weakness, and despair. *"The words point to an experience; they are not the experience... Hence being is indescribable in words and is communicable only by sharing my experience."*<sup>76</sup> The creative communion<sup>77</sup> with these individuals who are offering their voices/pain continues to be created together. Therefore, by teaching the voices/pain of individuals together, it should be possible to be aware of conditions, make objections, and in turn change one's own words and behavior. Given that *"the human word is more than mere vocabulary, it is word-and-action,"*<sup>78</sup> is it not the case that, through words, in order to be, it must become?<sup>79</sup>

Ikuyoshi Mukaiyachi of Bethel's House proclaims that through connections with people with mental disabilities, *"to become sick", this element or tendency of 'becoming' is one of the important potentials wielded by human beings.*<sup>80</sup> What "I" demands within these conditions in which asymmetrical voices exist is to learn the experiences of those who have been called *"mentally challenged."* In the words of feminist S. Phelan, we can express this as *"(be) coming out,"*<sup>81</sup> as a transformative behavior, which refers to an event wherein those in a position to define respond to objection by those who are defined. In other words, seeking future words equals to a response<sup>82</sup> together. This is to jointly create a different society in which people can live without anxiety,<sup>83</sup> in which the power relations between us and those who present their voices/pain are subjected to constant scrutiny and are overcome, and in *"a fully realized and thoroughly consistent dialogic position."*<sup>84</sup>

Authentic communion implies communication between men, mediated by the world. Only praxis in the

context of communion makes conscientization a viable project.<sup>85</sup>

Events are encountered during the course of *"descending"* together and discovering new words together. Offering "I" together is a response to the voices/pain of individuals. *"Separating people and problems"*<sup>86</sup> as a result comprises a single communion and affects major changes to the significance inherent in names within it. I aim to move from unilateral definitions toward an event in which *"I receive my name from other people and my name exists for other people."*<sup>87</sup>

## Conclusion

Words reproduce a real range of feelings within ourselves, including a type of despair generated while confronting vulnerabilities that we do not want to see, let alone show others. Moreover, *"if there is nobody to hear [weak and small voices/pain], then the narratives that they issue forth are the same as talking to oneself and will disappear on the spot."*<sup>88</sup>

It is important to make one's voice/pain heard and to hear those of others. Listening to voices/pain together through multiple "Is" means talking to each other and making each other heard. The voices/pain of multiple individuals create a single narrative community. To welcome presented voices means to descend and become weak together.<sup>89</sup>

Voices/pain as calls to transform are resistant to conditions. Irrespective of whether I am aware of it, "I" cannot forget the pain of having enforced pain on others within these systems. However, can the voices that they present and the response of the "I" who enforces them permit this mutual dialogue? Together, we will seek transformations of systems by changing the words and behaviors of "I" while wishing for this *"permission."* We will continue to (be) coming out and behaving through thoughts, words, and deeds.

Jesus arrived at Levi's table. The communion presented to each individual at this table was created. Connections are created through listening to voices/pain. Thus, *"but as a whole formed by the interaction of several consciousnesses, none of which entirely becomes an object for the other, even the observer is converted to a participant."*<sup>90</sup> This is an invitation to hear their voices. *"The reading and writing of the word would always imply a more critical reading*

<sup>75</sup> M. M. Bakhtin, 1984, C. Emerson,(trans.ed.), *Problems of Dostoevsky's Poetics*, Univ of Minnesota Pr, p. 68.

<sup>76</sup> E.Fromm, 1979(1976), *To Have or to Be?*, Abacus, p. 92.

<sup>77</sup> P. Freire, 1996(1970), *Pedagogy of the oppressed*, M. B. Ramos,(trans.), Penguin, p. 30.

<sup>78</sup> P.Freire, 2000(1970), *Cultural Action for Freedom*, Harvard Educational Pub Group, p. 21.

<sup>79</sup> P. Freire,1996(1970), *Pedagogy of the oppressed*, M. B. Ramos,(trans.),Penguin, p. 65.

<sup>80</sup> I.Mukaiyachi, Y. Yoshiharu & T. Kawamura, 1996, *House of Bethel teaches*, Hakushindo-bunko Vol.20, p. 39.

<sup>81</sup> S. Phelan,1993, *"(Be) Coming Out"*, *Lesbian Identity and Politics*, Vol.18, No.4, Theorizing Lesbian Experience, p. 773.

<sup>82</sup> P. Freire,1996(1970), *Pedagogy of the oppressed*, M. B. Ramos,(trans.), Penguin, p. 94.

<sup>83</sup> T.Kanai, 2008, *Society which can be differed*, Akashi Syoten, p.4,p. 206

<sup>84</sup> M.M.Bakhtin, 1984, C. Emerson,(trans.ed.), *Problems of Dostoevsky's Poetics*, Univ of Minnesota Pr, p. 63.

<sup>85</sup> P. Freire, 2000(1970), *Cultural Action for Freedom*, Harvard Educational Pub Group, p. 105.

<sup>86</sup> I. Mukaiyachi, 2009, *Technique previously*, Igaku-Shoin, p. 128.

<sup>87</sup> M. M. Bakhtin, 1976, *"План доработки книги проблемы поэтики Достоевского"* ( *On Revising Problems of Dostoevsky's*) Контекст-1976,Москва,Наука,1977,p. 312.

<sup>88</sup> Y.Noguchi, 2002, *Care as a narrative*, Igaku-Shoin, p. 42.

<sup>89</sup> I. Mukaiyachi, 2009, *Technique previously*, Igaku-Shoin, p. 48.

<sup>90</sup> M. M. Bakhtin, 1984, C. Emerson,(trans.ed.), *Problems of Dostoevsky's Poetics*, Univ of Minnesota Pr, p. 18.

of the world as "route" to the "rewriting" or the transformation of the world."<sup>91</sup> But to whom?

My own answer was given to me by friends from L'Arche. Today, an extraordinary number of people are lost, searching for ethical standards of a kind that nobody has anymore and questioning the meaning of life. Through L'Arche and two previous experiences, I discovered the importance of two requirements in life. One is to give people's lives meaning, both tender-hearted people with no religion and those who are searching for God, regardless of their religion. Another is to have an open heart and a clearly defined self (self-integrity). Only when we achieve these things will we establish ourselves through the places where we live, our families, cultures, education, and physical or emotional conditions.

An open heart does not mean weakness and it does not permit one to disregard the truth or justice. An open heart also does not mean that you are subordinate to the ideology of others. It is to be truly merciful and willingly accept other people; it means to listen to people, especially those who are weak, poor, or oppressed. By doing so, we can live in relation to such people.<sup>92</sup>

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## Application of Takahashi's Three-Level Structure Analysis to Biomedical Ethics in End-of-Life Care in East Asia in Consideration of Future Normative Ethical Directions: A Brief Report

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### 1. Introduction

The aim of this research is to investigate current situations concerning end-of-life care in Korea and other East Asian countries through literary analysis and to identify Takahashi's three levels of structure in biomedical ethics at the end of life in East Asia. This research also attempts to form a model for the future direction of normative bioethics in the area. Data will include quotes from several passages and results from English and Japanese publications, and will include newspaper articles, court decisions, official guidelines, and cross-cultural academic literature.

Culture represents the totality of ideas, beliefs, worldviews, values, attitudes, customs, traditions, social

behaviors, roles, human relationships, and communication patterns shared by or characteristic of a particular group. Such cultural groups may consist of communities, religious groups, societies, or nations. Culture is transmitted from generation to generation, and distinguishes the members of one group from another in diverse human activities. It should be noted that cross-cultural studies, such as the current one, have serious limitations when viewed from an ethical standpoint. For instance, dividing West and East is naturally too simplistic. There are various countries in both the East and West, with differences between individuals, generations, families, and regions, even within the same culture. Some aspects of culture change over time, while others remain constant. Some aspects may be common across diverse cultures, but individuals can significantly change their personal perspectives during their lives (1).

There exist clear differences in ethical attitudes toward end-of-life care, as well as the resources and standpoints used in investigating this topic. Many different ethical attitudes exist, even within the same country, as exhibited by the different resources and standpoints from which opinions are expressed. Such differences in perspective may stem from individual characteristics (age, generation, sex, education, income, religious faith, attitudes toward life and death, etc.), personal roles within the family (child, parent, spouse, blood relative, etc.), professional roles, official guidelines (soft laws), court decisions and legislation (hard laws), and academic papers concerning cultural traditions and morality.

Macer argued that to understand ethical viewpoints, in-depth cross-cultural dialogue and study is necessary, rather than defining belief systems as either Asian or non-Asian. Within cross-cultural ethics, it is interesting to observe the point at which something is defined as distinctly "Japanese" or "Asian" or "British." This point may depend upon what literature and practices the observer is familiar with (2).

Macer goes on to argue that there are key words that emerge from Asia, such as harmony and tolerance, respect and reverence, and ambiguity. There is diversity within every society regarding each individual's bioethics, as well as the relationships that shape a person's balance of principles and ideals. Although Asia has a rich tradition in viewing life, there remains a gap between the real world and the ideal. Few ideals for respecting life are actually applied to everyday situations, such as deciding how to use medical technology. However, this reality may not be all that different from clinical situations in most societies. Comparative ethics must break away from ethnic and cultural generalizations, and must begin to critically examine words, motives, and actions (2).

Blank highlighted the dangers of applying policies that appear to work in one country to another country, and noted the use of cross-national research in expanding the range of options open to policymakers. In this way, policymakers are able to explore the experiences of their counterparts in other jurisdictions in dealing with similar problems (3).

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<sup>91</sup> P. Freire, 2004, *Pedagogy of Hope, Reliving Pedagogy of The Oppressed*, R. R. Barr, (trans.) Bloomsbury Academic New, p. 33.

<sup>92</sup> J. Vanier, 1997, *Our Journey Home*, Orbis Books, p. 145.



While keeping the aforementioned limitations of cross-cultural studies in mind, the second section addresses current situations in Korea. The third and fourth sections consider similar situations in Japan, and China and Taiwan, respectively. This investigation did not extend beyond China and Taiwan, as it would be nearly impossible to compare all Asian countries and cultures. The fifth section discusses the structure of Asian bioethics, as well as its common norms and concepts. This paper concludes with proposed future directions for normative Asian biomedical ethics, although these proposals should be considered provisional.

## **2. End-of-Life Care in Korea**

It has been argued that the principle of patient autonomy may hold less significance in certain Asian cultures, particularly those with ties to Confucian traditions that place a higher value on family cohesion than individual preferences. To cite Korea as an example, a lasting influence from Confucianism can be seen in the family-centered social structure, which is based on elements of ancestor-worship, patriarchy, and filial piety (4). Thus, the autonomy of an individual may not necessarily be the foremost consideration within the end-of-life decision-making process. This is especially true when the individual's choice conflicts with the family's wishes or poses a detriment to the family's greater welfare.

This may partially explain why physicians of the Boramae Hospital case agreed to withdraw the patient's respirator (5). The Boramae Hospital case was presented before the Supreme Court of the Republic of Korea in 2004. In this case, Korea had its first legal exposure to end-of-life issues when two physicians were found criminally liable for removing the mechanical respirator from an unconscious, though otherwise recoverable, patient. Removal of mechanical ventilation was conducted at the behest of the patient's estranged wife, and resulted in his untimely death. The physicians agreed to withdraw the patient's respirator after the wife openly declared that her husband was an unemployed, abusive, alcoholic who would be better off dead than being a financial burden upon his family due to the medical costs of continued treatment (5).

Conversely, the Severance Hospital case, an epoch-making case in the field of Korean biomedical ethics, involved the decision to withdraw respirator support from an elderly woman. This patient was in a persistent vegetative state, and this case marked the first time that Korea's Supreme Court ruled in favor of dying with dignity. In this case, a 77-year-old woman, Ms. Kim, had suffered cerebral damage during surgery and had been in a vegetative state since February 2008. The patient's family requested removal of life support (respirator) from the patient, and advance directives suggesting that she would not want to prolong her life with artificial devices also existed. The court ruled that the patient's death was imminent, and that the medical interventions being performed were harming her dignity. The ruling declared, "We considered this patient as having entered the irrevocable death stage where

revival is impossible, important life functions have been lost, and death is imminent without the help of a respirator (6)." The Supreme Court reasoned that autonomy may be defined either under the theory of contracts or on the basis of constitutional protection of dignity, human worth, and the pursuit of happiness (5). The Court ordered that the respirator be withdrawn from the patient.

Despite the unique circumstances of the Boramae Hospital case, the judgment came to be misconstrued as a precedent forbidding any removal of life-sustaining treatment for incompetent patients, regardless of patient wishes (4). At present, it is reported that both the number of hospital deaths and the use of aggressive high technology life-sustaining treatments in Korea have increased in recent years. The concept of filial piety could make treatments for patients who are parents more intensive. Use of advance directives is uncommon in this society. Artificial nutrition and hydration are regarded as comfort care rather than medical treatments and, therefore, must never be stopped. These elements are illustrated by the Severance Hospital case described above (7).

Many professional organizations, such as the Korean Medical Association (KMA) and Korean Hospital Association (KHI), were quick to develop guidelines that embodied the spirit of the court decision (8). For example, the National Evidence-Based Healthcare Collaborating Agency of Korea published a "Social Consensus" on end-of-life decision-making in Korea in 2009, which issued the following five statements: 1) basic care such as fluids, nutritional support, and pain control should be maintained; 2) when a terminally ill patient expresses his or her wishes to refuse cardiopulmonary resuscitation (CPR) or ventilator support, CPR or ventilation care can be stopped; 3) the patient can express his or her wishes regarding life-sustaining treatments other than CPR or ventilator support; 4) the physician should take the patient's wishes into consideration when making a medical decision; and 5) euthanasia and physician-assisted suicide are unacceptable.

A citizens' campaign for writing advance directives was launched to mobilize and revitalize end-of-life care planning. Meanwhile, the recognition and participation of medical professionals have not met expectations. There may be several reasons for this, as medical professionals often require a more secure basis for following patient requests, such as exemption from liability (9). These controversies may continue until reasonable conditions or processes for withdrawing support are determined (10).

One cross-cultural issue raised by these points is whether patient autonomy, as the underlying principle for the use of advance directives, is a universal norm or a construct of Western traditions. If this principle is deemed a Western construct, it must be reconciled with alternative value systems that may place less significance on individual choice (5). Finally, in 2013, the Korean government began to establish a law enabling dying patients to have their life-sustaining treatments withdrawn. However, the law would not

apply to patients in persistent vegetative states, and would not allow removal of basic medical care such as nutrition, water, oxygen, and analgesics (11).

### 3. End-of-Life Care in Japan

The author and his colleague have previously described ethical issues at the end of life in Japan, with a focus on human dignity, in a recently published paper (12). This paper argues that, in Japan today, it is extremely difficult to honor the basic wish of protecting personal dignity at the end of life. A patient's right to refuse life-sustaining treatment has not been substantially warranted, and advance directives have not been legally enforceable. Unfortunately, it is not until the patient is moribund that all concerned parties begin deliberation on whether or not death with dignity should be pursued. Medical intervention is often perceived as a worthwhile goal to not only preserve life, but also to provide psychological benefit to the family, regardless of its effect on the patient. In order to feel that they are doing something, family members tend to act against the imperative "Do not inflict on others what you yourself would not wish done to you," by permitting extraordinary measures that they would not want themselves.

Another element of Japanese culture that complicates such decision-making is the necessity of unanimous decisions for end-of-life care. If there is conflict between a patient and his/her family on accepting medical intervention, the view of the latter is more likely to prevail due to different perceptions of human dignity. As a result, incapacitated patients in Japanese clinical settings often suffer through extraneous medical procedures, particularly during end-of-life care. Patient dignity is compromised by the national refusal to accept major bioethical principles such as having respect for patient autonomy, serving the best interests of the patient, doing no harm, and ensuring fairness at the end of life (12).

Some commentators claim that Japan is clearly a less-developed nation regarding the use of advance directives, as no laws have yet been established concerning advance directives or death with dignity (13, 14, 15). However, a majority (71%) of Japanese people have negative opinions about aggressive provision of life-sustaining treatments at the end of life. Among them, 43% would not want to receive extraordinary treatments such as respiratory ventilation, 20% would not want artificial nutrition and hydration, and 18% would not want any treatment (16).

Regarding contemporary cancer disclosure practices in Japan, it was reported that prognosis was disclosed to a 16-year-old boy with terminal cancer at Nagoya University Hospital. Doctors in pediatrics at the university generally disclose a cancer diagnosis to pediatric patients older than six years old now (17). Nevertheless, patients and their families in Japan still criticize the inappropriate disclosure of serious medical prognoses by physicians. For example, one patient was told unexpectedly by a physician that her computed tomography (CT) scan showed cancer, as she was visiting an outpatient clinic alone. The patient

complained that the physician should have attempted to reduce mental distress by informing her of the diagnosis in the presence of family members. She felt that the physician lacked sincerity toward his patients (18).

In another case, a physician told a cancer patient that he would only survive for one month after the patient explicitly asked the physician about his prognosis. The patient's wife later criticized the physician for blunt disclosure of the prognosis and claimed that there should be a more appropriate way to communicate this information with patients. She also asserted that the physician should have informed her that this prognosis was disclosed to her husband (18). These cases exemplify issues regarding communication of medical information between family members and married couples. An experienced Japanese physician reported that the majority of Japanese patients do not want to know their prognosis after being diagnosed with cancer (18).

Table 1: End-of-Life Decision-Making in the United States (US), Japan (JPN), and Korea (19, 20, 21).

Is there a legal right to refuse medical interventions?	
US	YES
JPN	Uncertain
Korea	YES
What interventions can be legally and ethically terminated?	
US	ANY and ALL
JPN	Probably NONE if interventions are deemed life-sustaining
Korea	YES for some interventions (relevant guidelines exist)
Is there a difference between withholding life-sustaining interventions and withdrawing them?	
US	NO
JPN	YES (As a principle, withdrawing treatment is considered unacceptable. Depending on the kind of intervention, both withholding and withdrawing treatment may be considered unacceptable.)
Korea	NO (by Korean Medical Association)
Whose view about terminating life-sustaining interventions prevails if there is a conflict between the patient and family?	
US	The views of a competent adult patient prevail.
JPN	Case-by-case and collective decision-making is predominant.
Korea	Similar to Japan. The views of a patient's family may prevail.
Who decides about terminating life-sustaining interventions if the patient is incompetent?	
US	Appointed healthcare proxy or a legally-designated hierarchy: 1) spouse, 2) adult children, 3) parents, 4) siblings, and 5) available relatives.
JPN	Family members without clear hierarchy or border, depending on power balance among family members.
Korea	Identical to Japan
Are advance healthcare directives legally enforceable?	
US	YES
JPN	NO (no laws of this matter exist)
Korea	NO

It seems that there are currently many unresolved ethical problems regarding end-of-life care in Japan. Masaki et al. pointed out that modern Japanese society exhibits cultural characteristics such as harmony without overriding principles, tacit understanding

requiring “telepathy,” cultural relativism, non-individual-oriented education and psychology, interdependence, and different implications with the same appearance (1). It is speculated that medical institutions have different policies concerning medical ethics issues in Japan, and that individual people have differing attitudes and overriding principles toward end-of-life decisions. It is impossible to know what is really going on at each medical institution in Japan regarding life-sustaining treatments, advance directives, truth telling, surrogate decision-making, and other serious ethical dilemmas.

In the final part of this section, Table 1 depicts a cross-cultural comparison concerning end-of-life decision-making in Korea, Japan, and the United States.

#### **4. End-of-Life Care in China, Taiwan, and East Asian Countries**

In this section, relevant situations in both Taiwan and China are briefly described. Taiwan has developed laws regarding terminal care and advance directives, while Korea, Japan, and China have yet to adopt similar regulations (22). However, dilemmas regarding truth-telling and aggressive cancer therapy have existed in Taiwan. It is argued that no cancer disclosures have usually been made due to Confucian culture (23). However, Taiwan has passed legislation that is intended to reduce unwanted suffering, in the form of the Natural Death Act. This act consists of 14 regulations, including the right to choose hospice palliative care, create a durable power of attorney, and document wishes to not undergo CPR (23). The Natural Death Act Revised Rules declare that patients may exercise their free will to sign consent forms authorizing withdrawal of CPR when they become incompetent. Under the revised regulations, physicians may withdraw futile treatment with the patient’s prior signed consent (23).

Chen et al. examined secular trends in individual autonomy and self-determination (IA/SD) in ethics and biomedical ethics articles published in Taiwan from 1991 to 2010. Results showed that secular trends in the proportion of total yearly biomedical ethics articles to total yearly ethics articles was increasing significantly, suggesting that Western biomedical ethics have become increasingly influential in Taiwan over the past two decades. Thus, the assumption that family autonomy and family-determination (FA/FD) takes priority over IA/SD in East Asian medical encounters is overly simplistic. Whether FA/FD or IA/SD takes priority in a medical encounter should be carefully evaluated (24). A study analyzing the content of continuing medical education (CME) courses on biomedical ethics in Taiwan showed that no courses were focused on Confucianism, and that the majority of CME courses were focused more on Western than East Asian biomedical ethics (25).

The same trend is also occurring in China. Modern trends in Western bioethics have been taught in China, and healthcare professionals are expected to act according to them (26). On the other hand, traditional

Chinese views of death are strongly influenced by Confucianism, Daoism, and Buddhism. Moral principles relevant to end-of-life care include medical humanism (caring for the human being, respecting it, and placing it at the center of attention), humane affection (Confucian), universal love and mutual benefit (Mohist), informed consent, respect for the end of life, and compassion (23). As for final decision-making, among the numerous parties involved, including government, hospitals, and ethics committees, the family remains the most important factor in decision-making at the end of life. Within the family, the father or head of household has to make the decisions and take primary responsibility. However, it has been claimed recently that children are playing a greater role because the decision-making procedure has become more democratic. No matter which part of the household dominates, the whole family will carry out the decision (23). This is because, for thousands of years, Confucianism has deeply influenced the culture, philosophy, societal values, and ethical considerations in East Asian regions, including China, Hong Kong, Korea, Taiwan, and Japan (2).

In summary, it can be argued that the Western principle of autonomy demands self-determination and self-sovereignty, assumes a subjective conception of what is good, and promotes the value of individual independence, whereas the East Asian principle of autonomy requires family-determination and family-sovereignty, presupposes an objective conception of what is good, and upholds the value of harmonious dependence (27).

#### **5. Three-Level Structure Analysis, Discussion, and Conclusion**

According to Takahashi’s Three-Level Structure Analysis, the second level of end-of-life decision-making in East Asian countries includes many diverse concepts, mixed values, and both Eastern and Western concepts and thoughts. These concepts and values include: informed consent, respect for patient autonomy, freedom, beneficence, doing no harm, privacy, surrogate decision-making, advance directives, patient’s best interests, quality of life, patient’s personal values, alleviation of suffering, respect for dignity, justice, non-discrimination, partiality and impartiality, patient’s human rights, appropriate resource allocation, solidarity, collectivism, common good, family autonomy, family paternalism, family determination, family sovereignty, and sanctity of life. It seems that some of the aforementioned norms and concepts are clearly incompatible with one another.

In a religious context, all of the countries discussed share common religions, such as Confucianism and Buddhism, although each nation has a particular dominant religion. For example, although Korea’s dominant culture favors Confucianism, 54% of the population is religious. Among these, half are Christians (Protestants: 37%, Catholic: 14%) and 47% are Buddhists (28). Similarly, Japan’s dominant domestic religion is Shintoism, which has been combined with

Confucianism and Buddhism in everyday life, all of which are reflected in Japanese views of life and death.

Therefore, it could be speculated that, according to Takahashi's third level of analysis, which reflects the deepest or most fundamental level in people's minds, Korea has a combination of Confucian, Buddhist, Christian, and Western thoughts; and Japan has a combination of Confucian, Buddhist, Shinto, and Western thoughts. Scientism (science-worship; an over-reverential attitude towards science (29)) may also play a significant role in modern Japanese society, though its impact in other Asian cultures is unknown. China and Taiwan may have a combination of Confucian, Buddhist, Daoist, and Western thoughts, as well as other traditional thoughts.

This provisional Takahashi Three-Level Structure Analysis may suffer from serious cultural stereotypes, as well as some degree of superficial academic cliché. It is also likely that the analysis includes serious bias, due to a lack of information concerning real people in the countries studied and an incomplete coverage of important resources. However, I believe that this study suggests that cultural tendencies in end-of-life care in these East Asian countries are more similar than different. The people of East Asia are likely to have common ethical dispositions and temperaments, and favor family collectivism.

It is possible that there are common difficulties across the world in decision-making and emotional distress related to end-of-life care, and that these difficulties are not limited to East Asian countries. For example, the following issues are common ethical, legal, psychological, and social problems in clinical settings in any nation: uncertainties in ethics and medicine; rapid and sometimes excessive progress of life-sustaining interventions; bewilderment about the goals of care; fear of death; inadequate advance care planning; patient incompetency; psychological difficulties in making healthcare decisions; disagreement among those concerned with patient care; diverse interpretations of quality of life, human dignity, and best interests; ambiguous criteria for termination of medical interventions; and loopholes in the law. These are all difficult problems to deal with, regardless of culture or nation.

Specific factors that contribute to the differences in end-of-life care among people, groups, and communities in East Asian countries include: attitudes toward gods, destiny, human dignity, life and death, healthcare system, political philosophy, other human beings (family and healthcare professionals), and the end (aim, objective) and meaning of life. These factors could also be categorized into the third level of Takahashi's analysis.

Having personally grown up in Japanese society, I do not know how or why I obtained my own present worldview and ethical attitudes towards gods, dignity, and all other things. I doubt that there is a definite answer as to why we, Asian people, have been predominantly family-centered, collectivist, and heteronymous. Are these attributes genetic in origin or acquired through a given community? Furthermore,

why do most contemporary bioethics educators at healthcare institutions in East Asian countries teach their family-centered learners Western bioethics? Further and deeper consideration of this matter is required in order to answer these questions. Such investigations may include neuroscience research on ethics, anthropological studies of ethnic morality, and genetic research, although these may involve forbidden or taboo subjects.

Nevertheless, the findings of the current study may provide some insight into appropriate methods of bioethics education in East Asia. Cheng-tek argues that bioethics without cultural concern will lose touch with the community. Since Asia has rooted itself so deeply in community-oriented life, Asian bioethics cannot ignore this characteristic. Developing culturally-relevant principles of bioethics has become a major task for Asians in the new millennium (30). Therefore, bioethics education that takes into consideration Asian cultural and social contexts may be necessary for healthcare professionals in the countries in question. Bioethics education that combines Western bioethics and Asian culture in a complementary manner may help in efforts to clarify the appropriate use of ethical knowledge in clinical settings (1, 31). However, the dilemma of balancing two opposing values and conflicting worldviews in consideration of serious ethical dilemmas remains unresolved.

In conclusion, concerning the future direction of East Asian normative bioethics, I am not sure which substantial normative principle or values should govern healthcare decision-making at this time. Although I personally prefer liberal individual orientation to family-oriented collectivism, I am aware that my inherent "Asian" ethical disposition may have an undeniable, significant impact on my own decision-making. I would consider myself to be liberal, yet strongly aware of my own Asian ethical tendencies.

Mutual understanding and acceptance is much better than confrontation and exclusion. Liberty is better than coercion. No ethical theory or cultural tradition is perfect. Similarly, no individual is perfect. Any ideology or worldview has its faults and limitations. To make this world better and people's lives happier, it is imperative to be ethically and culturally prudent, humble, and tolerant, rather than offensive, arrogant, coercive, or intolerant. In East Asian culture, it is essential to carefully balance individual dignity, which I believe is the most important part of my life, as well as the harmony and respect felt within family and community. The virtue of moderation (the spirit of the middle way) is required to achieve the sensitive and difficult task of balancing different values and beliefs. Finally, I confidently claim that a prudent, humble, and tolerant person would agree with Confucius' guidance to "not inflict on others what you yourself would not wish done to you" (32). This statement requires no family collectivism.

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## A Physician's Duty to Treat MERS-CoV Patients? An Ethical Assessment

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### MERS-CoV Epicenter: Saudi Arabia

Saudi Arabia (KSA) is considered to be the epicenter for outbreaks of infection due to the Middle East Respiratory Syndrome coronavirus (MERS-CoV), a zoonosis first identified in 2012.<sup>93</sup> As of 3 June 2014,

<sup>93</sup> Al-Ahdal MN, Al-Qahtani AA, Rubino S. 2012. "Coronavirus respiratory illness in Saudi Arabia." *The Journal of Infection in Developing Countries*, 6(10):692-694. See also Rollins, M. 2014. "Responding to the Challenges of Hospital Outbreaks of MERS-CoV in Saudi Arabia," *Arab Health*, 6; <http://arabhealthmagazine.com/responding-to-the-challenges-of-hospital-outbreaks-of-mers-cov-in-saudi-arabia/>; accessed 24 April 2014. Also see, Cauchemez S, Fraser C, Van Kerkhove MD, Donnelly CA, Riley S, Rambaut A, Enouf V, van der Werf S, and Ferguson NM. 2014. "Middle East respiratory syndrome coronavirus: quantification of the extent of the epidemic, surveillance biases, and transmissibility," *The Lancet Infectious Diseases*, January, 14(1): 50-56; <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3895322/>, accessed 14 May 2014.



the KSA Ministry of Health (MOH) reported a significant revision to the number of confirmed cases ( $n=688$ ), with a substantial increase in April,<sup>94</sup> the case fatalities at about 41% ( $n=282$ ),<sup>95</sup> although the case fatalities have approximated 60% in individuals with comorbidities.<sup>96</sup> Given the changing standards for clinical assessment of suspected cases, the number of patients being presented for laboratory confirmation along with differential diagnosis,<sup>97</sup> and asymptomatic patients in the initial stage of incubation who may be transmitting the virus unwittingly,<sup>98</sup> the prevalence of positive cases is likely to be underreported. The presence of antibodies in the KSA population may eventually see the case fatality drop significantly, although there is currently no antibody test available.<sup>99</sup> It remains unclear also whether the recent increase in cases is explainable as a seasonal incidence (such as occurred with the Severe Acute Respiratory Syndrome Coronavirus, SARS-CoV) or because of mutation in the virus.<sup>100</sup> Recent assessment of the virus genome at the

Institute of Virology, University of Bonn Medical Centre, which is a consultant center for the KSA-MOH, suggests no mutation, although it is unclear whether there is a functional change in the virus conducive to human-to-human transmission.<sup>101</sup>

That said, “data...presented at the Scientific Advisory Board Meeting of the WHO [World Health Organization] Collaborating Center for Mass Gathering Medicine, Ministry of Health, Riyadh, Kingdom of Saudi Arabia, April 28 – 29 [2014]” concluded that “overall the virus is stable and there is no sign of mutations indicating an adaptation to cause sustained human to human transmission.”<sup>102</sup> Nonetheless, the WHO has clearly taken the matter under advisement inasmuch as it considered, but then decided against, declaring the MERS-CoV situation a global “public health emergency of international concern” (PHEIC).<sup>103</sup> The panel made clear also that there are “systemic weaknesses in infection prevention and control,” with 68% of recent infection occurring through exposure in hospital, hence the importance of containing nosocomial infections.<sup>104</sup>

The majority of MERS-CoV+ patients are engaged by MOH hospitals throughout the country (designated specialist sites including medical centers in Riyadh, Jeddah, and Dammam), but positive cases are also being seen at hospitals of the Ministry of Defense, of the National Guard, of the Security Forces, of Saudi Aramco, in private sector hospitals, and university

<sup>94</sup> See McKay IM. 2014. “MERS-CoV detections: The April wave recedes...” 20 May, <http://virologydownunder.blogspot.com.au/2014/05/mers-cov-detections-april-wave-recedes.html>, accessed 20 May 2014.

<sup>95</sup> Ministry of Health of Saudi Arabia, Corona Virus Webpage, <http://www.moh.gov.sa/en/CCC/News/Pages/News-2014-06-03-001.aspx>; accessed 03 June 2014

<sup>96</sup> Assiri A, Al-Tawfiq JA, Al-Rabeeah AA, Al-Rabiah FA, Al-Hajjar S, Al-Barrak A, Flemban H, Al-Nassir WN, Balkhy HH, Al-Hakeem RF, Makhdoom HQ, Zumia AI, Memish ZA, 2013. “Epidemiological, demographic, and clinical characteristics of 47 cases of Middle East respiratory syndrome coronavirus disease from Saudi Arabia: a descriptive study,” *The Lancet Infectious Diseases*, 13(9), pp. 752-761, [http://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(13\)70204-4/fulltext](http://www.thelancet.com/journals/laninf/article/PIIS1473-3099(13)70204-4/fulltext), accessed 06 May 2014.

<sup>97</sup> Charrel, RN. 2014. “Invited Editorial, Emerging Infections and Sensationalism: in Aesop’s fable, the boy who cried wolf had a dreadful date,” *Clinical Microbiology and Infection*, 28 February, doi: 10.1111/1469-0691.12606, <http://onlinelibrary.wiley.com/doi/10.1111/1469-0691.12606/abstract>, accessed 14 May 2014. See also,

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<sup>99</sup> Opinion of Dr. Mohammed Khalid, Consultant Pulmonologist, King Faisal Specialist Hospital & Research Center, lecture on MERS-CoV delivered at Alfaisal University, Riyadh, 20 May 2014.

<sup>100</sup> Sprenger M, Coulumbier D. 2014. “Editorial: Middle East Respiratory Syndrome Coronavirus—Two Years into the Epidemic,” *Eurosurveillance*, 19(16), 24 April, <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=20783>, accessed 13 May 2014. See also, Cotten M, Watson SJ, Zumla AI, Makhdoom HQ, Palser AL, Ong SH, Al Rabeeah AA, Alhakeem RF, Assiri A, Al-Tawfiq JA, Albarrak A, Barry M, Shibl A, Alrabiah FA, Hajjar S., Balkhy HH, Flemban H, Rambaut A, Kellama P, Memish ZA. 2014. “Spread, Circulation, and Evolution of the Middle East Respiratory Syndrome Coronavirus,” *mBio*, 5(1), 18 February,

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<sup>101</sup> Update from ProMed. 2014. “PRO/AH/EDR>MERS-CoV-Eastern Mediterranean (42): Saudi Arabia, Genome Sequencing, Jeddah,” 26 April 2014; <http://www.virology-bonn.de> and <http://epidemic.bio.ed.ac.uk>; accessed 29 April 2014. See also, Kupferschmidt K, 2014. “MERS: A Virologist’s View from Saudi Arabia,” *Science Insider*, 06 May, <http://news.sciencemag.org/health/2014/05/mers-virologists-view-saudi-arabia>, accessed 07 May 2014.

<sup>102</sup> Memish ZA, Al-Tawfiq J, Drosten C, Assiri A, Alhakeem R, Albarrak A, Yezli S, Almasri M, Zumla A, Petersen E. 2014. “Middle East Respiratory Syndrome Corona virus, MERS-CoV. Conclusions from the 2nd Scientific Advisory Board Meeting of the WHO Collaborating Center for Mass Gathering Medicine, Riyadh,” *International Journal of Infectious Diseases*, <http://download.journals.elsevierhealth.com/pdfs/journals/1201-9712/PIIS120197121401491X.pdf>, accessed 14 May 2014.

<sup>103</sup> Branswell H. 2014. “WHO Panel to Consider Whether MERS is a Global Public Health Emergency,” *The Globe and Mail*, 13 May, <http://www.theglobeandmail.com/life/health-and-fitness/health/expert-panel-to-consider-if-mers-is-a-global-public-health-emergency/article18634896/>, accessed 14 May 2014. See World Health Organization, 2014. “WHO statement on the Fifth Meeting of the IHR Emergency Committee concerning MERS-CoV,” 14 May, <http://www.who.int/mediacentre/news/statements/2014/mers-20140514/en/>, accessed 18 May 2014. See also, Reuters. 2014. “WHO says deadly MERS virus does not constitute global emergency,” <http://www.reuters.com/article/2014/05/14/us-health-mers-meeting-idUSKBN0DU0X220140514>, accessed 14 May 2014.

<sup>104</sup> Roos R. 2014. “WHO offers more data on hospital role in MERS surge,” *CIDRAP*, 12 May, <http://www.cidrap.umn.edu/news-perspective/2014/05/who-offers-more-data-hospital-role-mers-surge>, accessed 15 May 2014.

hospitals.<sup>105</sup> It is not surprising, then, that both the general public and health care professionals are concerned about MERS-CoV incidence and adequacy of the KSA MOH response to recent developments in the disease frequency. Notably, the recently appointed acting Minister of Health complained of inadequate infection control procedures in hospitals as a contributing cause to recent outbreaks (i.e., secondary, nosocomial infections).<sup>106</sup>

One published study from Arabi et al. presents case treatment data for 12 patients for the period between December 2012 and August 2013.<sup>107</sup> This study concluded, inter alia, that both community-acquired and health care-associated MERS-CoV infections occur primarily in “patients with chronic comorbid conditions,” and that, in the case of nosocomial infection, human-to-human transmission clearly occurs “with unprotected exposure.” It is also the case that there are patients with high virus load so as to be highly contagious, especially in the hospital setting.<sup>108</sup> The latter fact points to the importance of hospitals assuring health care workers (HCW) of institutional compliance with standards of infection control, in all clinical settings of concern.

For reasons undisclosed to the public, following closure of the hospital’s emergency department for environmental decontamination as a measure of infection control, reportedly four consultant-rank physicians at the King Fahd Hospital in Jeddah resigned their positions, consequent to their refusal to treat MERS-CoV patients.<sup>109</sup> Public comment in the Saudi Gazette about this action was varied—e.g., that this act of resignation represents an “unethical attitude;” that it is a physician’s responsibility to treat patients “under any circumstances;” that we should allow for individual physician choice consistent with an evaluation of the circumstances so as to distinguish a professional act of “courage” from an act of “stupidity.” When consultant-rank physicians refuse to treat MERS-CoV patients in an evolving situation of infectious disease control, such actions elicit ethical review consistent with requisite professional standards.<sup>110</sup> In

<sup>105</sup> Ministry of Health, “Distribution of Corona Cases According to the Health Sector,” <http://www.moh.gov.sa/en/CoronaNew/PressReleases/Pages/mediastatemenet-2014-04-21-001.aspx>; accessed 02 May 2014.

<sup>106</sup> Muhammad F. 2014. “Fakeih: Hospitals responsible for spread of coronavirus,” *Saudi Gazette*, 14 May, <http://www.saudigazette.com.sa/index.cfm?method=home.regcon&contentid=20140514205095>; accessed 14 May 2014.

<sup>107</sup> Arabi YM, Arifi AA, Balkhy HH, Najm H, Aldawood AS, Ghabashi A, Hawa H, Alothman A, Khaldi A, AlRaiy B. 2014. “Clinical Course and Outcomes of Critically Ill Patients with Middle East Respiratory Syndrome Coronavirus Infection,” *Annals of Internal Medicine*, 160, pp. 389-397, 28 January 2014, <http://www.anals.org>; accessed 02 May 2014.

<sup>108</sup> Kupferschmidt, 2014.

<sup>109</sup> Saudi Gazette. 2014. “Doctors Resign Over Coronavirus Scare,” 15 April 2014, <http://www.saudigazette.com.sa/index.cfm?method=home.regcon&contentid=20140416202121>; accessed 24 April 2014.

<sup>110</sup> It is noteworthy that the American College of Physicians Saudi Arabia Chapter cancelled it planned “4<sup>st</sup> Chapter Congress—Medicine 2014” in view of a later date yet to be

what follows I engage this problem in light of international standards of physician responsibility.

### Applicable Standards

Physicians have a professional responsibility to combine technical judgment (consistent with what is medically indicated in a clinical context) and moral judgment (consistent with any number of applicable moral principles). The two moral principles of non-maleficence and beneficence, along with autonomy, are normally guiding of decision-making in the physician-patient relationship. That said, it is generally accepted that physicians may refuse to treat a given patient on grounds of conscience, despite criticism that such refusal is incompatible with professional obligations.<sup>111</sup> This refusal, of course, presupposes the physician is already engaged in a formal physician-patient relationship as attending clinician, and declines to continue treatment in that formal context.

The refusal to treat may reference a physician’s personal moral convictions and/or professional and organizational standards guiding technical performance and professional accountability in the clinical setting. Thus, one must be careful how one interprets “moral duty,” being sure to account for both empirical/clinical facts and governing ethical standards. This is undoubtedly so in relation to the disposition of patients suffering from MERS-CoV when it is expected that this is to be done according to technical standards of infectious disease control and, in the sociocultural setting of KSA, in a way consistent with Islamic principles relevant to deliberations about medical ethics. Such technical standards are especially important in disease surveillance, especially when there are cluster outbreaks (such as in KSA) that include secondary-type nosocomial infection in various hospital settings where HCW, including nurses and physicians (e.g., one Bangladeshi expatriate physician; one Sudanese expatriate physician), have been infected.<sup>112</sup>

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announced, citing as explanation “the recent outbreak of MERS-CoV in Saudi Arabia, which would potentially affect the health and safety of our ACP leaders, esteemed faculty, sponsors and delegates.” Source: Email from Khalid A. Qushmaq, Governor, ACP Saudi Arabia Chapter, 28 April 2014.

<sup>111</sup> See, e.g., Pope TM. 2010. “Legal Briefing: Conscience Clauses and Conscientious Refusal,” *The Journal of Clinical Ethics* (21)2, Summer, 163-80, <http://www.aafcp.org/cplm/files/10.pdf>, accessed 14 May 2014. Also see: Committee on Bioethics, American Academy of Pediatrics. 2009. “Policy Statement—Physician Refusal to Provide Information or Treatment on the Basis of Claims of Conscience,” <http://www.pediatrics.org/cgi/doi/10.1542/peds.2009-2222>, accessed 14 May 2014. Also see, Wicclair MR. 2000. “Conscientious objection in medicine.” *Bioethics*, 14(3), 205–227; also Wicclair MR. 2008. “Is Conscientious Objection Incompatible with a Physician’s Professional Obligations?” *Theoretical Medicine and Bioethics*, 29, 171-185; <https://pmr.uchicago.edu/sites/pmr.uchicago.edu/files/uploads/Wicclair,%20Is%20conscientious%20objection%20incompatible.pdf>, accessed 19 May 2014.

<sup>112</sup> For early assessment, see The WHO MERS-CoV Research Group. 2013. “State of Knowledge and Data Gaps of Middle East Respiratory Syndrome Coronavirus (MERS-

In May 2014, two physicians died after being infected by patients under treatment,<sup>113</sup> whereas two physicians treated on an innovative care basis recovered.<sup>114</sup> Cluster outbreaks are a more recent development, despite prior assessment from the MERS-CoV Research Group that, “sustained human-to-human transmission of MERS-CoV has not been observed,” and that, “Outbreaks have been extinguished without overly aggressive isolation and quarantine suggesting that transmission of virus may be stopped with implementation of appropriate infection control measures.”

The U.S. Centers for Disease Control (CDC) provide interim guidance for health professionals treating confirmed or suspected patients having MERS-CoV,<sup>115</sup> although there is concern that the WHO standards are inadequate.<sup>116</sup> The KSA MOH has adopted standards as a matter of stated practice, under the guidance of its National Committee for Infectious Diseases and National Committee for Infection Control.<sup>117</sup> Guidance

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<sup>113</sup> Dawood M. 2014. “MERS kills two doctors in Jeddah,” *Saudi Gazette*, 14 May, <http://www.saudigazette.com.sa/index.cfm?method=home.regcon&contentid=20140514205096>; accessed 14 May 2014.

<sup>114</sup> Khalid M, Al Rabiah F, Al Mobaieek A, Butt TS, Al Mutairy E. 2014. “Ribavirin and interferon (IFN)-alpha-2b as primary and preventive treatment for Middle East respiratory syndrome coronavirus (MERS-CoV): a preliminary report of two cases,” *Antiviral Therapy*, 15 May, <http://www.intmedpress.com/journals/avt/abstract.cfm?id=2792&pid=48>, accessed 21 May 2014. But see also, Al-Tawfiq JA, Momattin H, Dib J, Memish ZA. 2014. “Ribavirin and interferon therapy in patients infected with the Middle East respiratory syndrome coronavirus: an observational study,” *International Journal of Infectious Diseases*, 20, March, 42-46; <http://www.sciencedirect.com/science/article/pii/S1201971213003767>, accessed 21 May 2014.

<sup>115</sup> U.S. Centers for Disease Control, “Interim Infection Prevention and Control Recommendations for Hospitalized Patients with Middle East Respiratory Syndrome Coronavirus (MERS-CoV),” <http://www.cdc.gov/coronavirus/mers/infection-prevention-control.html>; accessed 24 April 2014; World Health Organization, “Assessment of potential risk factors of infection of Middle East respiratory syndrome coronavirus (MERS-CoV) among health care personnel in a health care setting,” 27 January 2014, [http://www.who.int/csr/disease/coronavirus\\_infections/en/](http://www.who.int/csr/disease/coronavirus_infections/en/); accessed 02 May 2014.

<sup>116</sup> Brosseau LM, Jones R. 2014. “Commentary: Protecting health workers from airborne MERS-CoV—learning from SARS,” *CIDRAP*, 19 May, <http://www.cidrap.umn.edu/news-perspective/2014/05/commentary-protecting-health-workers-airborne-mers-cov-learning-sars>, accessed 20 May 2014.

<sup>117</sup> Ministry of Health, “MOH Efforts to Combat the Middle East Respiratory Syndrome—Novel Coronavirus (MERS-CoV),”

for epidemiological surveillance is twofold in MOH directives: (1) “Staff of public health departments at health affairs directorates receive complaints or reports of infection, check contacts and coordinate to collect samples and send them to the regional laboratories with additional support for Al-Ahasa, Al-Qassim region to work in shifts, including weekends;” (2) “Infection control departments supervise the isolation procedures for the suspected and confirmed cases and provide personal protection tools within health facilities.”

These recommendations account for both personal and environmental risk from MERS-CoV, including data on rates of morbidity and mortality, modes of transmission (for MERS-CoV supposedly primary infection from dromedary camels,<sup>118</sup> with human-to-human secondary infection), problems differentiating positive and negative cases,<sup>119</sup> lack of vaccine and chemoprophylaxis, etc.<sup>120</sup> Accordingly, given this

<http://www.moh.gov.sa/en/CoronaNew/Pages/MOHEfforts.aspx>, accessed 02 May 2014.

<sup>118</sup> Roos R. 2014. “Study: MERS-CoV from Saudi camels matches human isolates,” 29 April, Center for Infectious Disease Research and Policy (CIDRAP), <http://www.cidrap.umn.edu/news-perspective/2014/04/study-mers-cov-saudi-camels-matches-human-isolates>; accessed 06 May 2014. See also, Briese T, Mishra N, Jain K, Zalmout IS, Jabado OJ, Karesh WB, Daszak P, Mohammed OB, Alagaili AN, Lipkin WI. 2014. “Middle East Respiratory Syndrome Coronavirus Quasispecies That Include Homologues of Human Isolates Revealed through Whole-Genome Analysis and Virus Cultures from Dromedary Camels in Saudi Arabia,” *mBio*, 5(3), May/June; <http://mbio.asm.org/content/5/3/e01146-14.full.pdf>; accessed 06 May 2014. Also, Nowothny N, Kolodziejek, 2013. “Middle East Respiratory Syndrome Coronavirus (MERS-COV) in Dromedary Camels, Oman, 2013,” *Eurosurveillance*, 19(16), 23 April, <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=2078>, accessed 07 May 2014. However, see also Eckerlie I, Muller MA, Kallies S, Gotthardt DN, Drosten C. 2013. “Short Report: In-vitro renal epithelial cell infection reveals a viral kidney tropism as a potential mechanism for acute renal failure during Middle East Respiratory Syndrome (MERS) Coronavirus infection,” *Virology Journal*, 10, 359; <http://www.virologyj.com/content/10/1/359>, accessed 12 May 2014. The latter report suggests that, given “autonomous virus replication in the kidneys,” there could be oral-urine transmission of MERS-CoV.” Hence, “If the kidney should indeed constitute a site of primary virus replication, shedding of virus in the urine might provide a possible source for human-to-human transmission, especially in health-care settings or among close family contacts.”

<sup>119</sup> See Al-Tawfiq JA, Hinedi K, Ghandour J, Khairalla H, Musleh S, Ujayli A, Memish ZA. 2014. “Middle East Respiratory Syndrome-Coronavirus (MERS-CoV): a case-control study of hospitalized patients,” *Clinical Infectious Diseases*, 09 April, <http://cid.oxfordjournals.org/content/early/2014/04/09/cid.ciu226.short>, accessed 14 May 2014.

<sup>120</sup> See Faure E, Poissy J, Goffard A, Fournier C, Kipnis E, Titecat M, Bortolotti P, Martinez L, Dubucquoi S, Dessein R, Gosset P, Mathieu D, Guery B. 2014. “Distinct Immune Response in Two MERS-CoV-Infected Patients: Can We Go from Bench to Bedside?” *PLOS One*, 14 February, <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0088716>, accessed 14 May 2014. See also, Al-Tawfiq JA, Memish ZA. 2014. “What are our pharmacotherapeutic options for MERS-CoV?” *Expert Reviews of Clinical Pharmacology*, 7(3), 235-238,



context, CDC and WHO recommendations are most important for clinical management of the MERS-CoV patient according to standard isolation procedures.

CDC recommends a MERS-CoV patient be placed in an Airborne Infection Isolation Room (AIIR), health care professionals (HCP) to use personal protective equipment (PPE) during all contacts with these patients. Respiratory protection includes use of a fit-tested NIOSH-certified disposable N95 filtering face-piece respirator. The KSA MOH initiated an Infection Control Risk Assessment (ICRA) in May/June 2013, and continues ongoing assessment through the recently appointed specialist national committee. However, the supply of available AIIRs and temporary isolation units is inadequate in number relative to the total number of cases as distributed across the various hospitals throughout the country. The fact is, as one consultant virologist observed recently, "...in some emergency rooms in some Saudi hospitals, patients are kept for a very long time because there are no beds available on the wards. If there are such highly contagious patients amongst them, then clearly you get hospital-acquired infections and that is the other thing we are seeing at the moment."<sup>121</sup> When both AIIR capacity and PPE are inadequate, with evidence of HCP secondary infection in the clinical setting, HCP concerns about risk assessment and management of MERS-CoV patients are clearly reasonable.

CDC cautions that a patient should be transferred as soon as feasible to a facility where an AIIR is available whenever an AIIR is not available. Pending transfer, however, the patient is to be isolated in a single-patient room with facemask on the patient, with the door closed, and in-out traffic minimized. This temporary solution also includes the recommendation that the patient not be placed in any room where room exhaust is recirculated without high-efficiency particulate air (HEPA) filtration.

These recommendations provide a current technical standard for assessment of professional duty when a physician declines to treat MERS-CoV patients. The four physicians who are reported to have resigned their

contracted positions with the government hospital in Jeddah apparently did so rather than be placed in a situation of having to treat MERS-CoV patients. Their action is not to be readily dismissed as ethically objectionable, given standards of infection control and prevention such as those recommended by CDC above in relation to operational capacity and infection control practices at KSA hospitals at the time of the decision taken by these physicians.

The World Medical Association's (WMA) "Declaration of Geneva" (revised, 2006), of course, expects that a physician, at the time of being admitted as a member of the medical profession, solemnly pledges to practice medicine with conscience and dignity.<sup>122</sup> 'Conscience' here presupposes a physician's right and duty of clinical judgment, even as 'dignity' references both the physician's dignity as a rational being and the patient's dignity consistent with patient autonomy in the formal physician-patient relationship. The health of the patient is to be a physician's first consideration, so that the physician will not permit considerations such as disease condition to intervene between the physician's duty and his or her patient. WMA's "Medical Ethics Manual," however, is clear that "like all human beings, physicians have rights as well as responsibilities."<sup>123</sup>

Consistent with the 1995 "Statement on Professional Responsibility for Standards of Care," WMA reminds that, "any judgment on a doctor's professional conduct or performance must incorporate evaluation by the doctor's professional peers who, by their training and experience, understand the complexity of the medical issues involved." Thus, any physician declining to treat MERS-CoV patients in Saudi hospitals should be subject to a standard medical staff peer review process prior to any institutional judgment about disciplinary action for alleged failure to perform according to duty, including contractual terms of appointment. Moreover, WMA reminds that physicians "have responsibilities to themselves, and to their families, as well," in which case physicians have the right of moral judgment with reference to the interests of various stakeholders that are not exclusive to the physician-patient relationship.

Principle VI of the American Medical Association's (AMA) "Principles of Medical Ethics" states that, a "physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care," with a federal court in one case deciding that a physician may not be subjected to "involuntary servitude."<sup>124</sup> The KSA MOH is responsible for assuring adequate AIIR and PPE capacity. Accordingly, in the face of current unknown

<http://informahealthcare.com/doi/abs/10.1586/17512433.2014.890515>, accessed 14 May 2014. Also see, Coleman GM, Liub YV, Mub H, Taylor JK, Massar M, Flyer DC, Glenn GM, Smith GE, Frieman MB. 2014. "Purified coronavirus spike protein nanoparticles induce coronavirus neutralizing antibodies in mice," *Vaccine* 32(26), 30 May, 3169–3174, <http://www.sciencedirect.com/science/article/pii/S0264410X14005180>, accessed 15 May 2014. See also, Almazan F, DeDiego ML, Sola I, Zuniga S, Nieto-Torres JL, Marquez-Jurado S, Andres G, Enjuanes L. 2013. "Engineering a Replication-Competent, Propagation-Defective Middle East Respiratory Syndrome Coronavirus as a Vaccine Candidate," *mBio*, 4(5), September/October, <http://mbio.asm.org/content/4/5/e00650-13>, accessed 19 May 2014. Additionally see, Tang X-C, Agnihithram SS, Stanhope J, Graham RL, Peterson EC, Avnir Y, Tallarico ASC, Sheehan J, Zhu Q, Baric RS, Marasco WA. 2014. "Identification of human neutralizing antibodies against MERS-CoV and their role in virus adaptive evolution," *PNAS*, 111(19), E2018-E2026, <http://www.pnas.org/content/111/19/E2018.short>, accessed 19 May 2014.

<sup>121</sup> Kupferschmidt, 2014.

<sup>122</sup> World Medical Association, "Declaration of Geneva," <http://www.wma.net/en/30publications/10policies/g1/>; accessed 24 April 2014.

<sup>123</sup> World Medical Association. 2009. "Medical Ethics Manual," 2<sup>nd</sup> Edition, 2009, <http://www.wma.net/en/30publications/30ethicsmanual/index.html>; accessed 24 April 2014.

<sup>124</sup> American Medical Association, "Principles of Medical Ethics," <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page>; accessed 24 April 2014.

risks and deficiencies in infection control and management in the hospital setting, and if done prior to undertaking a formal relationship as attending physician for a MERS-CoV patient, a physician's refusal to treat and resignation seem to be morally justifiable actions.

In the case of medical practice in KSA, however, one must consider a medical practitioner's professional responsibility also in terms of Islamic medical ethics. For example, the Islamic Medical Association of North America (IMANA) issued its own perspective on medical ethics, which has the status of considered recommendation and not the formal, quasi-legal status of *fatawa* (religious decrees).<sup>125</sup> From this perspective, a Muslim physician must balance his or her professional rights in view of the Islamic recognition of access to medical care as a fundamental right of the individual patient. Central to this fundamental right are several guiding Qur'anic principles, as well as instruction from the tradition of the prophet (called *ahadith*), identified in the IMANA perspective on medical ethics:

- 'Whoever saves a human life, saves the life of the whole mankind' (Qur'an, 5:32)
- There is no disease that Allah has created, except that He has also created its treatment.
- Harm has to be removed at every cost if possible.
- Accept the lesser of the two harms if both can not be avoided.
- Public interest overrides the individual interest.

Given the foregoing principles, a physician practicing in the context of MERS-CoV infectious disease control in KSA must understand the etiological and epidemiological variables of diagnosis and treatment, recognizing the linkage of disease surveillance to rates of incidence and prevalence. A physician's responsibility to a single patient, in this context, links automatically to professional responsibility to the public at large, consistent with public health goals. Despite individual physician's rights, so long as conditions of dignity are satisfied, the public interest for security against epidemic conditions of MERS-CoV disease frequency has priority over the individual interest of the physician not to be subjected to personal risk of infection. With reference to disease control, whatever the harm associated with MERS-CoV in terms of both community-sourced and nosocomial-sourced infection, it is the physician's responsibility to eliminate harm at all costs, if possible.

Possibility here, however, may be reasonably constrained by circumstances of clinical practice in individual hospital settings, including physicians performing without organizational assurances of requisite infection control and implementation of PPE standards. It is the responsibility of the KSA MOH and all hospitals handling MERS-CoV patients to provide this assurance to individual medical practitioners if they are to act consistently with the standard of eliminating

harm to the degree practically feasible. In this context, the physician must engage in the requisite deliberation to choose the lesser of two harms if both cannot be avoided; as would be the case, e.g., if the choice is between (a) refusal to treat that amounts to discrimination against a patient because of his or her MERS-CoV disease condition, and (b) a duty to act to minimize both community-sourced and nosocomial-sourced MERS-CoV incidence and prevalence, consistent with the individual patient's fundamental right of care and the priority given to the public interest, thus overriding the private interests of the physician.

In the context of such deliberations, it is consistent with a Muslim physician's religious comportment to believe also, as part of his or her clinical judgment, that treatment for MERS-CoV is reasonably to be given, despite current lack of an obvious definitive cure, vaccine or chemoprophylaxis. The fact is that, despite high mortality (especially among elderly patients with comorbidities), supportive care responsive to various elements of the clinical presentation does contribute to patient survival and recovery. The data presented by Arabi et al., e.g., are clear that treatment [including invasive mechanical ventilation, non-invasive positive-pressure ventilation (NIPPV), intravenous sedation, neuromuscular blockade, nitric oxide for refractory hypoxemia, prone positioning, high frequency oscillation ventilation (HFOV) as rescue therapy, tracheostomy if medically indicated, vasosuppressors, renal replacement therapy, broad-spectrum antimicrobial therapy along with use of corticosteroids and intravenous immunoglobulin] can be effective under conditions of isolation in intensive care units (for patients with comorbidities) or isolation at home (for those mildly symptomatic or asymptomatic) until such time as a real-time polymerase chain reaction (RT-PCR) test is negative. Al-Tawfiq and Memish provide additional case guidance on pharmacotherapy,<sup>126</sup> with more recent promising intervention identified in an inhibiting antiviral compound.<sup>127</sup>

## Conclusion

Given WHO, WMA, AMA, and IMANA standards of medical ethics, it is clear that there is ample reason for a physician to undertake treatment of MERS-CoV patients consistent with professional duty. It is also clear that there is ample reason for a Muslim physician in particular, practicing in a context where the target patient community is mostly Muslim, to assume his or her professional responsibility to provide requisite care

<sup>126</sup> Al-Tawfiq JA, Memish ZA. 2014. "What are our pharmacotherapeutic options for MERS-CoV?" *Expert Reviews of Clinical Pharmacology*, 7(3), 235-238. <http://informahealthcare.com/doi/abs/10.1586/17512433.2014.890515>, accessed 14 May 2014.

<sup>127</sup> Lundin A, Dijkman R, Bergström T, Kann N, Adamiak B, Hanoun C, Kindler E, Jónsdóttir HR, Muth D, Kint J, Forlenza M, Müller MA, Drosten C, Thiel V, Trybala E. 2014. "Targeting Membrane-Bound Viral RNA Synthesis Reveals Potent Inhibition of Diverse Coronaviruses Including Middle East Respiratory Syndrome Virus," *PLOS Pathogens*, 29 May, <http://journals.plos.org/plospathogens/article?id=10.1371/journal.ppat.1004166>, accessed 30 May 2014.

<sup>125</sup> IMANA Ethics Committee. 2005. "Islamic Medical Ethics: The IMANA Perspective," *Journal of the Islamic Medical Association*, 37, pp. 33-42; <http://www.imana.org>; accessed 02 May 2014.



for these patients. Notwithstanding, individual physicians practicing in KSA hospitals have the right to evaluate conditions of risk in the hospital clinical setting and to expect organizational compliance with WHO/CDC standards of infection control. The latter includes AIIR capacity and/or isolation rooms with HEPA capacity for confirmed or suspected cases being admitted into ICUs, along with PPE provided without failure in all hospitals where HCPs risk nosocomial infection. In the absence of the latter, physician refusal to treat MERS-CoV patients (a) prior to engaging in a formal physician-patient relationship and (b) other than in a clinical emergency is morally justifiable.

## Chinese Views of the Ethical Issues and Governance of Stem Cell Research

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### Abstract

In recent years, scientific observers and policy makers have recognized China as an emerging hub for stem cell research, along with South Korea and Singapore. Research centers in Beijing, Shanghai, Changsha, Tianjin, Guangzhou, Chongqing and Shenzhen have reportedly carried out stem cell research for several years in the fields of neural stem cells, cord blood stem cells as well as HES cell research, the concerns have been raised in China about the implementation of regulations.

With these developments, guidelines and regulations have also been debated and passed in China to address some of the many ethical challenges surrounding this research. These have included the "Ethical Guiding Principles for Research on HES Cells" and "Administrative Measures on the Clinical Application of Medical Techniques." But the concerns still especially relate to enforcement and compliance regarding the provision of 'unproven' stem cell treatments.

### 1. Chinese situation in the stem cell research

In recent years, most of the research done in universities, hospitals, and research institutes, research centers in Beijing, Shanghai, Changsha, Tianjin, Guangzhou, Chongqing and Shenzhen reportedly involving stem cell research have included neural stem cells, cord blood stem cells as well as HES cell research. Stem cell research includes basic research, applied research, stem cell treatment centers, and companies. There is a diversified focus on laboratory research. It aims to improve procedures for deriving and cultivating stem cell lines and also clinical research into potential stem cell applications in neurodegenerative diseases, e.g. muscular dystrophy, as well as other diseases. The Chinese government

provided direct funding through the Ministry of Science and Technology, the Chinese Academy of Sciences, and the National Natural Science Foundation, The Chinese government also provided direct funding through the 863 and 973 programs - the main national research funding programs for science and technology in China. The 863 program was initiated in 1986, and focuses primarily on the applications of research. Also called the High Technology R&D program, a key objective of the 863 program is to develop bioengineering technologies "for improving the quality of life" and places emphasis on commercialization and international cooperation. Projects seeking funding are evaluated using criteria on innovation, feasibility and commercial potential of the proposal (863 Program Website). The 973 program, also called the National Basic Research Program, was approved in June 1997 and focuses on building up basic research. The main 973 program priority project focused on stem cell research is named the "Stem Cell Research: Basic research and Clinical Applications". At least four other priority projects include research on stem cells: The Applicative Basic Research of Nerve Injury Restore and Functional Reconstruction, Basic Research for Treatment of Severe Trauma and Repair of Injured Tissues, Scientific Research on Fundamental Issues of Tissue Engineering, and Study on Mechanisms of Nonhuman Primate Somatic Nuclear Transfer and Therapeutic Cloning (973 Program Website).

With these developments, a number of guidelines and regulations have also been debated and passed in China to address some of the many ethical challenges surrounding this research. These have included the "Ethical Guiding Principles for Research on HES Cells (2003-460)" that were passed on December 24, 2003, by the Ministry of Science and Technology and the Ministry of Health. The Ministry of Science and Technology passed new regulations on scientific misconduct in 2006. The Ministry of Health passed regulations on the ethical review of biomedical research involving human subjects in 2007.

Although there is this increasing regulatory activity with a focus on stem cell research, a number of concerns have been raised in China about the implementation of regulations. These concerns especially relate to enforcement and compliance regarding the provision of 'unproven' stem cell treatments.

### 2. Ethical Guiding Principles for Research on Human Embryonic Stem Cells

Ethical Guiding Principles for Research on Human Embryonic Stem Cells (Promulgated by the Ministry of Science and Technology and the Ministry of Health, the People's Republic of China on December 24, 2003)

*1. The Ethical Guiding Principles for Research on HES Cell (hereinafter referred to as the Guiding Principles) are formulated for the purpose of bringing HES cell research in biomedical domains conducted in the People's Republic of China to accord with bioethical norms, to ensure internationally recognized bioethical guidelines and related regulations to be respected and*

complied with, and to promote a healthy development of HES cell research.

2. The HES cells described in the Guiding Principles include stem cells derived from donated human embryos, those originated from germ cells and those obtained from somatic cell nuclear transfer.

3. Any research activity related to HES cells conducted in the territory of the People's Republic of China shall abide by the Guiding Principles.

4. Any research aimed at human reproductive cloning shall be prohibited in the People's Republic of China.

5. HES cells used for research purpose can only be derived from the following means with voluntary agreement:

a) Spare gamete or embryos after in vitro fertilization (IVF);

b) Fetal cells from accidental, spontaneous or voluntarily selected abortions;

c) Embryos obtained by somatic cell nuclear transfer technology or parthenogenetic split embryos; and

d) Germ cells voluntarily donated.

6. All research activities related to HES cells shall comply with the following norms:

a) Embryos obtained from IVF, human somatic cell nuclear transfer, parthenogenesis or genetic modification techniques, its in vitro culture period shall not exceed 14 days starting from the day when fertilization or nuclear transfer is performed.

b) It shall be prohibited to implant embryos created by means described above into the genital organ of human beings or any other species.

c) It shall be prohibited to hybridize human germ cells with germ cells of any other species.

7. It shall be prohibited to buy or sell human gametes, fertilized eggs, embryos and fetal tissues.

8. The principle of informed consent and informed choice shall be complied with, the form of informed consent shall be signed, and subjects' privacy shall be protected in all research activities related to HES cells.

The informed consent and informed choice mentioned above means that the researchers shall use accurate, clear and popular expressions to tell the subjects the expected aim of the experiment as well as the potential consequences and risks, and to obtain their consent by signing on a form of informed consent.

9. Research institutions engaged in HES cell research shall establish an ethical committee which consists of research and administrative experts in biology, medicine, law and sociology with the responsibilities for providing scientific and ethical review, and consultation and supervision of the research activities related to HES cells.

10. Research institutions engaged in research related to HES cells shall formulate corresponding detailed measures and regulatory rules in compliance with the Guiding Principles.

11. The Ministry of Science and Technology and the Ministry of Health of China shall be responsible for the interpretation of the Guiding Principles.

12. The Guiding Principles shall go into effect as of the date of their promulgation.

During the process of the issuance of this guideline, we know that the Chinese government was aware of the benefits and value of embryonic stem cell research. Some leading Chinese stem cell researchers worried that if embryonic stem cell research was limited by the government, the development of Chinese stem cell research would be negatively affected.

### 3. Ethical issues about research on embryos

The standards for Chinese embryonic research using the somatic cell nucleus transfer technique, and the human embryonic stem (HES) cell research under the conditions of the embryonic research within the first 14 days, are similar to the standards used in the United Kingdom. This allows creating embryos from IVF and cloning for ES cell research and the Human Genome Organization (HUGO) supported therapeutic cloning. However, it met with objections from critics within China and from some foreign countries.

There were objections from a small group of scientists and scholars of China. They argued that HES cell research should be forbidden, because if human beings go against the natural law, human beings will be punished by nature. HES cell research violates human dignity and therefore is an affront to human life.

However, the majority of bioethicists from China argued that an embryo is not a person. An embryo is only a human biological life. A human embryo has a certain value, and it is due respect, but if there are valid reasons, it can be used in research. To the spare gametes or blastulas remaining after In Vitro Fertilization, and the fetal cells after natural or voluntarily selective abortion, the ethical issue is not an issue of "destructive embryo research." It is a fact that the cells from embryos are already being destroyed.

Concerning the blastulas or mono-sexual split blastulas by the somatic cell nucleus transfer technique, this is an ethical issue of creating embryos for research. The majority of bioethicists from China argued that a human embryo should not be manipulated or damaged without sufficient reason. It is wrong to deliberately create and destroy embryos for research, it is also wrong to create and destroy a person for research. Destructive embryo research should only be approved in exceptional circumstances. They argued that stem cell research has the potential to revolutionize medicine and save millions of lives. We are responsible for the people who die while research is delayed, and it is unethical to prevent or delay research into ES cells and therapeutic cloning. Ethical committees should work to facilitate this research.

Some bioethicists further stated that a 14 day-old embryo should be used for research. They quoted a majority view of the moral status of the embryo/fetus concerning medical science. A 14 day-old embryo is a cluster of cells without bones, organs or other traits. The embryo has a consciousness at around 20 weeks.

Some scientists supported using embryos to do research within the first 14 days. They said that to object to embryonic research is inconsistent with the values implicit in society, because there were so many abortions in China. Also, opposition to the use of

spared embryos from IVF is the same as opposition to IVF, because frozen embryos could be destroyed, infertile couples were permitted to destroy unwanted embryos rather than to donate them to other couples. For a comparison of HES cells research with IVF, spared embryos were destroyed to bring a new life into existence using IVF. Therefore, there is no difference with HES cell technology using spare embryos to produce embryonic stem cells to save one already existing life. It is wrong to prevent ES cell research, thereby placing a greater value on the lives of potential human beings than on existing human beings.

For the public in China, the ethical issue about embryonic research was not a matter of supporting or opposing research involving embryos within the first 14 days, or about the status of embryos, the fetus or an infant. What was important to the Chinese public, and what they considered valuable and worth protecting, were the patients. They thought a sufficient reason was that HES cell research has potential value in treating various human diseases and relieving the suffering of millions of people. On balance, the priority should be given to the health and lives of millions of patients. Therefore this research using embryos within the first 14 days should be permitted and supported.

Some bioethicists think that the cultural background of Confucianism is the root of Chinese public thinking about early human life. These bioethicists think that the tradition of Confucianism in public thinking provides the ethical explanation of the status of the early human life. Confucianism views a person as an entity that has a body or shape, and a psyche, and has rational, emotional and social-relational capacities. Therefore, a human embryo is not considered a living person. A person begins with birth. Destroying an embryo should not therefore be seen as killing a person. Also, in Confucianism, the ethical explanation of "Ren" means loving people, caring for others, and caring for the patient. "Ren" is an extension of the natural compassion that everyone feels in view of the hardships and misfortunes of others (1).

A Chinese bioethicist reviewed Western thinking about this issue and concluded that an early embryo certainly is not a person, after making clear what we mean by personhood. But why would we use the embryos for research within the first 14 days? And what are the reasons for our concern? We recognize questions and concerns from a wide range of Western scholars who have expressed disagreement about research on HES cells. It is therefore advisable to set a clear time limit, which will address the concerns of bioethicists who fear both a slippery slope of restrictions on research, and also of possible abuses. This clear time limit would permit research that promises to be significant for medical and therapeutic progress, and answer questions as to why it is permissible to use embryos for research within the first 14 days for research (2).

The choice of the embryos' first 14 days, or the appearance of the primitive streak, may appear arbitrary. However, there is significance with the primitive streak. Since embryonic development is a

gradual process, the appearance of the primitive streak indicates that the embryo proper is beginning differentiation and development of the individual, which has been widely discussed.

As philosopher Mary Ann Warren stated, it is not genetic human beings who are members of the moral community, but persons. She then went on to identify persons as beings who are conscious, self-conscious, thinking, possessed of the ability to use language, and so forth. Clearly, embryos do not seem to have any of these characteristics, and therefore embryos are not people and do not have the moral status of persons.

Concerning how to understand the moral status of the embryo, Warren propounded seven interactive principles to be used as complementary criteria of the moral status of embryos (3).

After weighing both pluralistic and single-criterion approaches to understanding how personhood and moral protectability are established, many Chinese bioethicists concluded that although the embryo within the first 14 days warrants serious moral consideration as a developing form of human life, it does not have the same moral status as infants or children. This is due to the absence of developmental individuation, the lack of sentience and most other qualities considered relevant to the moral status of persons, personhood, and also the very high rate of natural mortality at this stage. The important benefits to humans that research might achieve, together with counseling for embryonic research to be conducted under stringent guidelines, argues for some research on the human embryo within the first 14 days to proceed.

#### 4. Ethical issues about "Interspecies Embryos" research

Another controversy involving ethical research concerns the procuring of human eggs and embryos for research using somatic cell nucleus translation (SCNT) to create human-animal hybrids, or cybrids. This happens when an animal egg is emptied of its nucleus and is in turn enucleated from a human somatic cell.

One famous case of interspecies embryonic research occurred in China in 2001. On September 7, 2001, a report was published in the *Beijing Youth Daily*: that Professor Chen Xigu of the Experimental Animal Center of Sun Yat-sen University, transferred a skin cell nucleus from a seven-year old boy into a rabbit's denucleated egg, and created an embryo. He had been able to grow the hybrid embryos only to the stage at which they remained a cluster of undifferentiated cells. He was far from his goal of extracting stem cells from the embryos to use them for treatments. He stopped his research soon after the reports of his research by the mass media.

This was the most controversial case of that time. After reports of Professor Chen's research, stem cell research occupied a prominent position in the Chinese mass media. Two days after Professor Chen's case was reported, four scientists from the Chinese National Human Genome South Center published their views in the newspaper. They stated that Professor Chen's research violated human dignity, and was a direct

challenge to human life. A director of the Chinese Academy of Medical Sciences said to the mass media that such a mixed embryo would harm the safety of human beings, and that it violated social ethics.

A senior scientist also expressed concerns about Professor Chen's research. He said that when we are not able to respond to biomedical selection, we are not able to respond to the social and moral difficulties connected with bioengineering in a responsible way. If we do something we do not really understand, this is dangerous to human beings in the far distant future.

In China, the creation of hybrid embryos has been very controversial following the publication of research by Prof. Sheng Huizhen of the Shanghai Second Medical University (now belonging to Shanghai Jiaotong University) in 2003. Prof. Sheng, reported that she and her team had successfully transferred a human skin cell nucleus into a denucleated rabbit egg, created about 400 human/animal embryos, and then derived stem cells from them. Publication of the research had been rejected by a few journals, such as *Science*. However, it was eventually published in *Cell Research* in August 2003. It is an English language journal edited by Chinese, but belonging to *Nature* publishing group (5).

The publication of this research concerning hybrid embryos led to an international ethics debate, resulting in some to condemn such work on hybrids as unethical. However, Prof. Pei Xuetao defended the publication of Prof. Sheng's research. Prof. Pei argued that, whereas other researchers had recently done similar work in secret, Prof. Sheng had gone to great lengths to meet ethical standards and seek peer discussion. From a scientist's perspective, Prof. Sheng had the best of intentions, and had met high standards. However, Prof. Sheng had not been able to anticipate the ensuing scope of the ethical controversy. (6)

Prof. Qiu Renzong argued in favor of human/animal hybrid research "*because the use of human eggs in cell nuclear transfer research is inefficient.*" Prof. Qiu also supported animal/human hybrid research "*because of the scientific benefits and potential social benefits (human disease model, research in stem cell motion, regulation, differentiation, xenotransplantation research, etc.) and no noticeable harm is caused to any stakeholder.*"

Some scientists explained that one of the reasons was that there were not sufficient human eggs to meet the need of the proposed research. The ethical issue of hybrid research now turns on how to guarantee the rights of women who donate their germ cells voluntarily. Unlike sperm donation, donating eggs is an invasive medical procedure with physical, psychological and social risks for women. The perspective of some Western observers is that the profit made from obtaining the eggs from women, by third parties, makes this invasive medical procedure unacceptable.

##### 5. Informed consent for the source of stem cells

Ethical issues concerning the source of HES cells in China include how to protect the donors, and how to

execute the principle of informed consent in the Chinese clinics.

One of the most ethically controversial areas of HES cells (HESC) research concerns the donation of eggs and embryos for research by recipients of fertility treatment. This research relies on a steady supply of 'spare' eggs and embryos. As a result, the links between fertility treatment and stem cell research are intimate. It is common to find stem cell research facilities in close proximity to IVF (in vitro fertilization) clinics. This proximity can also create conflicts of interest, as there may be undue pressure on clinicians to stimulate 'extra' eggs or to create 'extra' embryos for research rather than reproductive purposes. The case discussions that follow underline that mechanisms for keeping patient and research interests separated are crucial. There should be clear institutional oversight mechanisms, and it suggests the consideration of a 'cordon sanitaire' between research and treatment locations.

**Case 1:** A couple who came from the countryside had an infertility disease for five years. They came to a specific Artificial Reproduction Technology (ART) hospital for treatment. Their situation met the indication of IVF-ET, following detailed examinations. Controlled Ovarian Hyper (COH) stimulation revealed good ovarian response, and IVF got 10 first-class embryos: two transplanted and eight surpluses cryopreserved. Concerning the cryopreserved embryos, both people agreed to donate the surplus embryos to stem cell research or other scientific research before the cryopreservation expired. However, they refused to sign the informed consent form, and insisted to do so only after a successful current pregnancy or delivery.

The couple wrote their ideas and requests on the informed consent form and promised to contact the researchers on their own initiative. Half a month later the wife was pregnant, and half a year later the expiration for cryopreservation was reached. However, the couples did not contact the hospital or researchers, and the correspondence they left was invalid. Under such a situation, shall we use the surplus embryos of this couple for HES cell research, or destroy them?

Some of the researchers thought that the couples had signed the consent agreement form donating surplus cryopreserved embryos for scientific research, which could be taken as their primary consent. After being told the details about the content and purpose of the research, the donors did not sign the informed consent form at that time, but still made a written statement for their donation. That statement meant to those researchers that they had already gotten the informed consent of both donors and researchers were therefore permitted to apply those surplus embryos for the HES cell research.

Those who were against it argued that formal canonical informed consent could not be replaced by some other primary intent statement. The donor's informed consent was not completely obtained until they signed the informed consent form. Moreover, during the embryo cryopreservation, those couples who had not signed the informed consent form might later

give up the donation. Therefore, those researchers believed they should not use these embryos obtained by inadequate consent, but instead destroy them.

It was understood by all that the IVF embryos were hard-earned, and the surplus cryopreserved embryos were more precious because of their good quality. After pregnancy these embryos became a residual resource for clinical application. Scientific research could make use of them, while destroying them was undoubtedly a huge waste of a scientific resource. On the other hand, before the pregnancy, these embryos meant the next chance for the couple to have a baby. Therefore the patients were not willing to donate the embryos under such conditions, until after cryopreservation expiration, or until a successful pregnancy, or even delivery.

When it came to donating eggs, the question of inducement is important in China, for example, in exchange for donating eggs to research, couples were given reduced IVF treatment fees. Some argued that this was not undue inducement, since harvesting eggs from infertile patients required invasive procedures as well as the use of drugs with potentially serious side effects. These risks made it all the more important to ensure that informed consent procedures were completely and fully comprehended by patients.

A second area in which informed consent was discussed concerned umbilical cord blood. One of the case discussions centered on how umbilical cord blood was transformed from being considered as 'biological waste', left over after childbirth to be disposed of at hospitals - to being considered a 'biological sample' with considerable value.(7)

**Case 2:** Pluripotent stem cells sourced from embryos, fetuses or adults tissues can all be called adult stem cells. Studies in recent years suggest that the differentiation capacity of these stem cells is much broader than the limited scope they were initially thought to have. Presently, haematopoietic tissue (bone marrow, cord blood and peripheral blood) stem cells techniques have become more and more mature. Highly purified stem cells differentiated from cord blood and blood have been universally received, and, relatively speaking, with little or no ethical dispute.

However, there are strict technical and ethical regulations for the collection and preservation of cord blood. "Technical regulations of cord blood stem cells bank," promulgated by the Ministry of Health of China, have clearly required that "collecting cord blood requires the mother's consent before delivery - and it must be explained to donors why it is collected, the potential harm to the mother or baby, measures to prevent and tackle risks, benefit of collecting and preservation, as well as other things relating to medical science and ethics, which include mothers having the right to decline without any discrimination."

However, in reality, to collect cord blood for stem cell research, with the agreement of obstetric departments in certain hospitals, some research institutions access umbilical cord blood through the placenta from the delivery. They pay to the obstetric department staff 10-15 Yuan for each tube (about 5 ml) as a service fee.

They do so, though, without the woman's agreement in signing the informed consent form.

The reasons for not getting the woman's agreement to sign the informed consent form may occur for several reasons. First, considering that the placenta is actually waste material, and collecting the cord blood will not harm the mothers or babies, it is reasonable to omit the informed consent process. Second, many patients are in the obstetric departments, and the medical staff are always busy. To collect cord blood and complete the informed consent process will increase the workload of medical staff. If the rules of the Institutes require that the medical staff get the signed informed consent of patients, the medical staff likely will refuse to cooperate and, research institutions will lose this source of cord blood.

Third, research institutions had sent staff to the hospital to get signed informed consent for cord blood collection. Since the research institutions' staff were not the hospital staff, people refused to cooperate with them. Furthermore, when patients were told that the cord blood collection was for the purpose of scientific research, patients feared that their privacy was unprotected and refused to give their informed consent.

Fourth, the purpose for these research institutions in collecting cord blood is neither to build a cord blood bank nor for its clinical application. It is only to extract the stem cells from cord blood and do some research in their differentiation. Since it will not affect any person, these researchers think it will not violate technical regulations and ethical principles (8).

There are questions and controversy in this situation. In traditional Chinese culture, the placenta was viewed as disposable. Since it was obtained in the hospitals, the hospitals had the right to deal with it. when we collect the placenta or the umbilical cord blood for scientific research, can we omit the informed consent process?

The answer to this question is that we should change from the traditional Chinese culture. We should consider the placenta as belonging to the mothers and get the informed consent from the mother. If obstetricians directly request the lying-in woman to sign the informed consent form for the cord blood to be donated for scientific research purposes, there will be no any ethics controversy.

Another issue is how to balance the right of the mother to have informed consent against the importance of the cord blood collection. The answer may be to educate all candidate mothers, before the delivery, to know the importance of the cord blood collection for scientific research.

Another question is whether there is any ethical defense for the research institutions paying the hospital staff who help to collect cord blood for the research institutions. The answer is that the payments to the hospital staff is compensation for the work they do for helping to collect cord blood. Compensation for travel costs and time off work was allowed. This case highlights the practical gaps between regulations and guidelines on the one hand and clinical realities on the other. It indicates a vast gray area of uncertain



implementation of, and compliance with, medical and ethical standards.

In China until recently it has been common practice for laboratories to pay hospitals a certain service fee in exchange for cord blood samples which they then can use for research (and not therapeutic) purposes. This was done without the knowledge or informed consent of the mother or father of the child.

However, in 2006 the technical management norms for the collection of non-autologous hematopoietic stem cells were promulgated by the Ministry of Health. At that time, the prescribed standard became that "collecting cord blood requires the mother's consent before delivery and it must be explained to donors why it is collected, the potential harm to the mother or baby, measures to prevent and tackle risks, benefits of collecting and preservation, as well as other things related to medical science and ethics, which include that mothers have the right to decline without any discrimination"

#### **6. "Unproven Therapies or Experimental Therapy" in China**

Unproven Therapies or Experimental therapy is subject to strict clinical protocols, ethical review and informed consent procedures. Experimental therapy must start with a small group of patients to demonstrate safety. Only then should testing begin on a larger group of patients. Ideally, where safety of the patient is the priority, it is embedded in a comprehensive system of ethical and social checks and balances. The key principle in this kind of experimental research is that of caution.

In China, Prof. Qiu stated that many clinics were offering stem cell therapy to gullible or desperate patients, often making unfounded claims about its effectiveness and charging as much as 20,000 RMB for treatment. It was suggested that there was a direct link to the commercialization of health care and the provision of expensive and unproven stem cell therapies.

There is currently insufficient scientific examination of available stem cell treatments. The conflicting results published from patient cases at a Beijing Institute for Neuroregeneration and Functional Recovery, for example, show a pressing need for more systematic evaluation of all new stem cell treatments. Critics do not question the potential of stem cell therapies for treating degenerative disease in the future, but instead fear that the regulations in China have created a loop-hole in which treatments can avoid rigorous safety and efficacy testing, and that may allow potentially harmful therapies to be marketed. The government currently does not disallow this type of treatment to occur, although some researchers in China hope the government will develop clear rules for stem cell treatments that would ensure patient safety and demonstrate the efficacy of new treatment (9).

One professor provided a case example in China. A biotechnology company claimed to have 'invented' neural stem cell therapy to treat neural conditions such as Parkinson's disease and spinal injuries. The

company worked with several hospitals, which recruited patients and which then provided patients with the neural stem cell treatment. After advertising, a great number of desperate patients from China and abroad went to these hospitals to seek the treatment of their diseases. Each course consisted of 4-6 injections and cost 12,000 RMB (€ 1,200). The company did not seek approval from the Ministry of Health and was not reviewed by an Institutional review board.

The first ethical challenge was how to safeguard patients who were often in very desperate situations and willing to take risks for almost any form of treatment. In China, 'experimental' stem cell therapies did not require approval from the State Food Drug Administration (SFDA), but did require institutional ethical review board approval.

Through numerous examples, in the areas of governance and regulation regarding stem cell research, it is clear that an important task in approaching standards on the practical levels of science and ethics is to face the challenge. Also, some Chinese commentators have suggested that the regulations on scientific misconduct from 2006 were much needed, as they raised questions about whether the current system of scientific peer review was sufficient to ensure good quality results and to deter misconduct.

#### **7. Governance in stem cell research/therapy in China**

Around 2010, a reporter for a Chinese newspaper named "*Science Times*" found that stem cell transplantation therapy in the clinical trial stage of technology, being the medical institutions for clinical treatment of diseases, such as diabetes, high paraplegia, and cerebral palsy, the per course fee ranged from tens of thousands of dollars, to hundreds of thousands of dollars. From the Chinese Medical Doctor Association, the reporter learned that, apart from hematopoietic stem cells in the treatment of blood diseases, the Chinese government has yet to receive and approve any stem cell clinical treatment for a medical institution. Such treatments not only compromise the patient's health, but could lead to popular misconceptions about stem cell therapy. The lack of guiding and specific rules and lack of professional standards, objectively caused chaos in stem cell therapy (10).

In March 2009, the Ministry of Health released the "Administrative Measures on the Clinical Application of Medical Techniques." The Administrative Measures states, among other things, that "...stem cell transplantation involves important ethical issues, safety and effectiveness remains to be the specification of clinical trial of further authentication" them into "third class medical technology". The approach also provides for clinical treatment, subject to the Ministry of Health's approval. The term 59 of the Ministry of Health released the administrative measures on the clinical application of medical techniques. They indicated that the approach introduced in 2009, "third class medical technology clinical trials management will be enacted

separately by the Ministry of Health." However, as of the beginning of year 2012, they still do not have the associated regulations.

Shen Mingxian, Director of Ethics of the National Human Genome Research Centre in the South, earlier disclosed in the Mar 2011, "The code of ethics of stem cell research and application in China" has entered the Ministry of Health's approval process, and will be officially introduced shortly after. The specification will continue to support the research and application of stem cells, and to strictly differentiate between preclinical researches, and to strictly separate the premise of clinical trials and clinical applications. The good news was, the Ministry of Health has shut down stem cell transplantation: a clinical study on approval. (11).

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## The Borrowed Organ (- Donation) Reciprocities: Long Live My (becoming Other's) Body and Spirit!

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### Abstract

Who cares for (other's) human bodies – organ donation as an extension and/or representation of one's existence? This brief explores organ donation processes, focusing on the (virtual and real) socio-reciprocities among the stakeholders beyond organ donors and receivers; highlighting the contradictions, developing along the past, present and future historical timeline within a wider opportunities structure available in 20th-to-21st century. By discussing the socially giving of human organ to other person – transplantation-medicine promises for better survival outcome with the borrowed body part(s), it articulates that, bioethics for organ transplantation (OT) medicine, is struggling with socio-cultural traditionalism and governmental regulatory initiatives, not least the emerging market-force driven higher pricing for the best possible survival outcome for the living (and for the donor too), with both real and virtual (face-to-face or the absence of it) reciprocities between the organ(s)-donor and receiver(s) take place.

This brief examines the contradictions of modernizing living and organ-donation processes in Chinese communities Hong Kong, with reference to the Three-Level-Structure of Analysis on Bioethics. Taking account of socio-technological innovations, initial findings show that, the concerned parties (biomedical professional and the relatives of the potential organ donors, vis-à-vis those recipient-patients) act differently, if not contradictory, within their own self-referential temporal logic, belief and emotions -- juxtaposing the gate-keeping function of bio-medical regime for (diagnosis -cum- prognosis) promoting "sharing or "recycling" (parts of) human bodies, which has been increasingly instrumental to define, as well as shaping, the meaning (and part) of human, body and soul, physical life, even without an explicit nor a well elaborated- shared ethical-normative framework.

**Keywords:** Bioethics, Biomedicine, Human Body, Organ Donation, Transplantation

### 1. Questioning Whose Body-Parts to Whom in Hong Kong?

Against all the odds of trials and errors in experimenting organ transplantation, Hong Kong has its first cornea transplanted in 1961, followed by kidney in 1969 – which laid the foundation for live organ transplantation in the 1990s. The subsequent biomedical technology advancement provides hope for patients who are in need of other's organ to replacing

their malfunction one; redrawing the boundaries and contours of the natural, vis-à-vis, the artificially transplanted organs, as well as redefining the ownership and usage of one's organ(s), readily harvested for other's survival. Yet, the bio-social transformation thanks to new biomedical science has been complex yet highly differentiated with changing society-technology nexus in variety of cultural-localities, as this paper attempts to demonstrate.

### 1.1 The Western Medical Institutionalization for Organ Donation in Hong Kong

The legal foundation for regulating human organ transplant in Hong Kong is Human Organ Transplant Ordinance (Cap. 465) (HOTO; Hong Kong Law: CAP465, 1995-2012); it regulates transplantation procedures, and the use, for research and other purposes, of human organs. Accordingly, organ transplants in Hong Kong, from both cadaveric and living donations, are subject to regulation under the Human Organ Transplant Ordinance (HOTO), the main purpose of which is to ensure that no commercial dealing is involved in organs for transplant, the Ordinance aims:

- to prohibit commercial dealings in human organs intended for transplanting;
- to restrict the transplanting of human organs between living persons; and
- to restrict the transplanting of imported organs.

Figure 1: Deaths in Hong Kong (Source: Beh 2013)

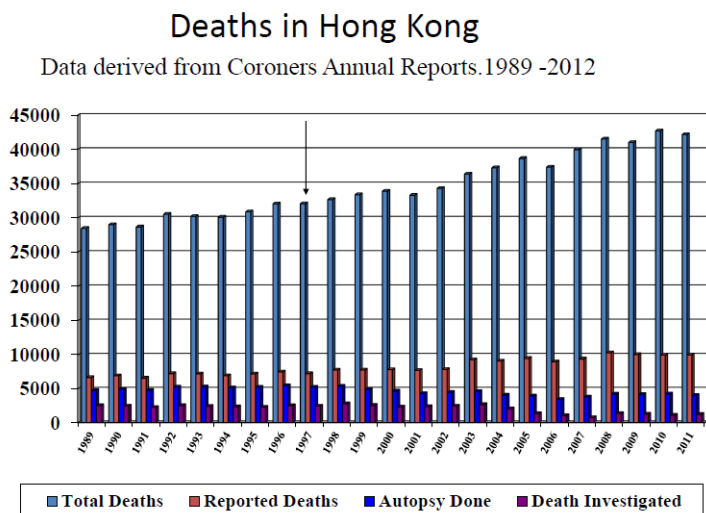


Figure 2: Milestones of Hong Kong Organ Transplantation

Year	Organ / Tissue
1961	Cornea
1969	Kidney
1991	Liver
	Bone
1992	Heart
	Skin
1995	Lung
	Combined Heart & Lung

(Source: Hong Kong Organ Donation <http://www.organdonation.gov.hk/eng/statistics.html>)

Hence, it is absolutely forbidden and illegal to perform any procedure for OT in commercial, market-pricing exchange or trading terms in Hong Kong, despite its high biomedical application in mostly public run hospital milieu. More importantly, the harvest from dead patients without prior and familial consent is not possible - that is very different from mainland China where the harvested organs from the dead are not uncommon within the state and black-market trading of human body-parts (Reuter 2013).

More specific, organ donation is the only source for transplantation yet there is large potential for it as the death rate in Hong Kong has been on the rise due to its ageing population. How to secure people's consent for donating their dead body-parts is the challenge for those-in-need survival.

For regulating transplantation, the Human Organ Transplant Board (HOTB), Board, a statutory body set up under Section 3 of the HOTO to perform the following functions:

- to consider applications made for the Board's prior written approval to carry out living non-related transplants (i.e. transplants between persons who are not genetically related or a couple whose marriage has subsisted for less than 3 years);
- to receive prescribed information about transplant operations;
- to receive certificates accompanying imported organs;
- to receive any information and documents that by the Ordinance are required to be submitted or supplied to the Board; and
- to require any information or documents that the Board may require to be provided under the Ordinance.

### 1.2 Catching Up with New Biomedical Science: Government Policy-Oriented

In spite of all scientific endeavours and its biomedical advancement in Hong Kong, organ transplantation is minimally done, vis-a-vis, other life-saving medical procedures. The overall numbers of organ transplanted are less than 10% of those waiting for the transplantation (Fig.3).

In all cases, the timely supply of the right organ is critical for any transplantation; Hong Kong's medical institutions are under such constraint. Here, there are many factors to shape, in shaping organ donation and transplant, whether transplants can be life-saving. In Hong Kong, the major medical and health service-provider, the Hospital Authority (HA), has mechanisms to handle and coordinate the clinical aspects involved in the process. But at the societal level, the key is still the attitude of the general public towards organ donation.

Yet, the legality bound procedure for human organ transplant is critical that, governed by the law(s) on human organs transplant, there are key requirements that

Any arrangement or advertisement involving payment for the supply of a human organ intended for transplant is prohibited.

Prior written approval must be obtained from the Board for any removal or transplant involving a live donor unless the donor is related to the recipient either genetically or by marriage which has subsisted for not less than 3 years. The prescribed certificate and supporting documents must be submitted to the Board before transplant involving the use of imported organs

can take place. Information on all human organ removals, transplants and disposals must be submitted to the Board within 30 days after the relevant event took place. A declaration must be submitted to the Board within 30 days after the transplant involving an organ removed for the donor's therapy.

Figure 3: Organ/Tissue Donations & Patient Waiting for OT under Hospital Authority (2004 - 2013)

No. of Organ/Tissue	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	No. of patient waiting for transplantation (as at 31.12.2013)
Kidney donation											
Deceased donor	44	50	53	58	65	87	74	59	84	70	1991
Live donor	6	8	13	8	12	8	7	8	15	12	
Liver donation											
Deceased donor	20	24	23	26	26	43	42	30	45	38	120
Live donor	56	38	48	41	42	41	53	44	33	34	
Heart donation	7	8	7	5	6	10	13	9	17	11	17
Double Lung donation	0	2	1	1	1	2	2	1	3	2	18
Single Lung donation	0	0	0	0	0	0	0	0	0	2	
Cornea donation (piece)	230	214	244	198	211	203	250	238	259	248	500
Skin donation	30	13	8	13	19	17	23	21	6	4	Uncertain
Bone donation	4	3	3	1	1	0	6	0	3	3	Uncertain

(Source: Hong Kong Organ Donation <http://www.organdonation.gov.hk/eng/statistics.html>)

Figure 4: Organ Donation Form Sample

### How to support organ donation?

Please record my wish to donate my organ(s) after death  
(\*Required Fields)

\*Name: \_\_\_\_\_

\*HKID No.: \_\_\_\_\_

Contact Address: \_\_\_\_\_

\*Hong Kong Daytime Contact Tel. No.: \_\_\_\_\_

E-mail Address: \_\_\_\_\_

\*I wish to donate upon my death: (Please tick)

All usable organs

The following organs (please select one or more)

Kidney  Heart  Lung  Liver

Cornea  Bone  Skin

\*Signature: \_\_\_\_\_

**Attention**

(1) Upon receiving your organ donation form, DH will contact you by telephone to verify your personal particulars. DH will issue a new form to you by post or via email using the address you provide if DH fails to establish contact with you.

(2) If you do not provide the requested information, DH may not be able to complete the registration process for you.

(3) Anyone successfully registered with the CODR office as a donor will not be issued any organ donation card, nor is he/she required to carry such a card around.

(4) If you have already registered with the CODR and would like to update your particulars or withdraw your registration, please re-submit the registration form or complete the withdrawal form online, by post or by fax. DH will update your record or cancel your previous registration after verifying your personal particulars by telephone.

### Statement of Purposes for Collection of Personal Data

(1) Your registration with the Centralised Organ Donation Register (CODR) is a voluntary act. All collected data in the CODR will be classified as personal and treated with strict confidentiality for exclusive access by authorised personnel for the following purposes:

i. arranging organ and/or tissue donation and transplant;

ii. performing relevant data management.

(2) Collected data in the CODR are mainly for use within the Department of Health (DH) but such data may also be disclosed to the relevant Government bureaux/departments or parties for the purposes stated in paragraph 1 above.

(3) Collected information in the CODR will be retained for 100 years from the date of collection, or until DH has acknowledged the death of the person whom the data refer, whichever is earlier.

(4) The organ donation registration form will be destroyed if DH fails to establish contact with you for verification of information, or after your personal data have been entered into the CODR.

(5) You have the right of access and correction with respect to your personal data as provided for in Sections 18 and 22 and Principle 6 of Schedule 1 of the Personal Data (Privacy) Ordinance. Your right of access includes the right to obtain a copy of your personal data provided by you during the occasions as mentioned in paragraph 1 above. A fee may be charged by DH for complying with a data access request.

(6) Enquiries concerning the personal data provided, including requests for access and correction, should be addressed to:

**CODR System Administrator**  
 Department of Health  
 21/F, Wu Chung House  
 213 Queen's Road East  
 Wan Chai, Hong Kong  
 Telephone No.: 2961 8441  
 Fax No.: 2127 4926  
 E-mail Address: [codr@dh.gov.hk](mailto:codr@dh.gov.hk)

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STAMP NECESSARY  
IF POSTED  
IN HONG KONG  
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無須貼上郵票

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商業回郵號碼: 7475

DEPARTMENT OF HEALTH  
CODR SYSTEM ADMINISTRATOR  
21/F, WU CHUNG HOUSE  
213 QUEEN'S ROAD EAST  
WAN CHAI  
HONG KONG

POSTAGE  
WILL BE PAID  
BY LICENSEE  
郵費由持  
牌人支付

(Source: Hong Kong Organ Donation <http://www.organdonation.gov.hk/eng/statistics.html>)



Figure 5: Living Donor Organ Transplantation Policies in Asia (Source: He, et al. 2010)

Economy	Donor restriction				Donor compensation	
	Living related			Living unrelated	Compensation	
	Immediate family	Close relatives	Emotionally attached		Kidney	Liver
Mainland China	Yes	Yes	Yes	No	—	—
Hong Kong SAR	Yes	Yes	No	No	—	—
Iran	Yes	Yes	Yes	Yes	\$2,000-4,000	N/A
Japan	Yes	Yes	Yes	Yes	—	—
Korea	Yes	Yes	Yes	Yes	—	—
Malaysia	Yes	Yes	Yes	No	—	—
Philippines	Yes	Yes	Yes	Yes	—	—
Saudi Arabia	Yes	Yes	Yes	Yes	\$13,300& other benefits	
Singapore	Yes	Yes	Yes	Yes	Still in discussion	
Taiwan	Yes	Yes	No	No	—	—

Figure 6: Global Transplantation Activities of Solid Organs, 2012 (Source: GODT )

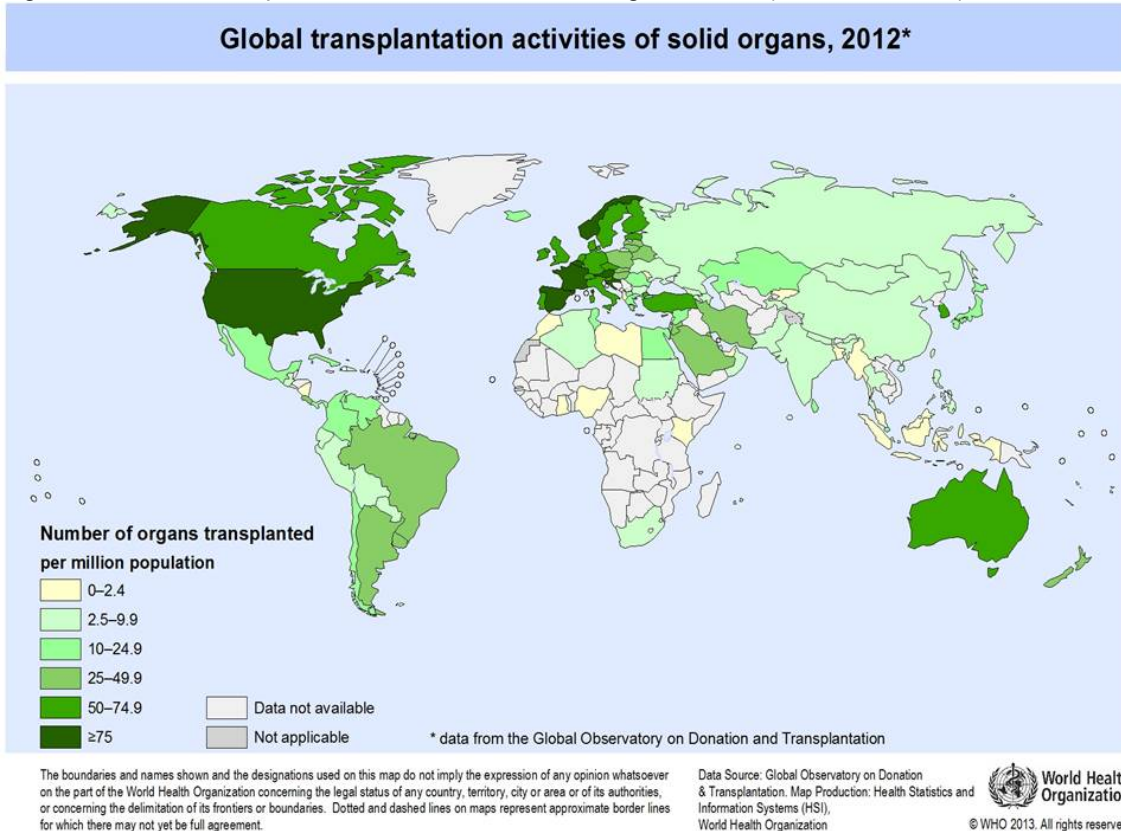


Figure 7: Dynamics of Organ Transplantation (OT) in Asia Hyper-Modernization Trajectories

	Inter-Corporeality & Temporality of OT When & Timing Issues	Agencies for (Against) Organ Transplant (OT) Stakeholders' Bioethics	Internality - Externalities Where: Arena, Setting & Domains
1st Level Locale of Egg-Sperm	Dead or Living Body-Part(s) availability – Patient(s) in Waiting	Modern Biomedical Science & Agencies	Body's Inter-Change from Donor-Patient – New Life Course Bio-Engineering
2nd Level Bio-Tech In Society	Regulatory Framework (e.g., HOTO, HOTB) within a Territorial-bound Jurisdiction (Country and Regional-State)	Biomedical & Legal Regulatory Framework for OT, vis-a-vis Donors - Recipients of OT, Faith-based Institutions like Church....	Clinical Settings & Networks of Somewhere: Licensed or Outside-the-territory-bound Transnational O.T.
3rd Level Transnational Cross-Cultural Philosophy	Historical Processing of Socio-Cultural Virtues of the New Human Body of Organ-Reuse+ Recycled: Global Opportunities Structure for Transnational OT	Transnational Agencies & Cross-Cultural Dynamics in a Globalizing World: Organ Traders and Market versus Altruistic Human Giving: The Gift Relationship in Fluidity of Family, Kinship and Lineage System?	Regional & Global Scales: New Life Course: Bio-Social Engineering and Extended Humanity with reused-New Body Parts? Interactions and Transformation between Scientific Knowledge Cultural Spheres

Given the limited supply of organs from the dead and living ones, Hong Kong government policy is clear that it is advocating a culture of organ donation in our society. "When promoting organ donation as a commendable life-saving act, we do not differentiate between cadaveric and living donations. Nonetheless, for practical reasons and as borne out by statistics, cadaveric donations will continue to be the main source of organ donations", as noted by the Secretary for Food and Health, Dr. York Chow, in Legislative Council, 1. June 2011. More specific, the Department of Health and Hospital Authority and various sectors in the community have been promoting organ donation through different ways, including rallying support of community leaders from various sectors for organ donation, so that more people become receptive and willing to donate organs (Fig. 4). Yet the biomedical and legal complexity for OT is mostly beyond the reach of the general public, given the resource-limited, overcrowded, wait-listed, medical and health institutional setting in Hong Kong, and it has limited the coordination efforts to promote organ donation as a social virtue of altruistic giving.

## 2. The Differential Embodiment of Organ (-Mobility) in Hyper-Modernizing Asia?

The availability, or sufficient supply, of human organs is the pre-condition for any transplantation procedure to secure another patient's survival. Hence, it is a somewhat one-way traffic for OT that critical timing is the very essence for sourcing, harvesting and subsequent transplantation of human organ – strongly argued by many medical professionals, the living donors-sourced transplantation is a good strategy that allows the optimal timing, and clinical procedure, for OT, and it may potentially lead to better outcomes (Abidin et al. 2013; Chan WM 2013; Lo 2012a).

For this, the fundamental is the donor's willingness to donate the organ for another (mostly unknown) person who is in critical sickness. Yet all psycho-social conditions prior to the decision-making for organ donation are both intrinsic for herself / himself, juxtaposing her/his networking and influences from others within a wider social milieu. Hence, the interplaying of the intertwined relationships with oneself to his/her social reciprocities should be stressed here – the donor's decision-making though is within the realm of clinical procedure for OT, it is more socio-historically rooted or anchored in one's socio-familial reciprocal network who has less control over – and mostly as expressed in terms of the worldview on one's (donor's) own, vis-à-vis, the other (patient) survival. Comparatively speaking, the harvest of human organs from the dying-to-dead one is more likely for the "donation". The obvious genesis for one's organ donation is beyond the end(ing) of life – organ donation after one's dead – below is an illustration for dead-body donation for medical research for (larger common good of) humanity.

### 2.1 Whose Dead Body for Medical Research: My, Your or Other?

Buddhism, Confucianism and Taoism (The Trilogy of) in Chinese culture have differential, and more often than not contradictory, influences on the essence and ontology of human body for both organ donor and recipient, as well as their family's interpretation on body-parts and spiritual-soul: their differential intertwining interplay acts positively for, and sometime negatively against, OT.

For example, Confucian (sometimes contradictory) ideas (-cum- ideal) that one's body is not one's body, but deriving from his/her parents, in terms of the fundamentals of filial piety – "my body is from my parents" 《孝經》"身體髮膚 受之父母 不敢毀傷 孝之始也". To highlight this, a case study (Chiu et al. 2012) on the attitude for body donation, after dead, for medical research is illustrative:

In spite of her Chinese cultural background, she does not hold fast to the whole-body-integrity belief of Confucianism, and protecting the integrity of her body was not an important factor in her decision to donate her body. She understands the dissection process and how her body will be handled, but she does not think filial piety is violated by the dissection of her body. She thinks that dissection is essential for the education of medical students and research development in Hong Kong (Chiu 2012: 296).

Hence, Confucian ideas or ideal for preservation of an intact body after death shape familial objections for organ donation. That might be the important factor making the organ donation rate as low as 3 per million population per year in 1980s to early 2000s.

Anecdotal data of the dead-body donor-registration (for one's own dead-body for medical research) was extremely low, though it has been improved to 600 in January 2013. Facing the crisis of the limited supply of dead bodies for medical education training: after a full community-wide campaign questing for dead-body for medical research, the registration gone up to 2,500 in September 2013 (Chan LK: 2013; Chan WM 2013). During the campaign, one professor from the Medical School at The University of Hong Kong stressed that "We need a minimum of 20 corpses every year. Our body donation programme was launched 40 years ago. In the past few years, we have only received three to five donated corpses".

But still, there is enigma about any possibly change of social attitude towards body (organ) donation after death – might be thankful to the good mixed-form of this trilogy, and the rightly re-interpret some other teaching from the trilogy of Chinese traditionalism and local folklores, to motivate potential body donors in Hong Kong. Undoubtedly, the influential forces are mostly from family members, medical professionals' relationships to patients and donors: still, social ethos and norms, expressed in terms of the contradictory public attitudes to new technologies, essence and meaning of life (and survival) in the organ-transplant matrix of humanity.



## 2.2 The Biomedical Proceduralism in OT Timing: Social Trust Reciprocities?

Obtaining (expressed or prior) consent is the most challenging task to increasing the number of cadaveric and living organs for transplantation; particularly in choosing Who, When and How to obtain the consent (from Whom - Which Family Member?) are the questionably procedural enigma for all stakeholders – it is obviously from historical data that there are less than 5% of (from both the dead or living donors) kidney being available in Hong Kong. This is further complicated by not just biomedical (versus) considerations within the matrix of the fragile and contingent psycho-socio-familial reciprocal networks for both donors and patients, but also the situation-procedural specific, time-bound legal and biomedics for organ transplant: in short, there are too many stakeholders in shaping the donation procedure and processing for OT.

Public intervention, as legal procedure undertaken by governmental agencies (say the HOTOB as stipulated by the law of HOTO) in OT represents the only societal basics (of forbidden commercial trading of organs) for, and higher order for social virtue of, the common good to save life, in addition to the mutual yet distinct consent from both organ donor and recipient respectively – beyond or not the one following a market-driven pricing for the body-parts.

In addition to the legal requirement for mutual consent for undertaking the risk and responsibility for both donating and receiving partners, the only condition for working (though not imply 100% success) out OT is the mutual trust between donor-recipient to or through medical professionals who are coordinating and operating the organ from one body to another one, yet in double-blind asymmetric, donating to receiving relationship - this is also extending to family-relatives network of both involving parties. Obviously, the double-blind conditions (of not knowing where the organ(s) goes to whom, and not to knowing where the body-part is come from) make a unique ethically-ground gatekeeping position for medical professionals who are merely bound by their own bioethical logics not just for operating the OT – but at the same time serving as a “fire wall” between the involving partners and their respectively socio-familial network. And the mutual trust-based firewalling effort is merely expressed in terms of the gratitude from the receiving ends and the belief of donation for serving or saving others; all are reflecting as the altruism of humanity at large. Yet, to maintain such mutual trust requires much societal endeavours, not least the consensus, derived from social reciprocities across different social timing and human interaction within and beyond one particular cultural space-milieu.

Build up mutual trust, as if in old traditional community, in a globalizing world is already a mission-impossible challenge. But the idiosyncrasy of Hong Kong is more complicated by its own history and socio-economic changes, transforming from a fishing village in 1850s to 21st Century’s super-modern city in Asia (Lai 2013).... Yet, the small number of registered

donors (of ca. 141,000 in February 2014) in Hong Kong reflects its socio-economic conditions, and the predicaments, to build up the necessarily mutual trust for timely OT. It is undoubtedly a daunting task for Hong Kong, a southern Chinese (Cantonese speaking) migrant society in advanced capitalism, to foster some form of (rejuvenated yet emerging?) mutual trust among people – particularly for trusting onto the Westernized medical professionals whose lingua franca is mostly in English with foreign biomedical scientific knowledge, all beyond the reach of many people.

## 2.3 Organ Donation (–Campaign): The Surviving (Beyond) Life Reciprocities

Against the dominant mode of monetary exchange in global advanced capitalism, the market for human organs trading is under-developed in most modern societies and in most cases, the for-profit business model for OT is forbidden – this is somewhat contradictory to the essence of hyper-modernizing societies in a globalizing world of everything has a price (tag) – readily to be sold and bought: how much or can there be body-organ pricing over human values?

For modernizing societies, societal consensus for organ donation is still developing and the commercialization of organ trading or sourcing is not fully addressing to – one major step for many developing economies towards modernization is to legally forbidden organ-for-sale and trading.

For majority of OT, it is thankful for altruistic organ donation without an open (though there is existence of black) market for human body-parts trading. Hence, the altruistic value for organ donation has its supremacy in terms of humanity (in modernizing and civilization terms) over the alternative of profit-driven market mechanism with money-price-based organ trading and exchange. The exclusiveness for OT is enshrined through detailed legality bound procedures, as well as the biomedical proceduralism rooted in bioethics and scientific advancement. But in Asia, there is still varieties and difference among societies, in terms of organ-donation regulatory controls and frameworks (Abindin et al. 2012; He et al. 2010 see Fig, 5).

But the advanced scientific knowledge might be wrongly interfacing with the local culture, shaping the low rate of organ donation and OT performed: partially by the passivity among health professionals in engaging potential donors and their families, as represented by the comparative low rate of organ donations from dead and living donors, as well as OT, in Asia – monitoring from the Global Observatory on Donation and Transplantation (GODT 2014) confirms this (see Fig.6).

Yet, there are cultural traditionalism and developmental (pre-modern belief) barriers for many Asian societies to echo the new calling for organ donation – to save other’s life; and Asians are more reluctant to donate organs than Caucasians:

Within Asia and even within individual countries, there are numerous ethnic, social, cultural, and religious factors contributing to disparities in deceased donation. In China, for example, Confucian values and, to a

lesser degree, Buddhist and Daoist beliefs, which associate an intact body with respect for ancestors or nature, have been shown to have a negative effect on the overall willingness to donate. On the other hand, there are striking differences in attitudes toward organ donation in various Muslim communities. Some religious thinking discourages deceased donation because of a sense of the sacredness of the body or a fatalistic approach to illness. Nonetheless, the commercial sale of organs has been widely reported in some Muslim countries (Lo 2012b).

Obviously, local traditionalism provides differential barriers and inertia against (or alternatively supports for) new biomedical offerings to keep individual survival by OT and extending their humanity. The traditionalism against the separation of body-part(s) outside oneself, the least to another foreign body, limits the workable living and dead body-part OT. Historically, the limited OT in Confucianism shaped East Asia societies is a good testimony. But the same the traditionalism for filial piety is undoubtedly a good partner for modern bio-reproductive technology to reproducing more for familial successions, as far as the functionality and instrumentality for the family survival. Here, assisted reproduction as an acceptable though not ideal, solution for family reproductive succession is along the patriarchy social contours: human reproduction (through various ways to create offspring) in Chinese societies has more than the instrumentality to realize socio-cultural virtues of filial piety and patriarch family succession, while reinforcing intergeneration contracts for family and kinship (Lai 2013).

The obvious question to overcoming the limits of traditionalism for human development is: as biomedical OT enables a better chance for individual survival but the question is where to have the matching-organ timely: could the new biomedical technology of OT become a boost for Chinese (traditionalism for) survival? How a biomedical link to bridge the thousand-year old tradition with OT-enhanced humanity?

Critical engaging with traditionalism for developing new norms for humanity common good, thanks to new biomedical technology, is a challenging one. The social virtue, and for the good deed of individual, for other human being survival, expressed in terms of "Organ Donation Saving Lives", are the key values in advocating the culture of donation of human body (in full after dead) and parts (organ for transplantation during one's life course). Since mid-2000s, medical professionals, NGOs and organ-transplanted survivors have been very active in organ donation campaign in Hong Kong (HKST, Nov.2013). To promote organ donation after death, Hong Kong Government has lately established the Centralised Organ Donation Register (CODR) in November 2008. The Register helps authorized personnel (such as the Hospital Authority's Organ Transplant Coordinator) to timely consult and solicit for donor's consent, as well as coordinating with medical agencies for organ harvest and transplant, benefiting those waiting-listed patients and their family: there were over 141,000 registrations recorded CODR in February 2014. This progressive development is also

benefited from a more pro-active approach by medical professionals who take the lead to inform the public through real life stories about the importance of saving someone (family as well) life with OT – the opportunities to serve a larger world with the donation of human organs at the end of life, or at the ending of life with clinically brain death (Chan WM 2013; See Hong Kong Government–Organ Donation Homepage for details).

Obviously, this is in line with the continuing health education and highlighting the role of the organ transplant agency to building up functional linkages between (potential) donor-recipients, their families and medical professional, as well as increasing the public awareness through cultural, religious and mass media, are essential in improving the rate of organ donations from deceased and living donors in modernizing Asia (Abidin et al. 2013; GODT 2014; He et al. 2010).

### **3. Trilogy of Organ-Transplant Bioethics and Reciprocities in Hong Kong**

To examine the contradictions of modernizing living and organ-donation processes in Hong Kong (under colonial-capitalism and mainland China under state-nationalist-socialism), the following sections addresses the Three-Level-Structure of Analysis on Bioethics. For understanding the dynamics of new life-making thanks to transplantation, we examine three inter-related spheres, mirror-imaging the Beauchamp (2003; Beauchamp & Childress 2008)'s three levels of biomedical ethics and the related structure, with specific reference to some distinctive yet inter-related mechanisms for coping with the transplanted body part(s), the "add-on", of human beings; namely, the interactions between/among biomedical technology gate-keepers and their clienteles, within the temporal (timing, when and how long?) and spatial (where transplant technology and its derivatives take place: from microscopic donated, plus to the borrowed, body-part(s) domains, along the genesis-timelines of new body-part(s) in hyper-modernizing society (Lai 2013).

Obviously, in our framework, there is a strong sense for new emerging opportunities structure thanks to differential modernization trajectories on the one hand; and the rise of the varieties of second modernity (Beck & Grande 2010), on the other. For Asia's modernization drama, Hong Kong exemplifies such – the very obvious paralleling (or partial) Westernization of Japan, China and South Korea demonstrates the thousand-year old socio-cultural structure and dynamics embedded in hyper-economic growth of the (Western?) modernization trajectories (Chang & Song 2010; Han & Shim 2010; Suzuki, et.al. 2010; Yan 2010;). More specific for indicative illustration is illustrated as follows (see Fig.6 illustration)

#### **3.1 The Enhanced Human Body – Organ as a Transferable Biomedic-social Process**

For the arena of the First Level of Analysis, human organ donation, transfer and transplant is considered as biomedical-social process within the health care institutional setting. Within the given institutional

arrangement and procedure: giving the old body-part(s) to another human being, or new life, is embedding the formation of both “intra-corporeality” (within one’s body-corporus) and “inter-corporeality” (between bodies-corporus), more even so for the new (alternative) genesis of life form, twining more complex nexus with natural evolution and artificial adding-new bodily-enhancing.

For both donors and those recipients of human body-part(s), as long as they are surviving, they are always under stressful conditions, before, at and after the transplanting-procedure; so do the relationships among their families and relatives: say the least is the emotional tensions, the ups-and-downs of psychosomatic stress before-and-during the transplantation.... Beyond personal and familial nexus of emotional attachment; it is the donor’s and recipient’s dynamics and their unique family history, vis-à-vis, the “business as usual” for OT professionals, which shape not just the complex process of novice human-part(s)-regeneration, but also redefines the essence of humanity as (to be) experienced by the (passive) recipients of new biomedical treatment-solution with adding-on, or the loss of, body-parts.

There are two contesting arenas following the relationship of human body transplantation with the inter-corporeality and temporality, agencies for (against) biomedicine, and the related externalities. First, thanks to OT biomedical science miraculous advancement, human body-parts, organ(s) in particular, can be replaced from the old-body to the new one, as compensatory or add-on parts, as if humanity is machinery. But the possibility of saving one’s life by OT is contingent upon the cooperation between and among all concerned parties – guided by health professionals: the functional relationships between the donor-and-patient, as well as their families are important. Yet, the relationship-building and maintenance among stakeholders are much not influenced by the differentials among agencies which/who hold different (Western) medical knowledge and (Chinese?) traditional beliefs and ontology on human body-cum-soul. With the given low rate for organ donation and OT in Asia, Hong Kong in particular, there are many unanswered question about the interfacing, and possible synergetic benefits, between the donors and recipients.

Second and obviously, there is great challenge for health professionals in approach families of potential donors (beyond the health institutional settings of hospital and clinics), to “solicit” the valuable human organ- parts for OT, as the organ(s) is not just having the bio-physical properties (say, living or death of brain-stem) but it is (they are) the integral embodiment of human souls and spirits, well beyond biomedical sciences can addressing to. The ambivalence on human organ donation, for both living and dead bodies, is reflecting the ontology and spirituality of human beings – which can hardly be comprehended in terms of contemporary biomedical sciences; and the ambivalence is expressed in terms of avoidance or the passivity among health professionals in approaching potential organ donors and their families before, during

and after the life-ending process (the socio-familial timing complex): wrong timing for “soliciting” the soul-cum-spirit embodied human organ(s) for transplantation. This can be shown by a recent survey of health professionals in Malaysia – which is illustrative about the complex (of socio-familial timing and organ-embodiment of human spirituality) for “soliciting” human organs:

Four hundred and sixty-two questionnaires were completed. 93% of health professionals acknowledged a need for organ transplantation in Malaysia. 48% were willing to donate their organs (with ethnic and religious differences). Factors which may be influencing the shortage of organs from deceased donors include: non recognition of brainstem death (39%), no knowledge on how to contact the Organ Transplant Coordinator (82%), and never approaching families of a potential donor (64%). There was a general attitude of passivity in approaching families of potential donors and activating transplant teams among many of the health professionals. A misunderstanding of brainstem death and its definition hinder identification of a potential donor. (Abidin et al. 2013: 187)

To recapitulate the under-optimality for OT in health care institutional arrangement in general and health care professionals in particular, all reflect the complex, if not chaotic, conditions where, how and to whom is the OT process direct to. Hence, there is urgent need to re-consider OT as an interfacing process among various socio-cultural agencies, as well as the psychosocial intermediaries in and beyond health crisis conditions whereby human organ(s, many parts of our body at large) are not just in great demand for other person’s survival, but also the explosive ethico-emotional dynamics to spill-over onto rational sciences of biomedicine and law.

### 3.2 Beyond the Bio-Medical (vis-à-vis, Socio-Cultural) Realm for OT

For the Second Level of Analysis, we wish to point out the following distinct yet interrelated contradictions. First, the biomedicine for OT is only available at the public health institution with strong state regulations but most decision-making (particularly) for organ donation is anchored upon the enigma of psycho-familial and cultural predicaments. Second, the administrative regime for OT is biomedical and legal- specific proceduralism without fully recognizing the complexity of human (individual) specific reciprocities to determine how and when organ-donation takes place. Third, the critical timing for biomedical procedure for harvesting-transferred and transplantation is differentiated, if not conflicting, from human individual’s offering for organ donation. Last but not least is the de-coupling between medical ethics for biomedical professionals are somewhat less transparent in terms of the proceduralism of institutional guidelines and protocols, from the perplexing social norms and psycho-social reciprocities of human agencies.

Sourcing of human organs has been a critical issue for any OT, more even so for ethical and morality issues concerned – as no such market ever exist

(GODT 2014; He et al. 2010). In East Asia's newly developed economies, living donor liver transplantation (LDLT) has been developed as an alternative (the only choice!) to overcome the problem of organ shortages, particular in the case for Acute Liver Failure (ALF):

Previous studies from Korea and Hong Kong, however, have shown that less than 10% of listed patients with ALF in Asia will receive a deceased donor liver transplant. The overall wait-list mortality rate is 45% to 60%, and this rate is markedly reduced if there is a potential living donor who has undergone an evaluation. Japan has an even lower deceased donor rate than Hong Kong and Korea. There were only 3 deceased donor liver transplants for ALF over an 11-year period, and 209 of 212 transplants (99%) for ALF came from living donors: this strongly indicates that there is no choice but LDLT in Japan. This contrasts sharply with the findings of the Adult-to-Adult Living Donor Liver Transplantation Cohort Study from the United States, which recorded only 10 LDLT procedures for ALF in 9 liver transplant centers over a 9-year period. LDLT for ALF is rarely needed in the West (Lo 2012a: 1006).

From the above discussion, the critical question is clear: social reciprocities for OT are beyond the limits of health institutions. Organ donation processes, have both virtual and real socio-reciprocities among the stakeholders beyond the organ donors and receivers; highlighting the contradictions, developing along the past, present and future historical timeline within a wider opportunities structure available in 20th-to-21st century. More specific, the novice social giving of the organ to other (mostly unknown) person – the OT promise for better survival outcomes with the borrowed body part(s), implies that, bioethics for organ transplantation medicine, is struggling to catch up with both governmental regulatory initiatives and the market-force driven higher pricing for the best possible survival outcomes for the living (and for the donor too), with both real and virtual (face-to-face or the absence of it) reciprocities between the organ(s)-donor and receiver(s) take place.

### 3.3 New Body-Part(s) in Gift Relationship Rejuvenates Old Social Reciprocities

For the third level of analysis; it is the rejuvenation of social virtue of giving: the innovative biomedicine enables social virtues like giving one's own body-part(s) to other(s) to upholding old functional social reciprocities, for the common good.

As socio-technological innovation OT opens up new spaces for the concerned parties (biomedical professional and the relatives of the potential organ donors, vis-à-vis recipient-patients) act differently, if not contradictory, with their own self-referential temporal logic, belief and emotions -- juxtaposing the gate-keeping function of bio-medical regime for (diagnosis - cum- prognosis) promoting "sharing or "recycling" (parts of) human bodies. The dynamics and processing of OT have been increasingly instrumental to define, as well as shaping, the meaning (and part) of human bodies

physical life, even without an explicit nor a well elaborated- shared ethical-normative framework.

More specific, the processes for human bodies' transfer re-constitute new identities for human beings (the body) -cum- the meanings of life and (from the) death (one) on the one hand, and the socio-cultural reciprocities in terms of the Gift Relationship (Titmuss 1971) between anonymous donors and recipients. Following the altruistic blood donation relationship between anonymous donors and receivers, the "Gift Relationship" coined by Richard Titmuss (1970), is an integral part of humanity (ethics and norms) which is beyond economic calculation per se. Yet compared with blood, risks for organ donation are indeed higher for both living donors and patients - an integral part of new biomedical asymmetric (one-way) partnership from the organ-donor to the recipient and the irreversibility of losing the organ for the former partner. More importantly, the risks of asymmetry and irreversibility at the critical stages of OT is exemplified by the so-called "near-miss" condition – aborted hepatectomy or potentially life-threatening "near-miss" events where a donor's life may have been in danger but no long-term sequelae occurred, is highlighted in a study that in a 126-"near miss" events,

approximately one in every 92 procedures. There were no differences associated with geographic regions. This rate is likely an underestimation representing those most memorable to the reporting individual, but this report does represent the first comprehensive report of actual risks faced by donors across various health care systems and practice models. The actual reported events are those commonly reported after liver resection such as bleeding, biliary injury and thrombotic events. High volume centers reported larger numbers of "near miss" events, but when indexed to number of LDLT procedures performed, rates at high volume centers were significantly lower than either low or moderate volume centers. This suggests that a prolonged learning curve, significantly more than the previously reported 20 LDLT cases (3), is needed to maximize donor safety (Cheah et al. 2013: 505).

Given the limited supply of organs from the deceased donation – the alternative sourcing of human organ from the living one, and without affecting the donor's health, is preferred for better chance for successful transplantation. More specific, the interfacing of the donor's organ and the patient's need are highly contingent upon the timing and complex clinical considerations: the acute organ transplantation provides only a very narrow time-space for meeting the specific supply and demand of a particular type of organ in biomedical clinical terms – the timing of deceased donor organ transplantation is dictated entirely by dying but not yet dead one – the God's will so to speak. In contrast, living donor one not only permits early or timely transplantation and thus can prevent wait-list mortality: the donor-organ evaluation and the related biomedical clinical preparations can be better planned and completed prior to actual OT (Lo 2012a, cf. Cheah, et al. 2013; Grant et al. 2013). Here,

the comparative advantages for good preparation and planning for psycho-social needs and adaptation for the living donor(s) and the surviving patient(s), and their families, are more than obvious.

### 3.4 New Biomedical Science: Organs Escape from a Globalizing World?

21st Century biomedicine has yet to re-produce human organs, though much advancement in regenerative medicine, like the development iPS cells and others, but many of the replacements of human organs need support from donors who can scarify themselves for the common good. Human wishes and preferences are far from rational, and are subjected to social-culturalization of the values and meaning for organ donation. Hence, the choices for the individualized way(s) to prolong one's life are more likely thanks to biomedical sciences.

The offering of the "add-on" or "replacement" of human body-parts (organs at large) in new biomedicine for people, empowering the continuing of humanity in many ways; not least the new or extended life with the possible replacement of major human organs. People likely will choose for new lifestyle(s) and opportunities to make up the lost of (reversing or rejuvenating biological) critical time (for having replacement or new organ) set by bio-historic limits.

At the society level, there is new opportunities structure supported by both wealthy groups and biomedical science advancement for human life extension beyond the wear-and-tear of the organ parts – demonstratively an extension of people alternative choice(s) to make for planning one's future (and legacy) and pro-(longing the) life course. For instance, people can now re-use any human organ anywhere - anytime (back to the future?) as they wish, given new biomedicine-stored up "other" (once owned) body-parts. Obviously the question is whose body-part(s) is to be chosen for OT – whether this is only for those privileged ones.

This is in line with hyper-modernizing systematic calling for individual(ism-driven self-) planning future in liberal, global advanced capitalism: one who can still be active as ageing (say, reactivating their body with new replacement of human body-parts and organs). Hence, a new choice-based auto-biography in "New Biomedicine Age" is more than obvious. The choice biography concept implies not just young people, but also the aging ones, to (re-)plan for their own (not historically defined, aged-limited and standardized life course). All these exercises are not just cognitive-mental one, but could be institutionalized into everyday life that people make alternative-planning of their own life course with new Weltanschauung (worldview) – the biographization of one's own life course (Vinken 2004; Macmillan, Ed. 2005).

Helping the self-biographization of life course of younger generation are the state policy, new sciences and new family-wealth and outlook in late 20th Century (Lai 2013). Both the state and the upwardly mobile, better-off family (in comparison with their previous cohort) dynamics reinforce to reproducing new life

beyond the historical bound age-limits. On the other hand, the apologetic and sympathetic attitudes of new, secularly individual rights-based regulatory framework for OT, foster new life rejuvenation even at advanced (60+) age cohorts. Furthermore, most developmental state's further investment for biomedical sciences (as future championing technologies of life sciences) reinforces the complex, but contradictory, constellation of the individual's life choice for new-bionic humanity; calling for new challenging (constructive destructive forces?) biomedical technological advances. One such complex matrix is a challenge to social (historical bound) norms and ethics on the equal opportunities for men and women (for life creation), with the promotion of progressive rights for everyone's sovereign body (and parts) for new human organ(s) to be harvested, reused and replaced.

With new biomedicine, contradictions are inherently embedded in economic hyper-developmentalism under the so-called globalization processes; challenging the formation of the "we" sense of belonging in many communities (undergoing destruction, if not broken up for transformative development); which is essential for the development of organ donation "culture". The calling for the "borrowed organ" for extending -cum-saving human life might be one of social virtues of human sacrifice – which has nothing to do with research and development asset and capability one society endowed. Likewise, they are more or less social processes for social formation of good wills for the other anonymous donors and unknown recipient, regulated by a given set of biomedico-legal framework anchored upon the agreeable ethical -cum- local-justice principles in one's social milieu. But the consensus building process is a challenging, if not impossible, one given the highly flexible socio-economic activities and mobility of people socio-geographically in hyper-modernizing, economic, developmentalism in East Asia where communities have been transformed in the last 30-plus years.

### **4. Alternatives beyond Transplanted New Life – Searching Organ or Soul-Searching?**

Our case study shows Hong Kong society with Chinese (local-)traditionalism is meeting up the challenges, and catching up with the rejuvenated social virtues for donation, of newly biomedical sciences from the West; not just in terms of positivist science and knowledge but also the very essence of ethics and norms which have been undergoing transformation in the last few decades (cf. Lai 2013).

Taking account of socio-technological innovations, our initial findings show that, the concerned parties (biomedical professional and the relatives of the potential organ donors, vis-à-vis those recipient-patients) act differently, if not contradictory, within their own self-referential temporal logic, belief and emotions -- juxtaposing the gate-keeping function of bio-medical regime for (diagnosis -cum- prognosis) promoting "sharing or "recycling" (parts of) human bodies, which has been increasingly instrumental to define, as well as shaping, the meaning (and part) of human bodies

physical life, even without an explicit nor a well elaborated- shared ethical-normative framework.

Our critical remarks are: the processes for human bodies' transfer are reconstituting new identities for human beings (the body). Futuristic biomedical science in 21st Century hypermodernity, for Hong Kong's catching-up modernization in particular, facilitates not just new technologies but likely to transform humanity with rejuvenations of multiple (partial organs) of humanity, new bio-medical parts from other bodies, with emerging novice technology-driven societal encounters, like new virtual realities and the back-to-the-future human relationship when traditional family-kinship can be historically or chronologically reversible: any living parts from cells to organs can be possibly recycled and re-made by biomedical re-engineering....

This paper starts with the question: who cares for (other's) human bodies – organ donation as an extension and/or representation of one's existence? It examines organ donation processes, focusing on the (virtual and real) socio-reciprocities among the stakeholders beyond the organ donors and receivers; highlighting the contradictions, developing along the past, present and future historical timeline within a wider opportunities structure available in 20th-to-21st century. Highlighting the social giving of the organ to other unknown person – transplantation medicine based promise for better survival outcomes with the borrowed body part(s), it articulates that, bioethics for organ transplantation medicine, is struggling to catch up with both governmental regulatory initiatives and the market-force driven higher pricing for the best possible survival outcomes for the living (and for the donor too), with both real and virtual (face-to-face or the absence of it) reciprocities between the organ(s)-donor and receiver(s) take place.

For the likely scenarios in future: the quest for human survival is the essence for organ transplant in Asia. Living donor transplantation has developed because there is no choice and it is rightly noted that: "Is it possible that it may in fact be a better choice?" (Lo 2012a: 1006) Furthermore, the quality of a living donor's organ is highly selective therefore good in quality, enabling a good prognosis with less complication -- such a strategy may be a good alternative, if not advantageous, for needy patients even in societies with adequate supply of the deceased donor organs.

Yet far from the paradigmatic shift towards the Western one, there is emergence of more alternatives – thinking -cum- thoughts on enhancing survival opportunity for everyone in need (of extra, replacing human organ): new differential meaning(s) of life for homo sapiens, happiness and wellbeing after the deceased whose body-parts still live in another person-body - human beings survive!

Our case study on Hong Kong highlights certain salient features of socio-cultural (vis-à-vis, Chinese traditionalism) and (Western) legal catching up of the advancement of Western biomedicine: the belated legal framework establishment in mid-1990s (1996-2012) while various OT breakthroughs were made in early

1990s - before the law legislation; and the rediscovery of the social virtue "to give" (donate one's body-part after dead) in the "gift relationship" – to maintain socio-cultural-familial bondages with OT, since 2010s; paralleling the biomedical professionals' engagement (for their own vested interest?) in public sphere to promote organ donation during the crisis of not-having enough body-parts for carrying out their mission (business practice?).... But there are more questions than biomedical science can deal with: with more organs available – thanks to the altruistic donation, this will transform the practice(s) for OT in future, as the legal-biomedical proceduralism will likely be challenged by more supplies of organ. The change is likely not just from the under-supply of the organs to the optimal supply, but towards a regime which quests for highly selective screening (in terms of DNA genomics) for better quality human organs, with a likely shift from the public-altruistic "gift relationship" to a highly selective one with more choice with screening - though it is far from the private-commercialization biomedical (taking the comparative advantages of the cross borders trading for) OT. The enigmatic paradox seemingly comes back in full cycle - for humanity (embracing both body and soul) survival: Whose (one's or the other's) and what (which body-part) bioethics for whom?

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