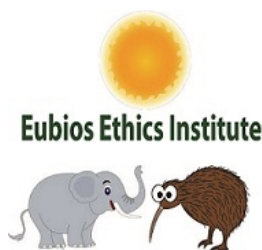


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## Editorial: Bioethics and the meaning of life

One of the common threads of the six papers in this issue of *EJAIB* is a critical one for all of us, and one of responses we could make when we ask what is “the question”? The question I refer to is what is the meaning of life? Each of us through our life journey will ask this question at least once, and although the mundane that constructs most of most people’s lives can

ignore that question, a bioethical life that is one where the love of life demands us to ask questions, will bring us back to that question.

Yuko Yokoseki and Michio Miyasaka attempt to reconstruct the meaning of life among Japanese bereaved spouses through a qualitative study of three peer support groups. This research study is one that does not explore an abstract theoretical topic, but an event and feeling that half the people in the world will experience. One of the joys and pains of life is that we live a life together with our loved ones but for most of that life we will not know who will be bereaved and who will end their life earlier. There are lessons for all relationships that we humans hold to be dear.

Endah Rahmawati et al. explore a related dilemma, but one with the hope of a new life in their paper on shared decision-making and relational identity in a pregnant woman with Eisenmenger syndrome.

Silvia Croydon provides an ethical and regulatory analysis of one of the most hopeful interventions for future life, namely heritable human genome editing. Given the long awaited success in somatic cell gene therapies, we as a species will need to continue to reflect on the correct timing to allow those persons who would like to attempt heritable genomic editing. Peter Ottuh discusses the ethics of human cloning.

From West Asia, Zahira Amir Ali describes some Pakistan cases of medical negligence by health professionals. Sukran Sevimli explores the ethics of unwanted pregnancy in some cases of rape reported in the media with legal restrictions on abortion in Turkey.

- Darryl Macer (Email: [darryl@eubios.info](mailto:darryl@eubios.info))

## Reconstructing the meaning of life among Japanese bereaved spouses: A qualitative study of three peer support groups

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### Abstract

This study aims to reveal how people who have lost a spouse reconstruct the meaning of life in three different peer support groups for the bereaved in Japan. We interviewed 20 study participants and conducted a qualitative analysis. Most study participants had a negative experience of their bereavement; however, by listening to others' bereavement experiences, they gained a feeling of fellowship, pieced together the fragments of the chaotic experience of bereavement, and reconstructed their experiences and sense of values in a coherent way from past to present. The study results reveal that commensurability could be achieved in the peer support groups and that the opportunity to re-encounter the deceased encouraged the meaning of reconstruction.

### Introduction

The population of Japan is in rapid decline and has continued to age. The annual number of deaths reached approximately 1.44 million (Ministry of Health, Labour and Welfare, 2022), the greatest on record. As elderly people pass away in large numbers, Japanese society is moving from being an aging society to the next phase, a "mass-dying society" or "*tashi shakai*" which brings about a variety of unprecedented issues. One of these is grief support for people who have lost family members.

In contemporary Japanese society, where relationships in local communities are thinning, people may suffer more from the physical and emotional impacts of the death of a loved one, particularly the death of a spouse. According to one meta-analysis, a statistically significant correlation exists between spousal bereavement and mortality risk, with greater risk of death in one to six months following the death of one's spouse (Moon, 2011). It has been reported that spousal bereavement can influence inflammatory and prothrombotic changes associated with cardiovascular risks (Buckley et al., 2012). Spousal bereavement also aggravates mental illness. People who have lost a spouse have a higher rate of psychotropic drug prescriptions, see general practitioners at a higher rate, and are more likely to use various pharmaceuticals (antidepressants, sleep medications, psychotropic drugs) (King et al., 2013). They experience depressive syndromes at a rate of

42%, 1 month after bereavement and a rate of 16%, 13 months after bereavement (Clayton, 1990).

In Japan (2019) survey, the rate of suicide among married people aged 60 and above was 19.3 per 100,000 people for men and 9.0 for women, whereas the rate among those who had lost a spouse was 46.7 and 12.4, respectively (Ministry of Health, Labour and Welfare, 2021, p.30). In a review of older people living alone in Japan after the loss of a spouse, more than half of the men did not have anyone to talk to about their problems, raising concern about the social isolation of men following bereavement (Kotani, 2017).

**Social change and groups for the bereaved in Japan:** Before the modernization of Japan, relatives by blood and marriage and local residents would join the bereaved person and support them in their grief through funerals, burials, and Buddhist memorial services. However, in recent years, due to the trend toward nuclear families, and societal changes such as the dilution of collective systems in local communities and the simplification of funerals, burials, and memorial services, it has become increasingly difficult to provide grief support (Itou, 2016).

In this context, peer support groups have been gaining particular attention in the recent years. In the United States, after trials of early programs such as *widow-to-widow* (Silverman, 1970) mutual aid for widows, many groups for the bereaved have been created in various places.

In Japan, a German Catholic priest Alfons Deeken conducted death education at Sophia University. In 1982, he held a seminar on death and grief for the general public, encouraging participants to talk about grief after bereavement, which was not commonly discussed in Japanese society up to that point. This was the impetus for creating peer support groups for the bereaved throughout Japan (Yokoseki, 2015). The main activity content of these peer support groups includes sharing experiences of bereavement, namely, listening to the sorrow of the bereaved and allowing the bereaved to talk about their sorrow.

**Reconstructing the meaning of life:** In peer support groups for the bereaved, talking about the experience of bereavement is the central activity. Recently, the central challenges of the grief process are thought to be giving meaning to loss and reconstructing the meaning of life and reason for living (Neimeyer, 2006). In peer support groups by the bereaved, the act of talking to others is thought to encourage the reconstruction of the meaning of life and the meaning of living, but how this happens is not fully understood.

This study aims to reveal how people who have lost a spouse reconstruct the meaning of life in three different peer support groups for the bereaved in Japan.

## Methods

**Participants:** This study involved 20 participants who belonged to groups for the bereaved (Group X, Group Y and Group Z) in Japan. All participants had lost their spouses at least three years prior, were considered physically and mentally sound candidates based on past interactions with group leaders and had agreed to participate in the study.

**Data collection:** The first author explained the study plan to the leaders of each group, and obtained their written approval for cooperation, including the selection of candidates for participation. The leaders then contacted the candidates by telephone, explained the outline of the study, and mailed or hand-delivered the explanatory documents to them. Approximately one week later, the leaders called the candidates to ask about their willingness to participate. For those who were willing to participate in the study, the leaders arranged a meeting with the researcher. The first author then met with the candidates at the designated date and place, explained the aims, methods, the anticipated benefits and potential risks, the discomfort the study may entail, and the plan to protect participants' privacy and maintain confidentiality of data. Candidates signed a consent form agreeing to be interviewed, recorded, and to allow discussion content to be used for presentation and publication purposes.

We conducted one interview for each participant, with an average interview time of 1 hour and 31 minutes. The interview format was semi-structured, and participants were asked to talk freely about seven items: (1) Relationship with spouse, (2) Reaction after their death, (3) Motive for joining the bereavement group, (4) Emotions when listening to people talk about bereavement, (5) Changes after talking about bereavement, (6) Changes in view of life and death, and (7) What new things they did. Interview content was recorded with permission, and notes were taken. We created verbatim transcripts from the recorded audio data and anonymized them. The anonymized text data was the target of analysis. The data collection period was July to August 2019. Ethical approval was gained from the Ethics Committee of Niigata University (2019-0036).

**Data analysis:** We conducted a qualitative analysis using the procedure below to find thematic categories across individuals: (a) We closely read the textual data for each participant and summarized their content, (b) We entered summarized data for all respondents into a spreadsheet for above-mentioned seven items, (c) We compared the data for each question, grouped similar items, and concisely summarized the content into subthemes, (d) We grouped together similar subthemes and reformulated their content in abstract terms to turn them into themes.

## Results

Table 1 shows a summary of the participants characteristics. There were 20 study participants (10 men, 10 women) in their 60s to 80s (average age 72.7). Of these, 5 participants had a bereavement period of under 10 years, 11 had a period of 10–19 years, and 4 had a period of 20 years or more (average period 14.2 years). We divided the interview items into three topics, with (1) and (2) on “post-bereavement reactions”; (3), (4), and (5) on “experience of listening and speaking”; and (6) and (7) on “changes in view of life and death.” Examples of specific themes are given here for two topics: listening and speaking experiences and changing views of life and death (Table 2).

### Topic 1: Post-bereavement reactions

**Psychological reactions** included feelings of loss, apathy, regret/remorse, relief. Their post-bereavement reactions often included the pain of losing someone who had always been there for them as well as the sense of loss in missing their confidant. By contrast, some people exhibited positive psychological reactions, such as relief.

**Physical reactions** included insomnia, lack of appetite, and poor physical condition. Of the 20 study participants, 9 complained of insomnia. There were also some who had lost weight due to lack of appetite, including some who had lost their appetite not only after the death of their spouse but also before the death. Some had lost the will to make meals just for themselves while their spouse was in the hospital, and others had lost their appetite and lost weight from the burden of caregiving.

**Social reactions** included isolation and social withdrawal, distrust in personal relationships, and the burdens of childcare and work. After bereavement, as mentioned above, some had reactions of isolation and withdrawal, not wanting to go out due to apathy or losing touch with personal relations because they no longer wanted to meet with people they had previously been seeing. The reaction of distrust in personal relationships was from people who were hurt when their friends said things to console them, and they felt that the friends did not really understand their feelings.

**Spiritual reactions:** Some people felt that they had lost their reason to live. However, some of the study participants, believed in a transcendent presence. Invisible connection to their spouses was experienced by some participants who felt that their deceased spouse was near them.

Table 1. Overview of participants

Participant	A	B	C	D	E	F	G	H	I	J
Gender	Man	Man	Man	Man	Man	Woman	Woman	Woman	Woman	Woman
Groups for the bereaved*	X	X	X	X	X	X	X	X	X	X
Age	77	62	85	79	70	71	87	70	87	62
Bereavement period	17	9	13	12	29	7	12	10	29	8
Cause of death	Subarachnoid hemorrhage	Breast cancer	Esophageal cancer	Cancer of the uterine body	Ovarian cancer	Stomach cancer	Prostate cancer	Lung cancer	Lung cancer	Ruptured aneurysm
Period of illness	1 month	19 years	3 years	5 years	4 years	2 years	About 2 years	10 years	2 years	0 days
Place of death	Hospital	Hospital	Hospital	Hospital	Hospital	Home	Hospital	Hospital	Hospital	Hospital
Participant	K	L	M	N	O	P	Q	R	S	T
Gender	Man	Woman	Woman	Woman	Woman	Man	Man	Woman	Man	Man
Groups for the bereaved*	Y	Y	Y	Y	Y	Z	Z	Z	Z	Z
Age	81	69	70	77	65	71	62	60	61	88
Bereavement period	8	25	22	4	16	13	11	13	13	13
Cause of death	Uterine cancer	Brain stem thrombosis	Liver cancer	Pulmonary disease	Cecal cancer	Cervical cancer	Myosarcoma	Brain tumor	Uterine cancer	Rheumatism
Period of illness	1 year	20 days	About 5 years	10 days	6 months	5 months	5 years and 5 months	1 year and 3 months	1 year	30 years
Place of death	Home	Hospital	Hospital	Hospital	Hospital	Home	Home	Home	Home	Home

\* The outlines of the three groups are as follows:

X: Approximately 50 members. Led by medical professionals, bereaved families, and music therapists.

Y: Approximately 50 members. Led by bereaved families.

Z: There are 164 registered households. Led by home healthcare providers and bereaved families.

## Topic 2: Listening and speaking

### **Realizing the diversity of bereavement experiences and the significance of verbalizing:**

Participants joined the group, listened directly to people's bereavement experiences in their own words, and realized that the circumstances of fighting illness or being at someone's deathbed and how people felt after bereavement were diverse for each person. Furthermore, as they participated and began to verbalize their own feelings and talk about their experience of bereavement, their previously chaotic emotions were put in order, and they began to see their own circumstances and future path forward.

**Feeling of fellowship:** Many of the study participants stated that their family and friends did not understand when they spoke about their feelings and that they could not talk about bereavement with co-workers or neighbors. Furthermore, the words of people who had not experienced bereavement, though with the intention of consolation, often added to the painful experience of the bereaved. In the midst of this, by attending groups for the bereaved and listening to others talk about their experiences of bereavement, participants empathized with others' feelings and found that they were not alone, giving rise to a sense of mutual understanding and fellowship.

The three bereavement groups surveyed in this study were not just for people who had lost their spouses but also people who had experienced a bereavement of any kind, so participants also listened to the bereavement experiences of people who had lost children, siblings, or parents. The study participants learned about various bereavement experiences from different standpoints and realized that grieving for people other than their spouses was also painful.

**Next steps:** When the study participants listened to and spoke about bereavement experiences, they expressed their sadness and pain and showed their own vulnerability to the other bereaved people there. In discussing their grief with others, participants became aware of their ongoing lives and thought about how to live and interact with people moving forward, uninhibited by sadness.

**Feeling of connection with the deceased:** Through verbalizing and talking about their own bereavement experiences, the study participants had a deeper sense of the presence of their deceased spouses and were aware of their connection with them.

## Topic 3: Changes in view of life and death

**Changes in sense of values that cannot be achieved alone:** On their own, the study participants remained entrenched in circular thoughts that did not progress, and they were stuck in their own way of thinking; however, their sense of values changed through listening to various people's bereavement experiences and talking about their own in the groups. They also felt the importance of listening to many bereavement experiences and of verbalizing and communicating to others what they had learned about death as well as the events and feelings that had arisen within them.

Table 2. Results of qualitative analysis

Topics	Themes	Interview quotes
Topic 1 Post-bereavement reactions	Psychological reactions	<i>The most painful thing was not being able to talk to her or see her face. I realized how much my wife had helped me. (Participant C)</i>
		<i>I felt apathetic, I didn't want to do anything. Somehow I lived through it. It was hard and I was down until about the second year. (Participant D)</i>
		<i>I thought it was me, I was the one who killed him. I mean, I didn't notice. That he might have been sick. That he was sluggish, that his blood pressure was high. I didn't notice at all. I thought I was a murderer. (Participant L)</i>
		<i>After all, she was facing death and didn't have much time to live. I wasn't fully there for her. I tried to face away as much as possible, or I ran away. This was my greatest regret, I felt like a horrible person. (Participant E)</i>
		<i>I think I felt relieved. Caregiving is hard too, you know. (Participant T)</i>
	Physical reactions	<i>I used to sleep six hours when my wife was here, but since she passed away, I sleep three to four hours. (Participant K)</i>
		<i>I felt like I wouldn't mind if I lost my life, so I only picked at things I wanted to eat while at home. ... I wasn't eating, so I lost seven kilograms. (Participant I)</i>
		<i>When my husband was in hospital, I didn't have much energy to cook meals for myself, and I lost about 5 kg in two months. (Participant O)</i>
	Social reactions	<i>I was tired from caring for my wife and lost weight. I was at my lowest weight when my wife died. (Participant B)</i>
		<i>Very few people lose their husbands at the age I did, so even when I talked to my friends about my feelings, they didn't understand. They tried to console me. But of course, it didn't quite work. More often they ended up hurting me instead. (Participant O)</i> <i>[The children] were quite a handful. I didn't have anyone to talk to about how to raise three children (one in junior high, one in elementary school, and one in kindergarten). (Participant E)</i>
Spiritual reactions	<i>Everything was meaningless. I thought there was no point in living. (Participant L)</i>	
	<i>For about two days [after he passed away], I felt so strongly that he was near me. ... I felt so clearly that he was still here, that's what it felt like. (Participant R)</i>	
Topic 2 Listening and speaking	Realizing the diversity of bereavement experiences and the significance of verbalizing	<i>There were all kinds of lives, and different ways of feeling after a death. (Participant P)</i>
		<i>With each repetition, I felt like things were being digested within me and organized into words. As I spoke, I sometimes noticed what I had been thinking for the first time. I felt like that must be the purpose of speaking. (Participant R)</i>
		<i>Talking with others about the experience of bereavement, you figure out what kind of path you're on. (Participant A)</i>
	Feeling of fellowship	<i>My siblings and friends didn't understand when I talked to them; they tried to be encouraging but ended up hurting me. But here, we had something in common, and that was comforting. I realized that I wasn't alone, that everyone feels the same way, and that was a relief. (Participant O)</i>
		<i>I am glad that I could come to a place like this to talk about bereavement, because it is a subject that I can never get through to my neighbors. (Participant P)</i>
	Relativizing one's own sadness	<i>I could not talk about my wife's bereavement at work. (Participant S)</i>
		<i>[I lost my husband, but] the stories of those who had lost a son or daughter were painful. (Participant R)</i>
		<i>Until then, it was like I thought I was the only one in pain. But actually, his parents must have been sad, and our children must have been sad. I was able to learn that through sharing. (Participant L)</i>
	Next steps	<i>We were crying and talking together, so it's like those of us who came could become one and share. Maybe we would be able to take a step forward. (Participant P)</i>
		<i>I think it was a question of how to live with the time I had left. As we shared our sadness together and empathized, I faced myself. After that, I found a way to interact with others going forward. (Participant M)</i>
Feeling of connection with the deceased	<i>Talking made me feel even more connected to [my husband]. (Participant R)</i>	
	<i>People who have just lost someone may not know this, but the deceased person is watching over you, so I think it's important for you to have an enjoyable life. (Participant Q)</i>	
Topic 3 Changes in view of life and death	Changes in sense of values that cannot be achieved alone	<i>The body may perish, but when we talk and verbalize, [our deceased spouse's] depth as a spiritual being increases. (Participant A)</i>
		<i>I think there's no way it would have turned out like this if I'd been on my own. I was going around in circles in my own mind, but in truth, maybe it's this other way or that other way, and I guess this is how, um, my sense of values changed. In a way, it was an awakening. (Participant M)</i>
	Acceptance of death and preparation for death	<i>Death comes for everyone, without exception, and that's not just something I know. I have listened to lots of experiences of bereavement. ... Learning on my own and learning from others. Properly verbalizing my own experience for other people as best as I could. (Participant A)</i>
		<i>Death was something I feared and dreaded, but it's something that will inevitably come, and it's not so scary anymore. (Participant B)</i>
		<i>Before, death was something I hated, but now I think it has dignity. I'm not afraid of death. (Participant L)</i>
	Living to cherish the present moment	<i>You have to think regularly about your own thoughts and actions in terms of how to deal with death. (Participant A)</i>
		<i>If I collapse, I absolutely do not want life-prolonging treatments. (Participant P)</i>
	Reception of spiritual feelings	<i>Human beings can die at any time. This is why I think we have to properly live each day. But we forget this in our day-to-day lives. (Participant J)</i>
		<i>I don't know what life will be like in a year, so I've decided to do my best right now with what I can. (Participant S)</i>
		<i>I don't know if there's an afterlife or not, but I thought believing in an afterlife would ease my worries about death. (Participant E)</i>

**Acceptance of death and preparation for death:**

Some participants previously had fear or dread of death; however, through group discussion, death became something that happens as a matter of course, something no longer frightening, and something with dignity. Furthermore, by joining groups and listening to various other people's bereavement experiences, more than a few participants came to think about preparations for their own death, such as the kind of medical care they wanted to have in the final stages of life.

**Living to cherish the present moment:**

By newly recognizing the reality of death, participants reflected on what they can do and cherish in the present. Some participants began volunteering in suicide prevention, helping young people who are socially withdrawn (*hikikomori*), and visiting with the elderly.

While some of the study participants had faith to begin with, others were led by transcendent experiences or group discussions to a new desire to connect to the deceased. Some people who were previously afraid of or anxious about death came to think that believing in an afterlife would diminish the fear of death in their lives.

**Discussion****Gaining a feeling of fellowship by listening to others' bereavement experiences:**

Yalom (1995), who studied and practiced group therapy, reported that patients who join therapy can hear other members disclose concerns similar to them and feel more in touch with the world. He called this a type of "welcome to the human race" experience. The participants of the present study attended groups for the bereaved. By first listening to others talk about their experiences of bereavement, they empathized with others' feelings and realized that they were not alone in their sadness and pain. This feeling of empathy, of not being alone, may have been connected with being welcomed by their peers, and this may have given rise to a sense of being connected to others through grief and loss. Furthermore, based on the notes of the bereavement groups they attended, listening to others talk about their pain is also a way for the listener to talk about their own pain (Yamato Seitoshiwo Kangaerukai, 2008). It seems that even without the bereaved person speaking about themselves, their own suffering and pain are being spoken for, and they are being empathized with.

Regarding negative experiences at bereavement groups, it has been reported that some people felt additional stress from listening to the stories of others and being overwhelmed by others' situations (Dyregrov et al., 2014); however, none of the participants of the present study said that they felt additional stress from listening to stories of loss.

**Reconstructing the meaning of life and living through telling peers about bereavement:**

Takahashi (2010), who is involved in bereavement

care in Japan, states that it is important to get bereaved families themselves to tell their stories and recount the past as an event of loss. However, it is difficult to talk about the experience of bereavement alone, and one needs an audience. An important role is played by the presence of someone who will reliably listen to one's story (Noguchi, 2003).

However, not just anyone makes a good audience. Morrigan et al. (2020) conducted an interview survey of the bereaved and found that among people with similar experiences, there was a comforting common theme, and they spoke of being able to talk frankly about what they thought and how they felt. The participants in the present study stated that they hesitated to talk about bereavement with co-workers or neighbors and that they felt hurt when their friends tried to console them. When it is difficult to talk about bereavement in one's social life, it seems that peer support groups provide an environment with equal footing due to having the same experience of bereavement, and people can easily put their inner thoughts into words and express their emotions.

Some people experienced the process of verbalizing the situation they found themselves in and its meaning; as one study participant said, "It feels like talking organizes things into words." By talking about their bereavement experiences with peers, the study participants may have connected the fragments of various experiences related to their loss, which had until then been scattered in chaos, and built them into a whole, consistent experience from past to present. As Riessman (2008) stated, "One can't be a 'self' by oneself; rather, identities are constructed in 'shows' that persuade." Perhaps, the bereaved built a new self by talking about their experience of bereavement with peers. Gilbert (2002) stated that people recreate their own experience in narratives and establish both order and social connections through the sharing of stories. The participants in this study adjusted their perception of the experience of bereavement, which had been chaotic within them, into something ordered and gained a desire to connect with other bereaved people and others in general.

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## Shared decision-making and relational identity in a pregnant woman with Eisenmenger syndrome

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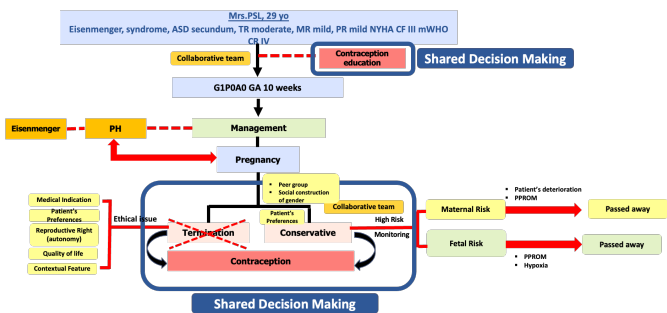
### Abstract

Pregnancy should ideally be avoided in a woman with Eisenmenger syndrome concerning the high maternal mortality rate and probable poor prognosis of the baby. However, the decision making of conceiving prevention and medical termination in patients with Eisenmenger syndrome is still dilemmatic. A 29-year-old, with non-corrective atrial septal defect P1A0 passed away three days after caesarean section due to pulmonary hypertensive crisis. She was diagnosed with Eisenmenger syndrome and had been educated related contraindication to pregnancy but she refused to terminate her pregnancy due to encouragement from her husband, family and peer group. Based on the four box methods, there are four approaches to make decision for pregnancy termination. First, *medical indication*; patient with Eisenmenger syndrome, non-corrective atrial septal defect. Second, *patient preference*; as a woman and wife the patient believes that she must be a mother. Third, *quality of life*; physically extremely poor for a patient with NYHA class functional II (high maternal mortality rate), however psychologically might feel better from patient's perspective to become a mother. The last, *contextual feature*; various external influence advocating for continuation of pregnancy despite the risk for mother, i.e. from her spouse, social construction of gender, religious values and misinformation/ low literacy of medical information in general society. In this case, medical indication and quality of life (from clinicians' perspective) were in conflict with patient's preference, patient's perceived quality of life, and contextual features, which caused clinicians to be in dilemma when advocating for pregnancy termination. Increasing the clinician capacity in ethical deliberation; empowering patient's capacity and educate society are needed to prevent from decisions which lead to the harm of patient. Further studies are needed to focus on how to understand and bridge the gap

between medical values (focused on prioritizing patient's safety and autonomy) and society's expectation or perception on women especially regarding maternal role.

**Introduction**

Eisenmenger syndrome is a syndrome with a congenital heart defect and results in large anatomic shunts which develop into severe pulmonary arterial hypertension and elevated vascular resistance (1). Maternal mortality in the presence of Eisenmenger syndrome is reported as 30-50% (2). Pregnancy should ideally be avoided in a woman with Eisenmenger syndrome concerning the high maternal mortality rate and probable poor prognosis of the baby (3). Termination of pregnancy is generally recommended for those who present early in the pregnancy (3). However, the decision making of conceiving prevention and medical termination in patients with Eisenmenger syndrome is still dilemmatic. Patients with Eisenmenger Syndrome must face various issues that greatly determine their decision regarding their pregnancy. In this paper, we discuss a case related to the decision-making process of a patient with Eisenmenger syndrome who continued her pregnancy even though the patient was recommended to terminate her pregnancy.



**Figure 1.** Case analysis decision making process of the Eisenmenger Patient. A female patient, 29 years old, suffered from Eisenmenger syndrome, had been educated to use contraception but refused and got pregnant; the patient was advised to end her pregnancy. ASD= Atrial Septal Defect; TR= Tricuspid Regurgitation; MR= Mitral Regurgitation; PR= Pulmonary regurgitation; NYHA= New York Heart Association; CF= Class Functional; mWHO classification= modified World Health Organization classification; PH= Pulmonary hypertension; PPRM= Preterm Premature Rupture of Membrane.

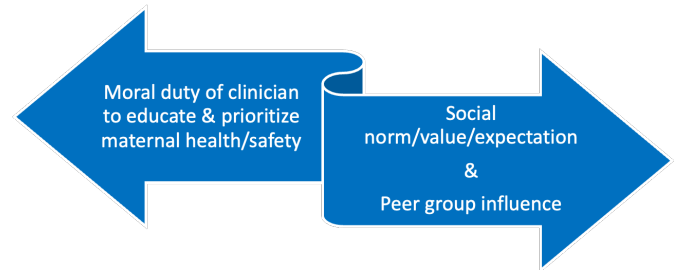
**Case**

A 29-year-old, Eisenmenger syndrome patient with non-corrective atrial septal defect P1A0 passed away three days after caesarean section due to pulmonary hypertensive crisis (Figure 1). She was diagnosed with Eisenmenger syndrome and had been educated about contraindication to pregnancy but the patient decided to conceive and finally, she was pregnant. Due to her clinical condition, a clinical conference was conducted to determine whether this patient

was fit to continue her pregnancy or not. A Multidisciplinary team of obstetrics and gynecology, cardiology, anesthesia departments and the hospital ethics committee discussed together to find the best solution for the patient. With many clinical considerations, the patient was advised to terminate her pregnancy, but she refused due to encouragement from her husband, family and peer group. At 27 weeks of gestation, the patient and her baby experienced worsening so a caesarean section was performed, and the patient passed away 3 days later. The baby also died one week later.

**Discussion**

The case illustrates an ethical dilemma where the clinician has a moral duty to educate and prioritize maternal health or safety but at the same time has to meet with the social norm or value or expectation and peer group influence (Figure 2).



**Figure 2.** Ethical Dilemma Highlight

Our attempts to comprehend and systematically analyze the ethical dilemma in this case, were guided by the Four-box paradigm/method by Jonsen, Siegler and Winslade, in order to facilitate our clinical decision making ethically. Based on the four-box method, there are four main aspects to consider in making the decision for pregnancy termination (Figure 3). First, *medical indication*; patient had been diagnosed with Eisenmenger syndrome, non-corrective atrial septal defect and this condition was a contraindication for pregnancy. Second, *patient preference*; patient expressed her wish to keep the pregnancy, as she believed that as a woman and wife, becoming a mother is a noble dream, without that some women may feel useless. As a wife, she believed her husband's request and opinion to continue pregnancy must be obeyed. Third, *quality of life*; from clinical perspective, patient's quality of life, physically, would be extremely poor, as patient with NYHA class functional II, would have limitations in performing strenuous activities, as well as a high maternal mortality risk. However, psychologically, quality of life might be considered better from the patient's perspective, as she believed that keeping the pregnancy is part of her duty as a woman and wife, hence she felt compelled to pursue carrying and delivering a child despite the risk of losing her life in the process. The last is *contextual feature*; the



influential external factors for patient's decision to keep the pregnancy were her spouse's request and opinions. Additionally, she was exposed to a peer group of women and mothers who had the experience of successful delivery. In broader context, the social construction of gender, and religion values were the factors that became the basis of patient reference in making decision to continue her pregnancy. Concluding the 4-box analysis we found that the aspects of medical indication and assessment of patient's quality of life in physical aspects suggested the ethical clinical decision was for pregnancy termination. However, this conflicted with the aspects of patient's preference, patient's perceived quality of life psychologically, and contextual features, which led her to continue pregnancy. We were inclined to consider this conflicting situation might have stemmed from patient's spouse and related peer group's low medical-health literacy, especially on Eisenmenger Syndrome, and complicated with the society's construct on gender and religious values.

Although the clinical conference by the multidisciplinary teams (obstetrics and gynecology, cardiology, anesthesiology, and ethical committee) advised to terminate her pregnancy, she and his family refused. Observing the patient's decision-making process is certainly an interesting thing in this case. In shared decision making the clinician should provide information to patients in order to enable them to decide autonomously and freely about treatment together with the doctor, without interference, force or coercion by others. However, the desired goal in this case (termination of pregnancy) had not been achieved, resulting in maternal death.

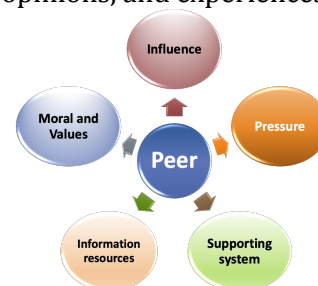
Four Box Methods	
<p><b>MEDICAL INDICATION</b></p> <p>→ ASD secundum, Eisenmenger, TR moderate, MR mild, PR mild                      NYHA CF III mWHO CR IV                      G1POAO GA 10 weeks</p>	<p><b>PATIENT PREFERENCE</b></p> <p>Value as a woman and wife</p>
<p><b>QUALITY OF LIFE</b></p> <p>→ NYHA CF II                      → High maternal mortality                      → Meaningful life with children</p>	<p><b>CONTEXTUAL FEATURE</b></p> <ul style="list-style-type: none"> <li>▪ Spouse's consideration in decision making</li> <li>▪ Peer group</li> <li>▪ Social construction of gender</li> <li>▪ Law, religion</li> </ul>

**Figure 3.** Four box method, an approach to make decision to pregnancy termination in the patient with Eisenmenger syndrome. The four-box method is an approach that is used as a basis for making clinical decisions regarding ethical dilemmas. This method consists of four boxes, namely: medical indications, patient preference, quality of life, contextual features.

We can learn a lesson in this case concerning the decision-making process, as it is not only about the informed consent of the patient and her family, but more than that, a shared decision making together with the patient and her family was needed.

Informed consent and shared decision making are very different processes. Informed consent is more focused on the process of conveying information related to the nature of treatment, risks, benefits, alternatives, and there is an opportunity for the patient to ask questions and then decide to refuse or agree to treatment (4-6). One level above is what is called informed choice where the process is the same as informed consent but there is an additional process of assessing patient understanding, discussing risks and benefits as well as alternatives and asking about patient choices. The most ideal process in making a clinical decision is shared decision making where we must identify patient needs, values, preferences, goals and discussing uncertainties of treatment, experience of providers, costs and two-way conversations with patients/family having a role in decision (4-6). Shared decision making is not a simple process, as it has several steps including reviewing the problem of patient, involving patient through the process, giving information about the risks and benefits of each option, discussing about patient concerns and expectation, developing decision and arranging of follow up (7).

To reach the best decision for the patient, counseling and education are a must. Patient education is part of management planning (8). Counselling and education should be done clearly, involving related parties (husband, family). Changing the patient's decision is not easy, it takes a complex long process. The essential steps of shared decision making are patient's participation and capability to assess patient's value and preferences and finally reach the best decision for patient's health (9). Declining medical termination in this case can be affected by culpability and responsibility, ideologies and religions, mistrust, and hope (10). Role of peer group in decision making cannot be ruled out since they can be as source of information, influence, pressure, support system and their moral values could affect each other (Figure 4). The decision making of patient in this case has been affected by her identity as a woman and wife and her dependency on others' (spouse, family, peer group, society) values, opinions, and experiences.



**Figure 4.** Role of peer group in decision making

In share decision making, patients can decide independently and freely about treatment with doctors, without interference, or coercion by others. In some circumstances, relatives (spouse and family) may be seen as obstructing or hindering the

patient's own decisions. Relatives may not act as third parties beside the doctor and patient, but as part of the patient's identity and thus be present in the decision-making process since beginning (11). Beside the medical professional support, the presence and support of the spouse and family are the main strength of the patient without expecting systemic support (12).

The fundamental lesson that we can take from this case is related to the process of a woman in making a decision. There are two basic factors that influence them in making decisions: identity and dependency (Figure 5). *Identity* includes their value as a woman, wife and daughter, personal characteristics, religion/belief and their health condition. Meanwhile, the *dependency* factors include values, opinions, decisions, and experiences by other people (spouse, family, peer group). Changing the identity and dependencies attached to each woman is not an easy thing because it requires a complex and long process.

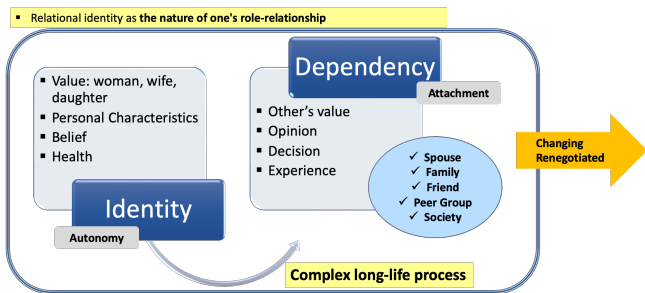


Figure 5. Factors that influence a woman to make decision.

**Conclusion**

Based on the case discussed above, we learned that patient's expression of preference and decision making, especially with certain identity and role assigned to women, was influenced by far more complex components such as spousal and peer support/ encouragement, as well as the broader issues of gender construct, religious values and medical-health literacy in the society. Several points need to improve in to how a clinician is able to deal with ethical dilemmas and identify patient values and preferences: improve counseling services to be more clear, informative, personalized, multidisciplinary, and empowering patient capacity; society education on women's health and reproductive rights literacy and fostering dialogues on understanding social construction of gender roles/expectations, increasing healthcare and peer group partnerships to foster aligned health messages/information (reduce misconceptions and misleading influence). Further studies are needed on how to understand and bridge the gap between medical values (focused on prioritizing patient's safety and autonomy) and society's expectation/perception on women especially regarding maternal role.

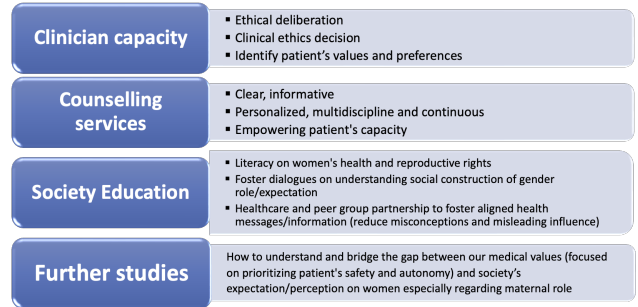


Figure 6. Future recommendation

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## Heritable human genome editing in Japan: status and continuity

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*Every year an estimated 7.9 million children, 6% of total births worldwide, are born with a serious birth defect of genetic or partially genetic origin. Had sexual reproduction been invented by scientists rather than resulting from our evolved biology, it would never have been licensed—far too dangerous!*

John Harris, Professor Emeritus, University of Manchester

### Introduction

At the 30<sup>th</sup> annual conference of the Japanese Association for Bioethics held on 8<sup>th</sup>-9<sup>th</sup> December 2018 at Kyoto Prefectural University, at the end of a session on genome editing, one of the prominent bioethicists in presence—a professor at a top national university who is heavily involved in shaping the regulation of bioscientific research and applications—stood up to express condemnation of the Chinese biophysicist He Jiankui. The professor had personally witnessed He's announcement a few days earlier at the 2<sup>nd</sup> International Summit on Human Genome Editing in Hong Kong regarding the birth of a set of twins following genome alterations with the clustered regularly interspaced short palindromic repeats (CRISPR)-Cas9 tool. This technology, he explained, was not yet ready for application in the clinic, nor was there social consensus in place about the moral permissibility of utilizing it in this way. The global scientific community, he expounded, had made it abundantly clear that this CRISPR-Cas9 is not to be employed in human reproduction at the current stage. Many national academies of science and medicine, he noted, had issued calls for moratorium, and there was even a multinational statement from the 1<sup>st</sup> International Summit on Human Genome Editing in Washington, D.C., in 2015 stating that, for the time being, it would be irresponsible to proceed with clinical use of CRISPR-Cas9. By ignoring these calls, He had breached a code of conduct in science, the professor argued, and to prevent the occurrence of more cases such as this, the establishment of an international monitoring body for clinical use of human germline genome editing was necessary—a project for whose pursuit he has now joined forces with his counterparts in other countries.

The legitimacy of condemning He's experiment

notwithstanding, what subsequently transpired at the above-mentioned Japanese gathering amounted to the participants throwing the baby out with the bathwater. A stream of ill-founded objections ensued with regards to the modification of the genome of embryos, and at no point until the end of that session did anybody stand up in defense of the principle that one day, when we have acquired technical competency in altering the genome of such tissue, there might be a compelling reason to do so. Indeed, attendee after attendee rose to express what appeared to be a dogmatically held view with regards to human germline genome editing. Changing the human germline, one gentleman argued with discontent, would result in a cascade of unforeseen and irreversible repercussions for the future generations. This line should never be crossed, claimed another, for, above all, there was no way of obtaining the consent of those who would stand affected – our descendants. We are at the beginning of a slippery slope with this CRISPR/Cas9 technology, a third participant asserted, because, if we allow its use for controlling diseases, we are bound to find ourselves next permitting it for all kinds of enhancements too. There is a potential with human germline genome editing, a fourth person joined the bandwagon, for mistakes to occur with horrendous consequences that are unimaginable from our current position.

The condemnation at this gathering of heritable human genome editing (HHGE) altogether was not an isolated occurring in Japan in the aftermath of the revelations surrounding He. On the contrary, the level of engagement with the question of HHGE by the attendees of this event could be said to reflect that which was sustained broadly in Japanese society at the time. Corroborating this statement is the finding of Daiki Watanabe et al. that the overwhelmingly negative coverage of the He affair here brought about a dramatic fall in public acceptance of the genome editing technology, not just in the field of human reproduction but also across agriculture and fishery breeding<sup>1</sup>. There was, indeed, a lack of proper engagement on the topic in this jurisdiction, with the only reaction seen in the media and other public arenas, such as the academia, being a reflex one, whereby commentators widely rushed to decry the whole concept of HHGE. No one could be seen to take the challenge of pointing out the flaws that underpin the common objections to this notion and highlighting the responsibility towards those currently without a therapeutic reproductive option to continue pursuing mastery of the technique. Even today, the difference is striking between the record of firm affirmations made in the aftermath of the He announcement by scientists and bioethicists in other countries of the prospective

<sup>1</sup> To be more specific, Watanabe et al.'s sequence of surveys revealed that the share of interview respondents saying that they find the genome editing technology "most impressionable" dropped from 269, or 39.4%, in 2016 to merely 83.4, or 3.03%, in 2018 and 78.7%, or 2.97%, in 2019, with, simultaneously, the number of those being "concerned about [associated] ethical issues" jumping from 0 in 2016 to 71.8 in 2018 and 79.6 in 2019.

value of prudently implemented HHGE (with five examples from two other biotech powerhouses, the United States and the United Kingdom, being: Daley 2018; Harris 2018a, 2018b; Daley, Lovell-Badge & Steffann 2019; Greely 2021), and the silence, on the other hand, that remains in Japan with respect to this subject.

The present article draws attention to this stagnancy in the Japanese debate on HHGE. Putting the question of HHGE in Japan in focus is important because of the significant loss that could occur for the community of people with heritable conditions by having this country, which has been able to contribute enormously to the so-called Human Genome Project (Cook-Deegan 1994; Sasaki 2019) and which boasts enviable bioscience capabilities, remain a passive observer in the evolution of the HHGE technology. Although Japan has recently invested heavily in the development of somatic therapies based on the induced pluripotent stem cell technology, this is but only one of the possible approaches to controlling disease. Furthermore, insofar as this approach has not yet been realized, consideration of HHGE as a reasonable alternative is warranted. With it being the case that technologies do not develop in a moral vacuum and that more often than not the public debate leads the way when it comes to their development, it seems important that the inaction on the part of Japan with regards to HHGE is highlighted and an insight is sought as to what the factors behind it might be. The present article can be considered as a thrust in this direction.

In what follows, the article first considers the state of HHGE science in Japan, utilizing in the discussion Japanese bioethicists' views, as expressed in a conversation with the author, on why this country diverges in this respect from its counterparts in the developed world. This is then followed by a more comprehensive overview of existing survey results with respect to the Japanese population's stance on the acceptability of HHGE. Both these parts of the article are to serve as further contextualization for the observation ultimately presented that there is a continuity in how difficult issues of bioethical nature are handled by the Japanese academe, and bioethicists more specifically.

**Japan's lack of scientific output on HHGE:** The disengagement in terms of the debate on HHGE in Japan is borne out by the fact that, as Hokkaido University bioethicist Tetsuo Ishii recently highlighted (Ishii 2020), there exist literally zero papers published by Japanese scientists reporting on experimental work in this field. Although this finding might not seem of significance when it is considered that the research on HHGE is still in a nascent state internationally, Japan is but a global leader in bioscience and a most heavy utilizer of in vitro fertilization (Croydon 2021a, 2021b, forthcoming),

and so the absence of any scientific output in this regard could be said to be at least conspicuous.

In relation to this lack of HHGE research activity, the reaction of some might be that the existence of a diversity of approaches, or a global division of labor, if you will, towards the goal of developing therapeutics and eliminating disease, is a good thing: what could be so wrong, they might say, with Japan putting, as it has since 2012, the majority of its efforts and resources towards developing technology for somatic treatments based on reprogramming adult cells, and other scientific powerhouses, such as the United States and the United Kingdom, for example, focusing more on obliteration of disease in the gametes or through the more traditional means of embryonic stem cell therapies?

The lack of scientific output in HHGE on the part of Japan would not have been so noteworthy if it represented a byproduct of a deliberate arrangement. Indeed, had it been the case of an international coordination and a conscious effort being in place to let each jurisdiction play to its strengths, Japan's lagging in the field of HHGE would not have been particularly notable. However, to the extent that there is no such arrangement, and in light of the above-described silence by bioethicists, one is led to hypothesize that perhaps existing hostile trends in the public perception of HHGE might be what is standing in the way of this science.

In relation to this hypothesis, it is pertinent to mention a remark made by a group of Japanese bioethicists in December 2018, just after the unfolding of the He fiasco. According to them:

Japanese scientists are extremely mindful of unspoken social norms (*kihan no ishiki ga takai*). Whilst in other countries, scientists would venture into HHGE even if there is a law or other regulation explicitly prohibiting it, in Japan, by contrast, even in the presence of a legal green light for HHGE, the scientists would not dare go into it. They would be too fearful that they would be breaching a tacit social consensus that tampering with the human germline genome is off limits<sup>2</sup>.

Although this is merely an offhand comment, in the absence of any other explanation of the reticence of Japanese scientists to work on HHGE, it appears worthwhile paying heed to it. Is it not more likely, indeed, that rather than resulting from the Japanese scientists' divergent view on the feasibility, or utility, of delivering therapeutics through HHGE, the absence of scientific output in this area here is a function of the latter being fearful of breaking a social taboo?

**Survey results on HHGE's acceptance in Japan: A comprehensive overview:** The fears of Japanese scientists put aside, is it really the case that there is a

<sup>2</sup> Author's translation from Japanese. Private conversation, 15 December 2018. Names of participants withheld for anonymity purposes.

resolutely established domestic public view on HHGE in Japan, which is what one might conclude from the above-mentioned survey results of Watanabe et al.? On this question, it would constitute a grave omission to fail to mention the existence of two other recent surveys on the level of domestic public acceptance of the use of the genome editing invention on human germline tissue—Uchiyama et al. 2018 and Hibino et al. 2019. Taken aggregately, these papers present a more nuanced portrait of the extent to which the Japanese public supports HHGE.

To explain concretely with regards to these surveys, the first one investigates the attitudes to human germline genome editing in two groups in Japan: one comprising 10,881 general adults (GAs), and another—937 patients (Pts) diagnosed with or at risk of developing a genetic condition, with the basis for bringing into an independent focus the latter being that, as stakeholders in the technology (i.e. as in being prospective clinical trials participants and beneficiaries of heritable genome editing, or, reversely, being candidate eugenic targets), they might hold divergent views from those of the general population. In confirmation of this hypothesis, the researchers reported that Pts were, to begin with, more aware of this technology than GAs, and that people with higher awareness of HHGE in both groups were more supportive of it, with over 50% of these more knowledgeable respondents agreeing that it may be used for diseases that shorten a baby's life or require long term care (Uchiyama et al. 2018). However, when asked if they had concerns about changing the genes of other humans, about the unexpected effects on the human body, and about the effects on future generations, in both groups and across all levels of understanding of HHGE, respondents predominantly indicated that they do, with this percentage being often in the higher 80s. To cite the researchers' summary of their findings, "despite low awareness and inadequate understanding about genome editing before responding to the survey, [the] respondents were accepting of its use in targeting of disease-related genes, albeit with substantial concerns about risks" (Ibid.: 748).

As for the second survey, it presents a complementary picture, in that it highlights that when given the option to select between more than just the binary answers of "I agree" or "I disagree" to questions about the acceptability of use of synthetic biology and genome editing, including with respect to human germline tissue, as much as around 80% of respondents in Japan, choose to give an equivocal, indecisive, judgement-postponing, reserved response (Hibino et al. 2019). To cite the researchers' own words with regards to what this outcome means:

This indecision was found to be related to the cognitive image of the self and future generations. Our survey analysis demonstrated that those with a narrow cognitive self-concept tend to postpone judgement on emerging biotechnologies. Those with

a broad cognitive self-concept tend to have a two-sided attitude and are more short-sighted but make judgements based on the impact of their decisions on the current and future generations (Ibid: 4).

To recap, the picture that emerges when the information from these surveys is taken holistically is one of a lack of a resolutely established domestic public view on HHGE and of the existence simultaneously of serious considerations regarding passing pathogenic gene mutations on to future offspring and anxieties about risks.

**Background: The precedent of human embryonic stem cell research (hESR):** Taking stock of the material presented hitherto, how do we make sense of the seemingly conflicting evidence that, on the one hand, Japanese scientists refrain from HHGE research, arguably due to their fear of breaching a social taboo, and, on the other hand, an urge being detectable here of the public to endorse this technology's use to alleviate pain and suffering? An insight regarding this, it is the contention of this article, can be found in earlier episodes of Japan's biomedical history. More specifically, a striking amount of parallels could be found between this case and that of hESR, with the quiet of the academics regarding the ethical aspects of the subject being the root cause of the stagnation of both the debate and the research.

To elaborate on the hESR case, in the late 2000s, the anthropologist Margaret Sleeboom-Faulkner attributed the stagnation in this area in Japan precisely to the disengagement of the academics, in addition to the policy-making elite, with the public on the issue of the moral status of the human embryo (Sleeboom-Faulkner 2008, 2010). Japanese bioethicists, she observed, avoided making uncomfortable comments in public. At a time when Christian groups had brought a moratorium on public funding for hESR in the United States to the embarrassment of the science community there, the Japanese science and policymaking elite, she argued, adopted the hackneyed view, arguably in a bid to posit Japan's superiority, that the local religious and cultural canons allowed for a moral void to exist surrounding the human embryo, meaning that there is no obstacle domestically to such research. This view, expressed by experts in the media and other outlets, that the embryo is of no moral concern to the people of Japan stymied the emergence of a public debate, with everyone becoming hesitant to share their real opinions in the open. As for how these experts corroborated their claim, Sleeboom-Faulkner noted their referring to the long-standing extensive practice of induced pregnancy termination here—if the embryo held a special place for Japanese people, we would not have been witnessing such a sizable abortion practice, the argument appears to have gone.

Furthermore, as a way of demonstration that it is, indeed, the state of the public debate that makes a difference as to whether a morally controversial biomedical practice picks up or not in Japan,

Sleeboom-Faulkner pointed to the process through which the 31-year Japanese moratorium on tissue donation at the other end of life—or more precisely, following brain death—was broken here. As had been elaborated by Masahiro Morioka, amongst others before her (Morioka 2012; also, Lock 2001), the promulgation in 1997 of the Brain Death and Organ Transplantation Law, which legalized organ procurement from brain death donors as long as consent exists from either the bereaved or their family, was precipitated by both: a declaration by a ministerial ad hoc committee that “medical criteria for brain death” is different from “the concept of human death”, with the latter being dependent upon “the consensus of the Japanese people”, and an ensuing publishing flurry of popular books on the subject. With regards to hESR, Sleeboom-Faulkner subtly suggested, Prime Minister Junichiro Koizumi might well have made Japan one of the first countries, short of a full law, to permit it, but without the public’s uneasiness about the use of embryos as a means to therapies being acknowledged in the same fashion as the anxiety about cadaveric organ donation was recognized, and reflected in a parliamentary draft bill, in the 1990s, the outcome of embryo donation and public funding stagnating was predictable.

Juxtaposing these two cases, the continuity between the Japanese situation with regards to hESR in the 2000s, as described by Sleeboom-Faulkner, and the current state of affairs here in relation to HHGE is striking. The discovery in the intervening years by Shinya Yamanaka of how to induce pluripotency in adult cells made it seem as if the obstacle to developing regenerative medicine here, and perhaps elsewhere, has been overcome. However, the fact that his discovery was endorsed is a vindication of Sleeboom-Faulkner—it is because the public had moral concerns about the embryo that they endorsed the narrative of Yamanaka.

To spell out what the parallels are between these two cases, similarly to their low-key approach to the thorny bioethical issues related to the human embryo in the 2000s, the Japanese elite—the academia and policy-makers—are now quiet about HHGE, reluctant to calm agitation that emerges from the mentioning of the term “germline” in the context of human genome engineering. Discussions with scientists reveal that they are keen on sustaining the illusion that debate about how the human embryo might be treated in the scientific laboratory is academic and redundant in the Japanese context. The simplistic old assertions documented by Sleeboom-Faulkner continue to be made with dogged persistence. In his attempt to posit a Japanese moral vacuum with regards to the human embryo, one younger bioethicist, for example, remarks that “most Japanese do not have a religion, and the roughly 30% who do affiliate with Buddhism are not taught anything about reproduction through this tradition” (Personal email communication, 30 June 2021). The Christian community is very small

in Japan, comments another established Japanese scientist, and as far as Buddhism is concerned, he asserts, it focuses more on what happens after death (Interview, Kyoto, 28 October 2019). In short, no acknowledgement is sought of any unease that might exist in the public with regards to the manipulation in the laboratory of the human embryo—ethical vacuity continues to be projected onto it.

### Conclusion

In the absence of an existing alternative method for overcoming certain reproductive problems and heritable conditions, it seems imperative that the battle for overcoming moral scruples with regards to HHGE within the public of a country such as Japan is fought in earnest. Whatever one might make of the number of people for whom there is a plausible useful function for HHGE in therapeutic-treatment terms—and indeed, this number varies wildly depending on whether only couples are considered that do not possess a non-disease promoting genetic variation to pass, or whether other cases are counted as well, such as where pre-implantation genetic testing has failed to produce a suitable embryo for transfer, or where changing a letter in the genome can mean the concerned person would not have to worry about developing a serious condition—the debate about it needs to take place. Whilst it is certainly not for the scientists/academics alone to make the decision as to whether performing HHGE is permissible, it is one of their responsibilities to place the debate about it in the broader public on the right footing. Insofar that simple truths about HHGE (such as that, as Stanford University Law Professor Henry Greely eloquently and repeatedly explains, there is no single entity that can be called “human germline genome” and which constitutes the holy essence of humanity, and that our genomes have changed from time immemorial and will continue to change not only ad hoc, but also as a result of our own actions (Greely 2017; 2019 & 2021)), remain an esoteric knowledge in Japan, the country’s bioethical community could be found culpable of laziness. As the case of cadaveric organ donation in Japan demonstrated, there is no substitute for an open public debate on a contentious bioethical issue. It is only by creating an atmosphere where plethora of perspectives can be voiced, with an acknowledgement of any anxieties and concerns that have surfaced, as opposed to maintaining silence or engaging in dismissal, that the HHGE science in this country can commence, for the benefit of all those in need.

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## Why inhumane? An ethical issue on medical negligence from health professionals

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### Abstract

Medical negligence in healthcare settings is an infidelity to the profession, and a sin towards human lives. Often used as a matter of excuse, blame game, irrational mistake, and frustration with stressful environments, it is overlooked and swept under the carpet. However, acknowledging the ethical values of the profession, sensitizing healthcare professionals to implement best practices, and reporting events to prevent harm in future, is certainly imperative. This paper shares an overview of medical negligence under an analysis of different biomedical ethical theories and shares relatable recommendations for future implications in healthcare practice.

### Introduction

Medical negligence is a long-standing ethical issue. Negligence is the act of omission or commission from a health professional that speculates due care (Burkhardt and Nathaniel, 2013). This breach of duty results in harm to the patient (Raja, 2017). According to Waraich (2018), there are various reasons for intentional or unintentional negligence. It includes a lack of awareness or experience of the problem, a culture of silence, system constraints like inadequate patient-provider ratio, sleep deprivation, poor communication skills, improper documentation and illegible writing, lack of professional ethics and faulty health policies. The paper aims to reflect on a case of negligence under ethical theories and find ethically sound justifications to deal with this issue.

A heart failure patient with hemoglobin level of 5.1mg/dl presented in the emergency room at one of the tertiary care hospitals of Pakistan. The patient's history revealed multiple transfusions; therefore, blood products were arranged in the blood bank. The doctor ordered to start transfusion after the

transfer of the patient to special care for close monitoring. However, after shifting, the blood transfusion was delayed for 2 hours due to the nurse's workload. Meanwhile, the patient's vitals deteriorated requiring inotropic support due to cardiogenic shock. The case was reported to the hospital's clinical affairs resulting in verbal disciplinary action against the doctor and nurse. This case presents diverse questions to be considered under the light of ethics:

- 1- How responsible do health professionals feel for their duty of care?
- 2- Is punitive action the only solution for workload-associated negligence?
- 3- Is equity in care more important than equality?

This article presents the overview of medical negligence, through a case description, under the light of various ethical perspectives, and shares recommendations for future implications in healthcare practice.

### Multidimensional analysis

The culture of a healthcare setting is based on the power of knowledge to treat. It is understood and socially accepted that health professionals, by default, may hold prime power and responsibility to treat patients. Consequently, patients develop trust towards health professionals. When such preventable negligence transpires, it directly harms the patient's quality of life.

In reference to the Islamic perspective of biomedical ethics, ethical decisions are based on revealed texts from Quran, Hadith and Sunnah rather than personalized intuitions. Since humans are intellectual beings, they are capable of correlating (*mulazama*) moral judgments with divine commandments. According to Sachedina (2009), Muslim jurisprudence is based on *istihsan* (prioritization of two judgments using juristic practice) and *istislah* (promoting benefit and preventing harm for the public) to achieve *maslaha* (public good). Harm is called "*darar*", which is an intentional or unintentional act committed by one person against another. Islamic bioethical judiciary preliminary focuses on the principle of non-maleficence as "No Harm, No Harassment". This is evident by the holy quote "In Islam there shall be no harm inflicted or reciprocated" (*la darar wa la dirar fi al-islam*) (Sachedina, 2009, p.47) and hadith "There shall be no [adopting of a course of action that leads to] harming of one man to another" (Sachedina, 2009, pg. 68). Thus, the principle of "No Harm, No Harassment" depends on five rules that are, "action depends upon intention, hardship necessitates relief, one needs certainty, harm must be rejected, and custom determines course of action" (Sachedina, 2009, pg.67). Muslims strongly believe that God does not harm his creatures. Pakistan being an Islamic state functions upon the above-mentioned Islamic guidelines.

From a legal perspective, the disciplinary committee of the Pakistan Medical and Dental

Council, have the authority to terminate the practice license of doctors who are found guilty of medical negligence (Raja, 2017). Additionally, the patient and family (victims) have a right to file a First Information Report (FIR) under Section 318 of Pakistan Penal Code 1860 which affirms that any intentional or unintentional act causing harm or death is sentenced as *Qatl-i-khata*, therefore, such individuals shall be punished with 2 years of imprisonment or monetary fine or both as per Section 304-A PPC 1860 (Raja, 2017). Furthermore, according to the Tort Law for misdemeanor, civil court sanctions victims to obtain compensation from hospitals under Fatal Accidents Act 1855 (Raja, 2017). Despite such stringent religious and national legislation, it is crucial to understand the issue of negligence and ways of prevention from an ethical paradigm.

**My position:** Health professionals should use the virtue of ethics, critical thinking and prioritization setting strategy to prevent medical negligence. They must implement the core concepts from ethical theories which are duty to care, protection from harm, provision of justice and acknowledging the rights of patients while making patient-care decisions. Since the patient had heart failure with severe anemia, blood transfusion should have been initiated from the emergency room or directly after transportation to special care as an acute lifesaving measure.

**Kantian theory versus rights of health professionals:** Deontology also known as Formalism and Kantianism infer a rationalist view. An act is considered right or wrong based on the nature of that act rather than consequentialism (Burkhardt and Nathaniel, 2013). These ethical acts become universal, and humans utilize reasoning to imply it in various situations. The rightness of an action depends upon the maximum that is a categorical imperative (universal acceptance) and practical imperative (performing duties owned to others). The two imperatives of duty go hand in hand to determine a professional code of ethics. Totten (2013) affirms that health professionals have the right to access tools that are necessary for them while performing their duty. This could be in the form of help from co-workers, personal time for relaxation and hydration and safety from harm or injury. In the above case scenario, although the nurse might have intended to care for the patient as a duty the workload resulted in negligence for which disciplinary action was taken. The dilemma arises whether disciplinary action against workload-associated negligence is justifiable or not.

**Consequence of my position:** If health professionals are forgiven for their negligence with no disciplinary action, this could be a wrong role model for others. Such an action would promote carefree culture amongst health professionals. They would not be bothered over their accountabilities.

**Counterargument for justification:** The duty to care for patients is the prime responsibility of health



professionals as per the International Council for Nurses Code of Ethics (Burkhardt and Nathaniel, 2013). Disciplinary action for unintentional negligence may result in demotivation, fear of reporting, mental and moral distress, and a high probability of future mistakes. Thus, if a conducive workplace environment is not created where subordinates reach out to help in managing busy shifts; it would lead to medical negligence.

**Aristotle's virtue and rights theory:** Virtue ethics, also known as character ethics, are a set of innate moral values that are socially acceptable and create a moralistic character which impact on an individual's judgment and actions (Burkhardt and Nathaniel, 2013). Beauchamp and Childress (2013) proposed four focal virtues for a moral character: compassion, discernment, trustworthiness, and integrity. Good character is formed if these virtues are enrooted to depict good nursing (Burkhardt and Nathaniel, 2013). Simultaneously, Rights Theory supports the provision of individual rights (right to safety, right to health care) that become an obligatory responsibility of society including health professionals (Beauchamp & Childress, 2013). According to Human Rights Convention Article 2 and 3, an individual has a right to life and to prohibition of torture, respectively (Gosney, 2013). In the aforementioned case, virtues were important to develop sensitive insight among health professionals. Acute judgement for early transfusion could have prevented life-threatening cardiogenic shock. Also, it is important to understand patient's bill of rights to attain correct and prompt treatment. Although blood products were arranged, they were not transfused timely.

**Consequence of my position:** If these two theories are not acknowledged and implemented by health professionals, that may cause desensitization and a lack of a professional attitude towards patients leading to negligence. According to the institution's Standard Operating Procedure (SOP), Blood and Blood Product Administration Module (2015), it is mandatory for doctors to write the reason for transfusion. Since the patient was symptomatically anemic and clear written documentation for the urgency of transfusion was not documented, this led to the act of negligence. If the doctor had demonstrated professionalism and sensitivity towards the patient, such delay in care would have been impeded.

**Counterargument for justification:** Nurses must understand overt and covert values while working in healthcare settings. The overt values are the explicit institutional values in the form of policies; however, the covert are implicit personalized values. The conflict between overt and covert values may end up in moral distress. Moral distress is a state where a nurse realizes the morally correct action but couldn't perform it due to institutional constraints. (Burkhardt and Nathaniel, 2013). In the above case, the nurse followed the doctor's order to transfuse blood after reaching the special care unit which

wasn't the correct decision for the patient but still followed. Currently, nurses must understand that they belong to an autonomous profession, and have a key obligation to their patients, not physicians. They should not follow physician orders if it's unethical, incompetent, or illegal which keeps the patient at risk of harm. Instead, nurses must advocate for their patients and communicate with doctors regarding the high or low spectrum of urgency and feel obligatory to rectify impending harm (Burkhardt and Nathaniel, 2013).

**Non-maleficence versus Rawls's theory of justice:** Non-maleficence, the first ethical principle, is to avoid harm to achieve beneficence (Burkhardt and Nathaniel, 2013). Failure of due care results in negligence associated with maleficence. If the risk is high, it can override beneficence. Concurrently, justice is to protect basic liberties by guaranteeing equality of opportunity (Bulletin of the World Health Organization, 2008).

**Consequence of my position:** If justice precedence is fair care to all irrespective of who needs the most attention, equality would remain affirmed. However, equity that depends upon need-based care will be compromised. Nurses must understand situations where harm outweighs benefit and should care for those first, who need the most (Burkhardt and Nathaniel, 2013).

**Counterargument for justification:** Priority setting is a skill that could promote non-maleficence. It is a critical thinking skill that plans nursing actions based on the urgency of care. For example, a patient with respiratory distress would be considered more liable than a patient with pain due to a hairline fracture. This urgency of action depends upon which vital organ is involved and what is its acute state. Poor implementation of priority-setting skills by health professionals leads to life-threatening consequences for patients. Nurses' experience and education, patient's health status, scarcity of resources, work dynamics, therapeutic nurse-patient relationship and cognitive strategies influence nurses' priority setting (Hendry and Walker, 2004). Thus, priority setting does not mean neglecting any patient from care rather, it is prioritization of patients for care.

### Recommendations

Reflecting upon the case scenario and the associated issue of medical negligence, a few recommendations are proposed at individual, organizational and national levels. At an individual level, physicians and nursing management must conduct debriefing sessions on sentinel events for root cause analysis so that health professionals can have an opportunity for self-awareness and self-reflection. Additionally, supervisors should provide summative and formative ongoing clinical performance evaluations and appraisals to appreciate their hard work through incentives and inform the need for improvement. Moreover, continuous nursing and medical professional education for skill development

on patient assessment, reporting findings, planning relevant interventions and reevaluations should be conducted to enhance their knowledge and promote evidence-based practice. This will reinforce health professionals to learn priority setting, use critical thinking and perform problem-solving skills efficiently. Biomedical ethics should be taught as a separate refresher course to all health professionals from all hierarchical levels (subordinates to leaders) to build sensitization. Moreover, medical and nursing faculties should plan undergraduate courses that could give an opportunity to students to understand real-life biomedical ethical dilemmas. At the organizational level, the Quality and Patient Safety department should run frequent quality assurance audits and promote a blame-free error reporting culture by reinforcing a safe disclosure policy. Moreover, keeping the principle of veracity and trustworthiness robust, negligence disclosure and apology should be informed to the entrusted family member of the patient after involving Hospital Ethics Committee (HEC). This would give a gesture of reconciliation and acknowledgement towards the special duty of care. They must be apprised of Tort system for either waiving of fee or monetary compensation for financial loss. To prevent future negligence, clear policies and protocols on the consequences of medical negligence should be formed to ensure professional liability. Human Resource department and managers should assure manageable duty hours and sufficient staffing to prevent work overload and physical-psychological exhaustion. Health professionals' competency checklists should be reviewed annually to verify credentials. Patient wellness programs and support groups should be initiated for psychological, social, emotional, and financial wellbeing. Research could be conducted to prevent negligence in future. A risk management strategy should be utilized to maintain effective communication, expertise in conscientious practice, autonomy, and empowerment among health professionals. Moreover, sufficient investment should be done in health systems to create corruption-free health for all.

Humans are imperfect beings and certainly may cause some errors (human error). Health professionals are the fundamental assets of our society with greater responsibilities to deal with human lives. With this responsibility, health professionals must ensure to follow core ethical principles of providing holistic care and essentially understand that there is no better service than the service you render to others. Therefore, systems to control negligence at individual, institutional and national levels must be formed to ultimately prevent future medical negligence.

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## The ethical aspects of unwanted pregnancy: Cases of rape reported in the media with legal restrictions on abortion in Turkey

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### Abstract

This study examines the ethical and legal issues faced by girls/women requesting abortions who were victims of rape, aspects which have received little attention to date. This is a retrospective study using a case-based approach to analyze the ethical and legal issues relating to incidents of unwanted pregnancy resulting from rape as reported in Turkish newspapers from 2010-2018. A total of 95 articles were discovered and categorized. These were then evaluated for content and analyzed in terms of the ethical issues related to the cases. Of these articles, 14 involved rape-related pregnancy cases. The six cases chosen for analysis in this study were carefully selected from newspaper reports between 2010-2018. The victims who requested abortions were between 9 and 26 weeks pregnant and aged 14-26 years old. Turkish courts approved

only two of the victims' requests. The cases in this study were evaluated by the authorities solely on legal grounds. The stress experienced by victims of rape is exacerbated by compulsory pregnancy; the fact that these victims were not allowed to terminate their pregnancies resulted in their further punishment. Requests for abortion should thus be assessed not only in terms of legality, but also on the basis of medical and especially ethical issues.

### Introduction

The objective of this article is to examine cases in which victims of rape sought to terminate the unwanted pregnancies resulting from sexual assaults. As sexual violence occurs in all parts of the world, unwanted/compulsory pregnancy is therefore a global issue, involving not only biological, psychological, and social health problems but also ethical and legal issues. A report by the World Health Organization has stated that every 2-3 minutes somewhere in the world a woman is a victim of sexual assault (Organization, 2013). Some victims who become pregnant because of sexual assault request abortions; when these requests are denied, the victims are then forced to endure further trauma (Gipson, Koenig, & Hindin, 2008; Holmes, Resnick, Kilpatrick, & Best, 1996; Satin, Hemsell, Stone, Theriot, & Wendel, 1991).

Even governments that support reproductive freedom as a human right may implement legislation restricting the termination of a pregnancy, for reasons pertaining to dominant religious beliefs, accepted morality, scientific conceptions regarding the fetus, concerns about decreasing birth rates, or simply as a continuation of traditional policies on abortion (Shaw, 2010). However, restrictive legislation has not managed to eliminate the controversy surrounding abortion, whether on legal, ethical, or religious grounds. In Turkey, abortion on demand is allowed until the 10th week; however, if the fetus is disabled or a heartbeat is not detected (Appendix1) the pregnancy may be terminated until the 24th week with informed consent (Regulation, 1983). A girl who has not reached majority can undergo an abortion with the written consent of her parents (Hall, 1990).

Unfortunately, outside of the legal limits placed on abortion, many feel that they have a right to involve themselves in women's reproductive choices by virtue of their claim to moral and religious values. For this reason, the status of the fetus must be clearly defined. Firstly, the fetus is an entity that cannot live independently of the mother and is not recognized as having individual rights. Secondly, the brain of a fetus has not undergone sufficient development to enable conscious thought. After fertilization, the newly fertilized ovum develops into a pre-embryo, then embryo, fetus, and finally neonate, who only then has the potential to be a fully autonomous individual to be granted all ethical and legal rights (Gillon, Higgs, Boyd, Callaghan, & Hoffenberg, 2001).

Women may wish to terminate a pregnancy for any number of reasons, including having been a victim of rape or incest, health issues (of the mother or the fetus), family planning goals, economic factors, etc. However, since rape and incest are actual crimes, pregnancies resulting from such actions should be evaluated on a separate basis. The expectations of rape or incest victims with respect to their (entirely unwanted) pregnancies should be seriously considered by the healthcare and justice systems when reviewing such cases; any reason provided by a woman for requesting an abortion should be analyzed on its own merits. To date, there has been little research regarding the issue of rape/incest victims requesting abortions in terms of the legal and ethical issues involved. Due to the lack of statistical data available to analyze such cases in detail, no study has as yet been able to determine the prevalence of pregnancy resulting from rape or incest. The objective of the present study was to incorporate analysis of ethical issues into the legal debate regarding abortion as it pertains to victims of rape, using cases reported in the Turkish press.

**What kinds of medical issues require ethical analysis?** The availability of abortion often leads to the state and/or society claiming a right to intervene in women's decisions affecting their bodies, as contrary to the principles of bioethics, which grant primacy to the concept of bodily autonomy.

The subject of abortion raises several scientific, ethical, and religious questions pertaining to the concept of the soul. Since every religion and/or belief system has its own definition of the concept of the soul (NCo., 2016), there is no global consensus as to the nature of the soul or the idea of life after death.

The first category of questions involves the embryo or fetus itself. If a fetus or embryo is accepted as human, how does one determine at what point life begins (Harris, 1985)? Is it immediately after fertilization, upon implantation in the uterus, at some point during development of the embryo or fetus, or at birth? The second concerns whose rights take precedence - those of the embryo/fetus or the mother? The third concerns the act of abortion itself. Should laws regarding abortion have definite limits? Who has the right to decide what these limits should be (Harris, 1985)?

The answers to these questions are still being debated, as there is little consensus regarding the ethical-legal, biological, and psychological aspects of abortion. This article addresses abortion in terms of medical ethics, a subset of bioethics prioritizing patient and human rights, and with respect to medical ethical principles (e.g., do no harm, beneficence, autonomy, justice, truth-telling) which hold that every human has a worth irrespective of gender, age, religion, or nationality (Beauchamp & Childress, 1994.).

Ethical conflicts related to abortion may result from the involvement of various institutions, such as social service (especially child welfare) agencies,

religious councils, medical associations, non-governmental organizations, etc. (Denbow, 2005; Fromer, 1982; Patil BA, 2014). In addition to legal restrictions that already limit access to abortion, some individuals and organizations consider it their right to intervene in women's decisions regarding their pregnancies. Can pregnancy thus lead to the suspension of the individual rights of women and girls?

**What happens to the victim?** Limiting access to abortion punishes women and girls in four ways:

1. The trauma of rape can lead to long-term psychological issues, including post-traumatic stress disorder (PTSD), as well as various physical injuries, such as sexual/pelvic floor dysfunction issues (Postma, Bicanic, van der Vaart, & Laan, 2013; Samsioe & Abreg, 1996). Mutluer et al. (2017) found that children and adolescents who had been sexually assaulted experienced PTSD and had bilaterally smaller amygdala, hippocampus, and anterior cingulate, and a thinner prefrontal cortex (Mutluer et al., 2018), all of which play an important role in the formation and storage of memories and cognitive behaviors. During rape, victims may be conflicted as to whether to surrender or try to escape, and after the assault by negative feelings (e.g., feelings of being objectified, defiled, and/or alienated from their own body) (Halvorsen, Nerum, Oian, & Sorlie, 2013).

2. Secondly, for rape victims forced to continue their pregnancies, full recovery from the trauma of sexual violation is highly unlikely (Halvorsen et al., 2013), resulting in their being doubly punished.

3. The trauma of rape may reach its pinnacle when the victim gives birth (Howlett & Stein, 2016). This increases the duration and intensity of the anguish caused by rape, causing the victim to feel further traumatized at having been violated at the most intimate level and turned into merely a vessel, rather than an autonomous person who possesses inherent value in her own right.

4. After giving birth, the victim faces a new ordeal, having to decide whether to accept or reject the baby. The rapist may even claim parental rights. Individuals in the victim's community may continue to speak of the incident long afterwards, creating an unpleasant and possibly traumatic environment for both the victim and her baby (DG., 2015).

**What happens to the fetus?** The fetus is a living being that has the potential to be an autonomous person with full moral status only after birth. Unfortunately, as there is no empirical evidence concerning souls, any discussion rests entirely on a priori arguments (Gillon et al., 2001). However, brain development is a meaningful measure of consciousness, without which there can be no concept of moral behavior. A recent study has indicated that infants born at 22 or 23 weeks can survive independently of the mother with appropriate intensive postnatal care (Mehler et al., 2016). Fetuses do not acquire the ability to feel pain until the beginning of the third trimester (Lee, Ralston, Drey, Partridge, & Rosen, 2005). Can

sentience be considered a reasonable criterion for granting personhood?

Moral status, defined as the ability of a conscious being to make judgments regarding the morality of an action, is another important consideration in the ethical debate concerning abortion. According to Warren, the gradualist approach grants greater moral/ethical status to the mother than to the fetus (M.A., 1997). Contemporary bioethics thus makes no distinction between an embryo at 14 days and a fetus at 24 weeks (Patil BA, 2014). Sentience is among the criteria for autonomy, along with consciousness, the ability to think independently, responsibility for one's own behavior, free will, and experience. Gillon noted that other vertebrates also possess sentience, while stressing that they lack moral accountability (Gillon et al., 2001). Although the fetus itself lacks self-awareness, it is at the center of most arguments concerning abortion.

### **Materials and methods**

This research was designed as a retrospective of ethical-legal issues pertaining to cases of compulsory pregnancy resulting from rape as reported in the Turkish press. The approach taken in analyzing the cases was based on human rights and ethical concepts. Key words were used to search Google and Turkish news organizations for the years 2010-2018. An exhaustive systematic review of incidents of sexual assault resulting in compulsory pregnancy was carried out by searching mass media, from newspapers to internet news websites. In determining the selection criteria, attention was paid to such factors as whether the same case was reported by other news agencies, whether a case was followed to its legal conclusion, and how the information was presented to and discussed by the public.

In choosing which cases to analyze, there were two main selection criteria. The first was determining the existence of barriers to the legality of abortion, including:

1. Requests for abortion can only be approved for individuals under the age of 18.

2. Pregnancies exceeding 10 weeks cannot be terminated.

3. Victims of rape/incest must make a formal complaint to the proper legal authorities, officers must collect evidence to prove that a crime occurred, and a medical report must be obtained (Appendix A).

Due to the amount of time involved to fulfill its requirements, a frequent consequence of the third condition, is the expirations of the legal period for an abortion.

Secondly, attention was paid to such factors as whether the same case was reported by other news agencies, whether a case was followed to its legal conclusion, and how the information was presented to and discussed by the public (Appendix B). A thorough legal analysis must take into account such factors as age, duration of pregnancy, and informed

consent, while ethical analysis incorporates a broader spectrum of factors by which to evaluate a case and according to which health care professionals can better understand the needs of the victim (before, during, and after pregnancy). The selected cases therefore included those that presented legal problems and in which one or more legal barrier existed.

We located 95 news items, categorized and counted these articles, evaluated the articles for content, and analyzed the ethical issues. Out of those articles, 14 concerned rape-related pregnancy cases (Appendix B). The six cases chosen for analysis in this study were carefully selected from newspaper reports dating from 2010-2018. When determining the selection criteria, a number of common features were identified that represent a large number of existing cases, including the age of the victim, whether the rapist was a member of the family, and at what stage in the pregnancy the victim requested an abortion, and requests for abortions resulting in different legal outcomes.

In addition, the author of this study also reviewed statistical data collected by the Turkish government. Two important reports were unearthed: (i) The Turkish Statistical Institute (TUIK) reported that accusations of sexual assault, including rape and harassment, have increased at all levels of Turkish society by 30 percent in the last five years (28, 29), and (ii) The Children's Rights Commission of the Human Rights Association's Istanbul bureau reported that 440,000 children under the age of 18 gave birth in the last 16 years. It also stated that 46% of sexual crimes were committed against children, and that the rate of child sexual abuse in Turkey was the third highest in the world. Children were found to have been abused in all settings, including in their dormitories and in schools by their teachers and school staff, as well as in their homes by close relatives. However, in Turkey only 5% of rapists were identified; the statistical reporting on this issue is therefore incomplete. As is often reported in news articles, many victims do not tell their family members until their pregnancy becomes visible, nor do they file complaints with the proper legal authorities. The cases selected for this study thus represent only the tip of the iceberg.

**Evaluation of the Data:** News reports of pregnancies resulting from rape were evaluated as qualitative data. Analysis of qualitative data includes organizing the data and categorizing it, researching patterns, identifying important points, and deciding how to approach the data for purposes of discussion (Bogdan & Biklen, 1998).

**Limitations:** This study was restricted to six sample cases due to space limitations. The cases are nonetheless varied enough in their details that they may be viewed as being representative of a much larger number of similar cases.

## Results

This study is significant in that it analyzed the issue of abortion from a strictly ethical standpoint. When abortion is evaluated solely on the basis of legality, the autonomy of rape victims is compromised, and justice is not realized. The special circumstances engendered by cases of rape should be assessed from an ethical standpoint. This discussion should increase awareness of this issue and hopefully push societies to take more effective measures to prevent rape and incest, as well as to improve how their legal systems treat the victims. Those who have not had the misfortune to be a victim of rape or incest cannot fully comprehend how traumatic these crimes can be.

The cases analyzed in this study are as follows:

**Incident 1:** Ms. N.Y. was 26 years old and married with two children. After being sexually assaulted by a male relative, men in her village began referring to her as a "bad woman" or prostitute. To protect her honor she then killed her rapist. However, by that time she was approximately 20 weeks pregnant. She stated that she did not want the child and desired an abortion, even if it were to result in her death. Nonetheless, she was not able to procure an abortion and gave birth in prison in November 2012, after receiving a life sentence for murder (Arkan/Yalvac, 2016; H.N., 2016). The question of whether a 20-week-old fetus can be aborted was evaluated according to Article 99 of the Turkish constitution. N.Y. lived in a small village and was not able to travel to a city without her husband's knowledge to have an abortion. She was five months pregnant when she killed her rapist. Article 99 of the Turkish Penal Code (6) states abortions can be performed for medical reasons between 11-20 weeks (Birliđi, 1984). It also (2) states that in the absence of medical necessity, a person who induces a pregnant woman to miscarry a fetus over 10 weeks old can be imprisoned for two to four years, even with the consent of the pregnant woman. Two rights are in conflict here: one is the right of the fetus to live, the other is right of the mother to bodily autonomy.

**Incident 2:** A 16-year-old girl's petition for an abortion was denied by the magistrates' court in January 2014 on the grounds that "ending the pregnancy is considered a violation of the fetus's right to life" barring exigent circumstances (Newspaper, 2014). The girl was 16 weeks pregnant at the time she submitted her petition, and likely was not aware that she was pregnant much prior to that. The court based its decision on Turkish law, which does not allow abortions after 10 weeks except in cases where the health of the pregnant woman is at serious risk or the fetus has severe disabilities or deformities.

**Incident 3:** A 14-year-old girl taken to a hospital with complaints of abdominal pain was discovered to be 2.5 months pregnant. The hospital authorities informed the police because they suspected that she was a victim of rape. The girl, accompanied by a psychologist, said that she had been raped several times by her neighbor. The police then detained the

person that she identified. The court granted permission for the pregnancy to be terminated (KAYA/ORTACA, 2016).

**Incident 4:** A 15-year-old girl was raped by her brother. The family, fearful of legal sanctions, tried to cover up the rape, putting the girl's life at risk by having a maternal aunt induce an abortion when the girl was 6.5 months pregnant. The aunt then buried the fetus. The girl's sister reported this to the police. The mother and aunt were taken into custody and the brother was sought by the police (KOCAER, 2009).

**Incident 5:** A 15-year-old girl was raped and requested an abortion when she was 9 weeks pregnant. Her request was rejected by the magistrates' court. The judge who examined her file stated that there was no regulation in place for children aged 15 and under in his jurisdiction and thus he could not issue a ruling regarding the termination of her pregnancy (Cumhuriyet, 2014).

**Incident 6:** The request for an abortion made by a 16-year-old girl who became pregnant as a result of rape was rejected by a local court, which declared that "the right to life of the fetus is more important than the mother's mental health". At the insistence of the girl's family, the prosecutor's office sent the case to a higher court. Citing the legal statute stating that "in the event that a woman is impregnated as a result of a crime, on condition that the victim is not more than 20 weeks pregnant and consents to an abortion, termination of the pregnancy will not be punished," the prosecutor requested that permission for the abortion be granted. The higher court found in favor of the girl. Had the family not persisted however, the 16-year-old victim would not have been able to receive an abortion (DEMİR, 2014).

## Discussion

Our research illuminates the need to recognize and understand issues facing victims of sexual assault. Societies should aim to decrease prejudice against and infra-humanization (Baldry, Pacilli, & Pagliaro, 2015) of rape victims.

A report by the World Health Organization (WHO) stated that sexual assault may involve the risk of unwanted pregnancy; however, few studies have examined the likelihood of pregnancy resulting from rape (Organization., 2013). The National Women's Study in the U.S. found that 5.3% of the rapes of adolescent girls aged 12–17 years resulted in pregnancy and reported a similar rate for adult women, with 50% requesting to terminate their pregnancies (Holmes et al., 1996).

This study was carried out in the hope that it may lead to a more open discussion of relevant cases involving sexual assault and compulsory pregnancy, and also contribute to the literature on helping victims. Unfortunately, in many societies rape is explained away if not justified by certain assumptions (e.g., rape is somehow encouraged by the victim; it is merely an attempt to satisfy the rapist's sexual appetite or a misguided expression of

love) (Ellsberg, Jansen, Heise, Watts, & Garcia-Moreno, 2008; Keogh, 2007). In fact, tolerance of rape only serves to protect the rapist and further punish the victim; such punishment includes actions to protect the fetus if the rape results in pregnancy. In Turkey, there have been numerous reports of rape victims forced to marry their rapists in order to protect the honor of the victims and their families.

The World Health Organization considers sexual violence to be a serious public health and human rights problem. In particular, female rape victims face not only the violence of the assault itself but also the possibility of becoming pregnant and being forced to carry the child to term. Although many rape victims request abortions, the age of the embryo/fetus may present a significant legal obstacle. The victims discussed in the current study tried to hide their sexual assaults, preferring to keep it secret, out of shame or simply in an attempt to forget such a traumatic experience (Machado, Fernandes, Osis, & Makuch, 2015). The cases selected for the present study all occurred within the past 8 years, and the rape victims all faced the possibility of compulsory pregnancy as a result of the inadequacies of the legal system in this regard. Three of the victims whose cases are reviewed herein were not able to obtain a legal abortion because of the legal limits placed on the procedure with respect to the age of the fetus. These cases are worthy of special consideration as they call attention to the ethical issues pertaining to compulsory pregnancy. Examination of these ethical issues is the first step in a process that will ideally lead to legislation to address the injustices associated with compulsory pregnancy.

Reproductive and abortion rights are closely related to population policy. Evolving concepts of human rights, women's rights, and children's rights beginning in the second half of the nineteenth century have resulted in challenges to current population policies. The adoption of principles of medical ethics and bioethics and the codification of patient rights have led to the emergence of new perspectives regarding population control.

Rape is a serious offense whose negative effects, which include psychological damage and a significantly diminished quality of life (Mehler et al., 2016), are compounded further when pregnancy results. While rapists go free or, more rarely, receive prison sentences, their victims must deal with the trauma of rape and, sometimes, the problem of unwanted pregnancy as well (Arkan/Yalvac, 2016; Cumhuriyet, 2014; DEMİR, 2014; Kaya/Ortaca, 2016; Kocaer, 2009; Newspaper, 2014). Victims of rape who become pregnant as a result can request an abortion to at least end the trauma of unwanted pregnancy. This request should be assessed in terms of its medical, legal, and ethical dimensions, in accordance with the nature of the case.

Article 28/1 of the Civil Code of the Constitution of the Republic of Turkey states that the rights of the individual begin with live birth and end with

death (Meclisi, 1982). Civil Code 28/2 regulates the child's right to exist in the mother's womb. In other words, when a baby is born and takes his/her first breathe, he/she is granted full human rights in addition to legal rights. The Universal Declaration of Human Rights expresses the fundamental nature of inalienability in Article 1 thusly: "All human beings are *born free* (author's emphasis) and equal in dignity and rights." The use of the word "born" indicates that human rights do not apply to a fetus. The European Commission on Human Rights (1967) declared that "the life of the fetus is intimately connected with, and cannot be regarded in isolation of, the life of the pregnant woman" (Gillon et al., 2001).

The medical definitions of the terms "fetus" and "neonate" are consistent with those of legal and ethics regulations. However, doctors have an ethical obligation to protect both the patient and her fetus from harm (Lyerly, Little, & Faden, 2008); a conflict may thus arise between the interests of the pregnant woman and those of the fetus. In fact, the main basis for legal and medical principles regarding the status of the fetus is the fact that the fetus cannot survive independently of the mother before approximately 22-23 weeks, after which it is only possible with intensive neonatal care (Ishii, Kono, Yonemoto, Kusuda, & Fujimura, 2013). A fetus also cannot accept moral responsibility, because it has not undergone the brain development necessary for conscious thought. The ethical dimensions of fetal development are critical to an ethical understanding of the abortion debate. Does society place more importance on fetal rights than on the rights of the pregnant woman?

Doctors evaluate this issue within a legal-ethical framework. Principles of medical ethics (do no harm, beneficence, autonomy, decision making, and justice) provide a framework in which to assess the rights of the pregnant woman/girl (Flagler, Baylis, & Rodgers, 1997), fetus, and the specifics of a given case. Pregnancy should not mean loss of bodily autonomy for a pregnant woman, nor should society have the right to intervene in a pregnant woman's decision regarding her own body. The physician's priority should be to treat the rape victim while respecting her decisions. In order to prevent further harm to rape victims, physicians and ethicists must proceed from an ethical standpoint when making their evaluations.

*In the first incident*, a 26-year-old married woman killed her rapist. She was sentenced to life imprisonment and was not allowed to undergo an abortion because she was more than 20 weeks pregnant.

*The victim in the second incident* was a 16-year-old girl who only realized she was pregnant at 16 weeks. The court did not grant her permission for an abortion.

*The third incident* involved a 14-year-old girl who was 2.5 months pregnant. The court approved her

abortion because she was less than 10 weeks pregnant.

*In the fourth incident*, a 14-year-old girl who had been raped by her brother tried to solve the problem by herself instead of going to family court or requesting medical assistance from a healthcare professional. More comprehensive legislation is needed to protect such victims and should incorporate ethical principles with a view to human rights.

*In the fifth incident*, a 15-year-old girl was 9 weeks pregnant when she requested an abortion. The court rejected her request because there was no law pertaining to children 15 and under in its jurisdiction, and thus no regulation regarding the termination of pregnancy for minors.

*The sixth incident* concerned a 16-year-old rape victim who was 10 weeks pregnant at the time of her request for an abortion. Her request was rejected by the regional court on the grounds that a fetus's right to life was more important than the mental health of the mother. The family appealed the decision and permission for an abortion was granted by a higher court.

Although all the victims in the selected cases requested to terminate their pregnancies, only victim was initially granted permission for an abortion by the legal system. The social-legal community needs to understand that the relationship between a pregnant girl/woman who has been raped and her fetus is not adversarial; rather, both are victims of rape. When discussing the rights of the fetus, it should be kept in mind that a fetus is not granted personhood and moral responsibility, while the primary victim of the rape, the pregnant girl/woman, does have personhood and full human rights (Organization., 2013). The woman and girls in cases 1, 2, and 4 were raped and their requests for abortion were assessed solely on the basis of legality, whereas evaluations of their cases should have included ethical principles as well. The outcome of these incidents was loss of autonomy on the part of the rape victims, who were also subjected to psychological trauma, while the rapist either received either minimal or no punishment (Daro, 2006.; Flagler et al., 1997; Howlett & Stein, 2016).

Why is the importance of the victim's life not taken into consideration? Why is a fetus considered more important than the mother? Why are special medical and ethical evaluations not required for these women and girls? Goodwin (2016) has addressed these issues, stating that preventing access to abortion is a form of punishment of pregnant women. According to a report on human embryo research by the Nuffield Council on Bioethics, the modern bioethical approach is based on the concept of gradualism, which distinguishes the moral status of the embryo/fetus from that of the mother, and as such accords each a different worth (8).

In conclusion, requests for abortions by victims of rape and incest should be evaluated in terms of a medico-ethical-legal framework, so that the victims, rather than their rapists, are in a position to determine their future. Evaluations made on the basis of ethics will protect women's autonomy, prevent further harm, may improve the prospects for some form of justice, and help the healing process. Governments should consider ethics consultations when victims of rape or incest request abortions and expand legal regulations to that end.

#### Appendix B. Legalized abortion in Turkey.

1. Is it a legal right? Yes, abortion is legal in Turkey until the 10th week of pregnancy. Abortion that is not medically necessary is available upon request with the informed consent of the pregnant woman/girl.

2. If the mother is under 18 years of age, both she and her guardian must consent to the procedure. Girls under 15 years of age cannot be granted permission for an abortion solely with the consent of their guardians; they must first make a report to the judicial authorities.

3. Is a married woman required to receive permission from her husband? Yes. If the husband cannot accompany his wife to the procedure, then he must provide signed authorization. He must also provide documentation that he accepts full legal responsibility for the procedure. Without the permission of the husband, legal responsibility for the abortion resides with the physician.

4. If a pregnancy exceeds 10 weeks, under what conditions abortion is legal? Abortion after 10 weeks is only allowed if the pregnancy threatens the life of the mother, or in cases where the fetus is severely deformed, or the baby would be severely disabled.

5. If a woman (or girl) becomes pregnant as a result of being raped and wants to terminate her pregnancy before 10 weeks, is her declaration sufficient? A simple statement declaring "I was raped" is not sufficient; the woman must prove that she was raped. She must first file a complaint with the public prosecutor or the police, then undergo a medical check-up to furnish evidence of rape. Her pregnancy cannot exceed 20 weeks. According to Article 99 of the Turkish Penal Code (TCK) 5, obtaining an illegal abortion is punishable by imprisonment for a period of five to ten years.

If there is no medical necessity but the woman has given her consent, the prison sentence is for two to four years. If the woman is more than 10 weeks pregnant, the abortion is not legal. In such situations, a woman consenting to an abortion shall be sentenced to imprisonment for up to one year or be imposed a judicial fine.

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**Ethics approval:** This study was approved by the Ministry of Health, University Ethics Committee.

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## Cloning prospects in 21<sup>st</sup> century humanity: An ethico-theological discourse

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### Abstract

Ethical and theological debates about human cloning are getting hotter in recent times. Nowadays, cloning research is more common than ever before because of developments in biotechnologies, public outrage, and religious and ethical issues. Yet, despite concerns about its effectiveness and safety and the potential danger, studies demonstrate that human cloning does not produce a class structure. This paper aims to contribute to the research and debate on human cloning from the perspectives of ethics and Christian theology. Using the descriptive and critical analysis methodology, the paper reveals that while it is unethical, human cloning still has the prospect of benefiting future humanity by appealing to sick persons, infertile couples, those who want to avoid undesirable genetic traits, single and same-sex couples, and parents who want to clone a dead child. It concludes by calling on public authorities around the world to exercise their statutory responsibilities to maintain the unity, coherence, and organization of new technologies in society along the dictates of the United Nations Universal Declaration of Human Rights, which recognizes the dignity, rights, and freedoms, and moral growth of humanity.

### Introduction

Religion has been rattled by science, which has called into question human conceptions of God's might and the role that humankind plays in the cosmos. The popularity of cloning research is rising because of developments in biotechnology, public debate, and religious and ethical issues. Future generations may benefit from the advancements that result from these debates. Since the Industrial Revolution (IR), there have been both cautionary and optimistic expectations of technological and societal transformation. Although it is important to support the freedom of inquiry and discovery, opponents of human cloning technology have advocated that immoral scientific adventurism has to be reined. The moral limits of the United Nations (UN) declaration concerning human cloning may be called into question by biotechnological advances in the twenty-first century. For instance, the social teachings of the

Church reflect its dedication towards human salvific warfare and care for the future of humankind. The ethical and theological explanations of the practices of the church teachings are intended to provide a methodical approach to human problem-solving so that discernment, judgement, and choices will be in accordance with reality, and collaboration and hope will have more influence on the state of the world today. The truth about human beings, managing diversity and plurality, and the start of a new period that is focused on humankind's future are the major difficulties that humanity is now facing in the twenty-first century.

Human cloning has been proposed as a means of enhancing humanity's genetic potential, but there are many insurmountable challenges and disadvantages. The aim of this paper is to contribute to the research and debate on human cloning from the perspectives of ethics and Christian theology to offer solutions to the issues affecting humanity as a result of the current advancement of the technology. The paper argues that despite its potential, human cloning may be challenged in the twenty-first century. Yet there is a need for more ethical, theological, and religious debates to create more awareness for the twenty-first century humanity. The paper is significant because it aids in ethical and theological discernment, encourages positive attitudes and moral behavior, and informs the faithful of the church's social morality teachings.

**Human cloning and its nature:** Creating duplicates of a biological thing, such as genes, a cell, or a human being, is known as cloning. The concept of human cloning was initially proposed by J.B.S. Haldane, who did so by using the phrases "clone" and "cloning," which have been employed in agriculture ever since the early 20th century (Thomas, 2013). Therapeutic cloning and reproductive cloning are two often discussed varieties of human cloning. In therapeutic cloning, human cells would be reproduced for use in treatments and organ transplants. Even though it is a topic of ongoing study, as of 2023, it is not used in any medical settings worldwide. Somatic cell nuclear transfer (SCNT) and induced pluripotency are two popular techniques for therapeutic cloning that are currently being studied (Trounson & DeWitt, 2013). Instead of only replicating certain cells or organs, reproductive cloning would include creating a human being from scratch. A certain kind of cell may be replicated in the laboratory through the process of cloning in order to study its characteristic features. Identical twins naturally produce individual humans, and Dolly was the first animal to be cloned from an adult cell (Daar, 2003). By extracting the genetic material from the egg and inserting the cell nucleus into the oocyte, which would be subsequently induced to begin embryonic development, it is possible to clone an animal via SCNT.

Some scientists think that it is not possible to clone a person because the technology is not there yet. Mammals have been cloned successfully, but a

lot of pregnancies end up being miscarried on their own, which has terrible economic, physical, and emotional effects. Ayala (2015) says that cloning has caused animals to have serious health problems, like being overweight, dying young, having deformed limbs, and having weak immune systems. Stem cells from cloned human embryos could be used to fix damaged nerve cells, transplant organs, and do other medical treatments. Still, most concerned people and many religions would still have ethical concerns about cloning people. Moreover, because a person's character, personality, and qualities other than their anatomy and physiology make them up, it is impossible to clone their deoxyribonucleic acid (DNA).

**Human cloning in theological and philosophical timelines:** To understand how to evaluate genetic research from a theological and philosophical point of view, it is important to quickly look at how religious practise and human cloning have caused disagreements over the years. In this way, the philosophers, theologians, and religious thinkers who have talked about the ethical implications of cloning humans can be put into four different time periods that overlap. The first debating period began in the 1960s. This early debate was prompted by a context of expanded options and control over reproduction, such as the accessibility of birth control pills, the potential for potential substitutes, technologically assisted reproduction, such as in-vitro fertilization (IVF), and advocacy of cloning preferred genotypes by eminent biologists and geneticists to prevent overloading the human gene pool with harmful genes and endangering the survival of the human species (Campbell, 2002). Charles Curran, Bernard Haring, Richard McCormick, Karl Rahner, Joseph Fletcher, and Paul Ramsey are just a few of the notable theologians who participated in these early talks regarding genetic engineering and human cloning. Given the current state of the debates, the latter two, Joseph Fletcher and Paul Ramsey, staked out diametrically opposed stances and contemplated a world of human cloning that is perfectly relevant. Compared to the hereditary roulette of sexual reproduction, human cloning, in Fletcher's (Campbell's, 2002) opinion, is a better method of reproduction. Laboratory reproduction, according to him, is radically human since it is intentional, planned, decided upon, and willed. Ramsey (Fletcher, 1979; Ottuh, 2020a), on the other hand, views cloning as a moral barrier for society and medicine that could only be crossed at the risk of jeopardizing reproduction and humankind. He notes three horizontal border-crossings of cloning, first from one person to another, and two vertical border-crossings—from person to God.

The first IVF infant, called "Louise Brown," was born in 1978, marking the start of the second period of theological as well as philosophical debates about human cloning (Ramsey, 1970; Ottuh, 2020a). Although Christian theologians focused on the moral

questions raised by IVF, Jewish intellectuals like Seymour Siegel and Fred Rosner focused on human cloning. They were not as critical of human cloning as Ramsey or as supportive of it as Fletcher was (Rorvik, 1978; Ottuh, 2020a). The United Church of Christ provided the first recognized and official protestant answer to the cloning debate in 1977. This religious organization gave a broad summary of the science and morality of human cloning. According to Ottuh (2010d), during this time, other religious organizations, including some particular denominations and the World Council of Churches in 1975, 1982, and 1989, as well as the National Council of Churches of Christ in 1980, 1983, and 1986, also released resolutions or position statements cautiously endorsing genetic intervention strategies for therapeutic purposes (Lynn, 1973; Ottuh, 2010d). Campbell (2002) opines that when some religious leaders expressed their opinions on genetic engineering in 1979, the then-United States President Jimmy Carter asked the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research to look into the scientific, moral, and social implications of gene splicing.

The third period of the theological and philosophical debates began in 1993, after conflicting responses to the blastomeric differentiation of embryonic cells at George Washington University Campbell, 2002. Initially, the Roman Catholic Church vehemently objected, branding the study as intrinsically wicked in a Vatican editorial (McCormick, 1993). Moreover, according to the conservative Protestants, the study went against their core beliefs in personhood and humanity. Some Protestants, on the other hand, acknowledged the research's potential medicinal advantages and preferred regulation over a ban (McCormick, 1993). With the unprecedented cloning of Dolly the Sheep, religious disputes entered their fourth and most current phase. The Catholic and Protestant organizations reiterated their prior stances in this instance. On the other hand, several other Protestant theologians have voiced cautious approval for cloning studies and human cloning considering the notion of human cooperation with continuous divine creative activity.

In this renewed discussion of the ethics and morality of cloning research and its applications for human cloning, the testimony given to the USA National Bioethics Advisory Commission (NBAC) in the public hearings on March 13 and 14, 1997, offers the most carefully considered statements of theological examination (Verhey, 1995). From the historical history of religion and human cloning shown above, some general yet normative generalizations may be made including extended theological and philosophical discussion of the question of cloning that foreshadows and clarifies much of the current debate; proof that there are several valid religious and philosophical viewpoints on human cloning; proof that theological and

philosophical positions reflect societal pluralism; that despite advancements in scientific knowledge and technical prowess, the values that underlie theological and philosophical objections to human cloning have proven resilient and persistent, influencing public debate on the issue; and that the religious debate is no longer restricted to theologians with formal training; It has grown to include other occupations, such as science, other religions, and the education of religious believers. This indicates that theological and religious positions have advanced to become knowledgeable moral discourse groups on concerns relating to reproductive and genetic technology.

**Human cloning prospects:** Although it had been a matter of discussion during the early modern period, scientists and decision-makers have begun to investigate the technology seriously in terms of its potential benefits. Cloning embryonic cells to produce pluripotent or even other stem cells that may be utilised for organ transplantation, regenerative medicine, or to cure or prevent illness is known as stem cell therapy (Ayala, 2015; Ottuh, 2010a). A common type of stem cell therapy is bone marrow transplantation, and stem cells can be utilised to treat sickle cell anaemia. Growing organs for transplantation using stem cells that include the genome of the organ recipient is one of the most promising uses of therapeutic cloning. The therapeutic development of nerve cells is a regenerative medical application that has the potential to have significant negative health effects on both society and those who have been injured (Ayala, 2015; Ottuh, 2010c). While it is possible, mitochondrial replacement (MR) is a kind of gene therapy that modifies the embryo and has a poor success rate (Ayala, 2015). Whether the advantages of MR may last into old age is uncertain and disputed.

One of the merits of human cloning technology is that it has enabled critical knowledge about human developmental biology in modern times. Humans' pluripotent stem cells (iPSCs), on the other hand, produced in culture, are aiding in providing information and insights into human embryogenesis. Prospectively, several developmental illnesses and abnormalities may be resolved by researching signal transmission and genetic modification in the developing human embryo (Ayala, 2015). Researchers studying the developmental trajectory of humans have found greater support for the idea that these pathways are conserved across species. In addition to serving as model systems for the development of new drugs, induced pluripotent stem cells (iPSCs) and cells produced via SCNT are important for studying the origins of most human and animal illnesses. Additionally, research is being carried out to see whether stem cell treatment can be used to cure cardiovascular disease, diabetes, and injuries to the spinal cord in the future (Cartier & Aubourg, 2010). Thus, stem cell treatment can be used, as it involves the application of stem cells to

cure or eliminate a disease or condition. While genetic engineering is not yet used in clinical settings, it is actively being studied. The promise of iPSCs as a dependable source for producing human neurons currently demonstrates the possibility for regenerative therapy in the brain and for neural ailments.

Most scholars have argued that human cloning might be a safe and successful means of human and animal reproduction, enabling couples who are resistant to current infertility therapy to have genetically related children. Others have argued that human cloning can also be utilised to prevent the transfer of detrimental genetic characteristics to children. According to DeWitt (2013), the Human Genome Project (HGP) has uncovered the genetic underpinnings of many illnesses and is now starting to identify the specific location of genes considered to be responsible for them. Thus, couples seeking to prevent harmful gene transfer may find cloning appealing since it does not require the intentional eradication of defective embryos. In addition, Ottuh (2010a) posits that cloning could help single people and same-sex couples who want to become pregnant without the assistance and possible complications of gamete donors. However, it is postulated that lesbian couples who utilise donor artificial insemination may face concerns about parenthood if they use donor gametes (Ayala, 2015). Cloning technology may also be utilised to help parents who have lost a child and to remove gamete donors from the reproduction equation. Others, however, dispute whether the benefits of conception in this way and under these conditions would extend to the cloned child. As a result of the above, cloning technology would be acceptable to an uncompromising utilitarian in this situation if the benefits were seen to exceed the demerits.

One cannot talk about cloning potential without talking about its potential risks or demerits. The most significant information in most cloning research and debates is the worry about the effectiveness and safety of human cloning, the danger to the clone's uniqueness, and the possibility of lessening the number of distinctive genomes born into the world. Cloning creates specific conditions and experiences that mould the clone's life, yet it shields them from the cell donor's formative environment (Parvin, 2009). Human clones would anticipate that a treatment for their specific condition will be accessible when necessary, given the expected exponential growth in genetic diagnostics and gene therapy. Yet, the risk of human clones becoming commodities is increased since parents would want a return on their cloning investments and be intolerable of any flaws in their commodity. While eugenics is being advanced in human culture via the use of cloning, research has proven that this does not result in a class structure. History has shown that eugenics may be practised without the use of cloning, as illustrated by the Holocaust, cultural genocide, and laws requiring

forced sterilisation (Richardson, 1998). Cloning humans does provide parents with the option of selecting the phenotypes and genotypes that would come together to create their children, albeit it is unlikely to give humans any more opportunities to manipulate their progeny than they now have.

**Ethico-theological response:** According to Ottuh (2010a), cloning ethics refers to a range of ethical perspectives on the use and potential of cloning, particularly human cloning. To treat patients who are ineligible for transplant, prevent immunosuppressive medications, and delay the consequences of ageing, proponents advocate the development of therapeutic cloning. The position of stem cells from embryos, which is related to the abortion discussion, is the main point of contention for opponents of cloning technology. However, religious believers are split, with some believing that the technology usurps the divine's role in creation while others perceive no conflict between Christian beliefs and the good and possibly life-saving effects of the technology. Since it is straightforward and may be used to determine whether a human action is morally proper or wrong, utilitarianism and other ethical models and theological principles are popular moral theories that can be used to judge the morality and humanity of human cloning (Ottuh, 2010a). Yet, these ethical and theological principles have two significant flaws that include exaggerating advantages while ignoring disadvantages and disagreeing on which values are most important.

**Utilitarian principle:** Ottuh and Idjakpo (2021b) say that in utilitarianism, a decision is morally right if it makes most people happier and morally wrong if it makes most people sad or the opposite of happy. This is true for everyone involved in the action, not just the actor. Thus, if the balance of negative repercussions exceeds the positive outcomes, utilitarian ethics might support a ban on human cloning. This is due to the fact that reproductive cloning might be advantageous for four different groups: infertile couples, couples looking to ensure that a harmful genetic feature is avoided, single and same-sex couples who choose not to employ gamete donors, and parents looking to clone a dead child. But only after balancing the advantages and disadvantages of cloning can its overall usefulness be determined.

**Principle of respect for human dignity:** The most significant points in the ethical and theological debates on cloning are that a fair society, in its quests for advancement, must respect human dignity; therefore, all technological and scientific advancements must be motivated by an understanding of the supremacy of the individual over society and its quest. Therefore, it is argued that every technological and scientific advancement under the control of public authorities must keep a close watch to ensure that any limits set on freedom or any responsibility located on favorite activities are never going to be damaging to personal dignity.

For Ottuh (2010b), human cloning violates human dignity by using humans as experimental objects (technically called "instrumentalization"). The human person cannot be used as a tool for carrying out technological and scientific projects that are imposed by some authorities.

**Natural law theory:** Natural laws guide universal ideals. People are united by natural law, which upholds universal ideals. It provides the moral framework for establishing human society and is unchangeable and unaffected by human wickedness (Ottuh & Idjakpo, 2021b). People cannot establish a meaningful and enduring connection with others if their understanding of the moral law's universality is clouded. All humans can only become accountable and be able to defend public morality when they have freedom that is founded in a common nature. Those who believe they are the only source of reality and truth are unable to coexist peacefully and cooperatively with other people in society. Human cloning is manipulative and unnatural; therefore it negates the laws of nature.

**Principles of freedom and human rights:** Ottuh and Erhabor (2022) argue that one of the most important efforts to meet the unavoidable needs of human dignity is the trend towards the recognition and declaration of human rights. The Magisterium of the Church has praised the Universal Declaration of Human Rights for its positive contributions, which Pope John Paul II (2006) referred to as a significant turning point in humanity's moral development. The foundation of human rights is the inherent dignity of every person, which is first and foremost recognized and comprehended by reason. The supernatural perspective of considering that human dignity was assumed and restored by Jesus Christ, for instance, is in his incarnation, death, and resurrection, which makes the natural basis of rights look all the more firm. For Ottuh and Erhabor (2022), human rights ultimately come from humans and God rather than from the will of other human beings. These rights can be upheld collectively as well as individually since they are universal, unalienable, and inviolable. They include meeting humans' basic needs in the material and spiritual domains and must be consistent with the requirements of human dignity. The teachings of Pope John XXIII, the Second Vatican Council, and Pope Paul VI have all provided significant indications of the notion of human rights, which is universality and indivisibility (cited in Ayala, 2015). These include the right to life, the right to a loving family, the right to a moral environment that fosters the development of the child's individuality, and the right to one's own personal progress. According to Ottuh (2020a) and Ottuh (2010b), human reproductive cloning violates human rights, including women's reproductive rights, the right to life, the right to a loving and choice family, the right to a choice moral environment, and the right to a child's individuality.

**Principle of the common good:** The common good is everything in society that makes it easier and

more convenient for people to reach their own happiness. It can't be split up, it belongs to everyone, and the only way to get, keep, and get more of it is to work together. Ottuh (2021) asserts that a society that prioritizes the common good is one that desires and aims to stay in the service of people on all levels. No manifestation of social activity can avoid the problem related to its own common good since it is a necessary component of its importance and the real reason it exists (Thomas, 2013). The requirements of the collective good are linked to respect as well as the integral advancement of the individual and his basic rights, and they depend on the social circumstances of each historical era. A good legal system, environmental preservation, and the delivery of basic services to everyone are included in this list of requests, along with peace and the structure of the state's authorities. For Ottuh, Ottuh, and Aitufe (2014), everyone in society is involved in achieving and advancing the common good; no one is immune from doing so in accordance with their own capacities. He added that everyone has the right to take advantage of the social circumstances that the pursuit of the common good results in. As achieving the common good is the reason political power exists, the state likewise has an obligation to do so. In order for the common good to be achieved with the assistance of each citizen, the state should ensure the coherence, unity, and organisation of the civil society of which it is a manifestation (Ayala, 2015). Most religious, theological, and ethical debates on human cloning portray it as anti-society and anti-human because of its unnaturalness and potential risks. Anything that is anti-society and anti-human is a negation of the common good; hence, public authorities in charge of protecting the common good have the responsibility to ban or control cloning technology.

**Principle of solidarity:** The concept of solidarity refers to the necessity of acknowledging the interconnectedness of individuals and social groupings, the freedom granted to individuals for their own development, and the readiness to sacrifice oneself for the sake of others. It emphasizes the social character of people inherently, their equality before the law in terms of rights and respect, and their shared journey towards closer togetherness. Solidarity is a human value that establishes the hierarchy of institutions. Through the development of laws, market rules, and judicial systems, structures of solidarity must be cleansed (Pope John Paul II, 2006). It is a genuine moral quality that serves the greater good and is shown by a dedication to the welfare of one's neighbor and a willingness to sacrifice one's own interests on behalf of the other. Many people are aware of the close relationship of interdependence between people and the quick proliferation of real-time communication methods. The domestic and global lives of many states are negatively impacted by exploitation, tyranny, and corruption, and there are still glaring disparities between industrialized and developing

nations. Ottuh (2010c) asserts that most opponents of human cloning have labelled it an exploitative enterprise. Cloners will exploit the poor, especially women, by, for example, harvesting their embryos with or without their consents. On the other hand, cloners carry out human cloning for economic gains to the detriment of the public. Besides, only the rich or wealthy in society can afford the technology since it is very expensive. Thus, public authorities should promote ethical-social solidarity, which is an essential moral imperative ingrained in all human connections, in order to prevent the perilous effects of committing injustices on a global scale.

**Deontological principle:** If a person must make a decision that will either satisfy one's moral responsibility while violating another, deontology and the conflict of duties dilemma will occur. For instance, if an only child were injured in a car accident and developed kidney failure as a consequence, the parents would decide to clone the ailing child in order to conceive and raise a second child who might one day donate their kidneys. As it denies many people the chance to reproduce in a way that optimizes their well-being and consequently promotes the well-being of future offspring, a prohibition on cloning certainly raises important considerations about the moral duties surrounding human or sexual reproduction. In this sense, cloning would be illegal if it were permitted because doing so would violate the moral imperative to ensure the freedom to reproduce. In a deontological sense, it is difficult to forbid human cloning because of the conflicting and ambiguous moral responsibilities that accompany both reproductive technology and the growth of science. On the other hand, human cloning may be considered intrinsically unethical by deontologists because it denies many people the chance to reproduce in a way that optimizes their well-being and, by extension, that of their offspring. But if humanity has a moral duty to increase its knowledge of how human life is created, then humanity may ethically seek the most secure techniques for human cloning. However, that is not immediately obvious since everyone brings their individual moral conscience to the cloning discussions.

**Creational principle and God's free will action:** According to Ottuh (2020b), the Christian Scriptures point to the idea of creation and God's free will, which is according to Israel's confession of faith: God is the Creator and freely grants existence and vitality to all things, including human beings. In the Garden of Eden, where God positioned the first humans as the cultivators and keepers of the products of creation, they were likewise invited to be the outward symbol and vehicle of divine gratuity. Thus, cloning humans attacks the creational principle and God's free will. This is because cloning humans is unnatural.

**Personalism as a principle:** The dynamic image of God is seen by the church in both males and females and in each individual. The Bible declares that

people are God's creations and that the thing that makes them unique and distinctive is that they are made in God's likeness and image (Ottuh, 2020b). In this sense, human beings have the dignity of being individuals, capable of self-knowledge and self-possession, voluntarily offering themselves, and coming into communion with other human beings. According to Ottuh and Jemegbe (2020), God sets human beings at the centre and apex of the created order, and through grace, human beings are required to enter into a relationship with the Creator and to provide humans with a faith-filled, love-filled answer that no other creature can provide. The connection between God and humans is one that already exists, and it is expressed in the social and relational aspects of human nature (Pope John Paul II, 2006). Only human beings have the potential for God, and human existence is a journey and a search for God. Therefore, human beings find a mirror of God in their neighbors, who represent their ultimate good and fulfillment. All of this is predicated on the idea that a person is someone who actively participates in his or her own development and that of the society to which they belong.

**Synthesizing the responses:** The possibility of human cloning in the future is very unknown due to its ethical, legal, and technological obstacles. Scholars contemplate that the prospect of recreating humans like once-in-a-generation sportsmen or super-geniuses could be alluring if human cloning were ever to be accomplished. Even if human cloning were to ever take place, researchers assert that for many qualities or characteristics, environment or nurture would have a far greater effect than genetics or nature. As a result, cloned humans would probably vary greatly from the original in many ways. Recent genetic data and evolutionists both support the African origin of modern humans, which started there and then spread to other parts of the globe (Ayala, 2015). By matching their genetics, proteins, and other substances, one can determine how strongly linked human beings are to other species of primates. Nevertheless, studying fossils and tools will help people comprehend how humans' lineage evolved through time. Humans live in socially structured groupings, and culture is a defining social characteristic of humans. It encompasses all of the products of the human mind in general, including social and political structures, modes of operation, moral and religious norms, language, common sense, and scientific knowledge. Due to cultural inheritance—a uniquely human method of accomplishing environmental adaptation—culture evolution has taken over as the predominant process of human evolution. Humans have two different types of heredity: biological and cultural. Hence, human sexuality, not asexuality, is part of biological heredity. This concurs with Ottuh and Onimhawa's (2006) submission that sexuality is a divine heritage of humanity. Only hereditary qualities may be passed on to the progeny under vertical heredity, which is the case in biology.

Lamarckian heredity is not the same as cultural inheritance, because cultural inheritance is not only vertical, but also horizontal and oblique. A person's traits may be picked up from and passed on to other people in their generations, regardless of whether they are related, as well as from and to any other people they come into contact with. According to Ottuh and Idjakpo (2021a), cultural inheritance enables cultural evolution, a fresh method of environmental adaptability unavailable to nonhuman animals. Humans have been adjusting their surroundings to their genomes more often during the past several millennia than their genes to their environments. Even without anatomical development of fur or hair, this has allowed them to expand from the hot tropical and subtropical parts of the Old World to the whole universe, with the exception of the icy wastes of Antarctica. By creating flying robots, they have also more effectively and adaptably conquered the air, and the space mission has begun while waiting for mutations that would enable people to breathe under low oxygen pressures or operate without gravity (Thomas, 2013). Since cultural adaptation is a more successful kind of adaptation, it has outlasted biological adaptation throughout the history of humans. The Church has contended that the predominance of the human person does not correspond to an individualized or mass perspective and that the human person is instead an organic, harmonious reciprocal connection. The basis of human oneness is the spiritual and eternal soul, which was formed with the body in perfect harmony (Ottuh & Onimhawa, 2020). Because the resurrection of the body has been promised, reason and free will are intertwined with all of the corporeal and sensory capacities. Given that God created it and will bring it to life on the final day, it is reasonable to value physical life rather than detest it. Humans have two distinct qualities: they are metaphysical beings who are capable of transcendence and who are open to learning deeper truths. They are also material creatures that are physically connected to this physical planet.

The Church argues that the union of soul and body is so fundamental that one needs to regard the soul as the shape of the body. Since God created humankind and intended it to be so, human nature is built on relational subjectivity, and the human person is fundamentally a social creature (Pope John Paul II, 2006). A society is a collection of people who are connected by the universal concept of unity. Therefore, humans' ability to separate themselves from other living things on earth is a natural trait. Social interaction is a reflection of humans' character and part of what makes them humans. The human being is compelled to live in society from the very beginning and can only develop and fulfill his purpose in relationship with other people. Yet arrogance and selfishness may result in antisocial behavior. The social character of people varies, and a healthy social plurality is necessary for the common

benefit of all. It is necessary to support voluntary organizations and institutions in order to foster the broadest possible involvement in a community. In addition to fostering humans' traits, particularly a sense of initiative and responsibility, this socialization also supports the protection of their rights.

### Conclusion

The philosophical and theological discussions surrounding human cloning began in 1978. Today, the prevalence of cloning research is rising due to advancements in biotechnologies, public outcry, and ethical concerns. From a theological perspective, the foundation of human oneness is the spiritual, eternal soul, and human being is an organic, harmonious reciprocal interaction. Research shows that human cloning does not create a class structure, despite worries about its efficacy and security, the risk to the clone's identity, and the potential to reduce the diversity of genomes. According to theology, people must be aware of their Creator and respond to him in a way that shows love and faith. Although human reproductive cloning is considered immoral, it is still appealing to infertile couples, couples who are hoping to avoid negative genetic characteristics, single and same-sex couples, and parents hoping to clone a deceased child. Rapid advancements in animal cloning and rogue attempts to start the human cloning process have ensured the viability of cloning as a potential method of human reproduction in the future.

The best approach to dealing with the issue of cloning in the future is with reasonable legislation rather than impenetrable obstacles. Humanity's job in the twenty-first century is to figure out how to use cloning to its fullest potential, because the structures we build now will shape the future. Even though it's important to support the freedom of scientific inquiry and discovery, scientists who do things that are wrong need to be stopped. In order to sustain the oneness, coherence, and organization of new technologies in society in accordance with the principles of the United Nations Universal Declaration of Human Rights, which affirms the dignity, rights, and freedoms of all people, public authorities around the world are called upon to uphold their legal obligations in this regard. While human cloning technology may be challenged in the twenty-first century and beyond, there is a need for more ethical, theological, and religious discussions to create more awareness about the potential risks and benefits of human cloning for twenty-first century humanity.

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