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PROTOCOLS AND FATWA IN MALAYSIA ON WITHHOLDING AND WITHDRAWAL OF LIFE-SUSTAINING TREATMENT IN INTENSIVE CARE UNITS: AN OVERVIEW

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ABSTRACT

For many Muslim patients, families and intensive care physicians, deciding on whether to withhold or withdraw life support remains challenging. This point of transition from active intervention to the palliation process requires a crucial decision-making process. The decision involves conveying information to families to be well prepared beforehand, especially during the process of withdrawing life-sustaining treatment. Once the final decision to withdraw life sustainment has been made, procedure on cessation of care, treatment withdrawal and nature of follow-up support will be informed to the family members. This is especially so considering that the relationship between Islamic ethico-legal guidance and clinical protocols on such matters remains scattered and difficult to interpret. In light of this gap, we conducted a short review to aggregate clinical protocols and rulings from Islamic fatwas on whether, and when, it is permitted to withdraw and/or withhold life-sustaining care. This article aims to explore relationship regarding decision in withholding and withdrawing life-sustaining treatment, based on guidelines by Malaysian intensive care unit protocol and the fatwa in Malaysia. The methodology chosen for this study is content analysis of the relevant published literatures. We found the decision for withholding and withdrawing life sustaining treatment in intensive care unit are correlated between the ICU protocol and fatwa in Malaysia. In addressing the withholding and withdrawal of life-sustaining measures, the Muslim health-care workers as well as families should take a more cohesive approach, as this is parallel to the fatwa in Islam.

Keywords: *withholding, withdrawal, protocol, fatwa, Malaysia*

Introduction

According to Malaysian Society of Anaesthesiologist Consensus in 2004, life support treatment or life prolonging treatment refers to all treatments that have the potential to delay the patient's death. Examples include cardiopulmonary resuscitation, artificial breathing, specialised treatments for specific illnesses such as dialysis, vasoactive medications, antibiotics administered for a potentially fatal infection, and artificial nourishment or hydration. Pacemakers are also considered if they are used to treat life-threatening arrhythmias. In an intensive care unit, the terms withholding and withdrawal have various synonyms. Based on Clinical Practice Guideline Malaysia in 2005, the phrase "forgo" can refer to both terminating (withdraw) and not starting (withhold) a treatment. Also, "Limitation of treatment" is another term health-care workers and their families experience an emotional divide between those two, owing to the misconception that discontinuing therapy means "giving up on the patient". Some doctors may be hesitant to begin therapy based on the belief that it cannot be stopped once it has begun. Treatment should never be withheld, even if there is a slim chance that the patient will benefit, simply because it is easier to withhold than to withdraw. When there is a lot of uncertainties, it's better to begin a treatment and see if it benefits the patient, then only discontinue if it doesn't.

The practice of withholding or withdrawing life support treatment is widely adopted in intensive care units according to Prendergast and Luce (1997). Most intensive care unit (ICU) deaths happen following a decision to forgo life sustaining treatments (DFLSTs) that normally comprise two procedures, withholding and withdrawal (Eidelman, 1998). However, there are cultural variations in accepting these practices. The health care workers need to be aware that the possible cultural differences lead to multiple attitudes regarding these issues and open discussion is needed to enable such patients to have a pain-free, dignified death (Vincent, 2001). This issue is not only applicable to adults who are admitted to ICU, but also includes neonates in neonatal intensive care unit (NICU) (Lantos et al., 1994). The life-supporting treatment is practically withdrawn in critically ill patients when continued therapy is thought to be futile in restoring the patient to better health (Gordon et al., 1995).

The transition process from active treatment to palliation can be rapid, requiring re-adjustment and better understanding from all members involved (Hoel et al., 2014). The final decision to limit or continue life-sustaining treatment has always been a conflict. Some families resist or oppose doctors' suggestions on the time to stop treatment (Wilkinson et al., 2011). A national survey in adult ICU in the United States has suggested that most critical care physicians have incorporated some concept of medical futility into the decision making at the bedside (David et al., 1995). The DFLSTs on hospital mortality remains independently associated with death after adjusting on comorbidities and severity at ICU admission and that usually occurs within the first ICU week. There are many determinants of DFLSTs which include demographic factors (age, gender), comorbidities, reasons for ICU admission, and severity scores at ICU admission (Azoulay et al. 2003). The knowledge and skills in interpreting clinical ethics have also been an issue. Physicians have strongly advised for more open discussions about end-of-life care to allow for discontinuation of futile treatment and to reduce conflict (Beck et al. 2008.).

A study by Breen et al. (2001) revealed that at least one health care provider in 78% of the cases has described a situation of DFLSTs coded as a conflict. The conflict occurrences between staff and family members are in 48% of the cases, among staff members in 48% of the cases, and among family members in 24% of the cases. The most common conflicts are over the treatment decision itself as well as regarding social issues. A national survey done in Portuguese intensive care units has showed about three quarter of 175 respondents indicated that only the medical group should make this kind of decisions. Fewer than 15% of the respondents stated that it should involve nurses, 9% involve patients and fewer than 11% involve patients' relatives in end-of-life decision (Teresa et al., 2003).

A Global Overview on Issues Relating to Withholding and Withdrawal of Life-Sustaining Treatment

A retrospective audit in Australia has shown 34% ICU patients had treatments withheld, and 47% had withdrawal of life-sustaining treatment (WLST). There was no statistically significant difference in ICU length of stay between the groups (Jorge et al., 2009). A postal survey in New Zealand showed that less than 10% of ICU admissions had therapy withdrawn or withheld and only a small percentage (21%) of ICUs had a formal policy in this issue. There was a varying time frame in deciding whether to withhold or withdraw therapy (Ho et al., 2004). A prospective survey in France showed 11% of life-supporting therapies were withheld or withdrawn (withholding in 4·6% and withdrawal in 6·4%). Meanwhile, 53% of deaths in ICU were preceded by a decision to limit life-supporting therapies with the most frequently cited justifications were futility and poor expected quality of life. The decisions were strongly correlated to the simplified acute physiological score and mostly taken by all ICU medical staffs (Edouard et al., 2001). A cohort study in the United Kingdom ICU reported 31.8% decision to withdraw active treatment, with multifactorial decision: older age, pre-existing severe medical conditions, emergency surgery or medical admission, cardiopulmonary resuscitation in the 24h prior to admission, and ventilation or sedation/ paralysis in the first 24h after admission (Wunsch et al., 2005). Portuguese national survey on intensive care physicians stated that DNR (do not resuscitate) orders are applied in their units. Among other data, 98.3% stated that decisions were to withhold treatment and 95.4% stated that decisions made to withdraw treatment (Teresa et al., 2003).

A multi-professional survey in German intensive care units revealed 91% of respondents reported being confronted with the issue of limiting life-sustaining treatment at least once a month (Jox et al., 2010). A multi-center study in Argentine paediatric intensive care units also reported on do-not-resuscitate orders and withholding new treatments were the most common LSL (life support limitation) (Althabe et al., 2003). A total of 23% had treatment withheld or withdrawn as reported in Norwegian intensive care unit and the most common main reason for withdrawing treatment was poor prognosis (Hoel et al., 2014). A prospective observational study in Lebanese intensive care unit recorded 9.6% of all admitted patients to ICU were given withholding and withdrawing life-sustaining treatment. Therapies were withheld in 38% and were withdrawn in 7% of patients who died. Futility in care and poor quality of life were the two most important factors supporting these decisions. Cultural differences, the lack of guidelines and thoughts contribute to the ethical limitations on the decision-making process (Yazigi et al., 2005). Other factors associated with withdrawal of mechanical ventilation in neurology or neurosurgery intensive care unit are: more severe neurologic injury, diagnosis of subarachnoid hemorrhage, or ischemic stroke, older age, and higher Acute Physiology and Chronic Health Evaluation II probability of death. Marital status, premorbid functional status, clinical service (neurology vs. neurosurgery), attending status (private vs. academic), and type of health insurance were not associated with decisions to withdraw mechanical ventilation (Diringer et al., 2001).

Communication has also been an issue as ICU patients are typically lack of decision-making capacity, and physicians know patients' wishes in only 20% of EOL (End of Life) decisions (Cohen et al., 2005). Communication are often limited to "family conference" attended by several family members and members of the ICU team, including physicians, nurses, and social workers. Understanding and improving communication about end-of-life care between clinicians and families in the ICU are important elements in improving the quality of care in the ICU (Curtis et al., 2001). Knowledge on the decision-making process gives an advantage to the experts should they need to further elaborate to the family members. Such guidelines or recommendations must be available to assist medical staffs to reach this decision (Devictor et al., 2001). The locality or setting will not cause much difference in decision-making for withholding and withdrawal of life sustaining treatment in ICU. A prospective study in Europe reported the decision-making process appears to be similar between northern and southern European countries. The respective contributions of the family and medical staffs in the final decision itself also seem to be identical. However, the level of parents' information about the decision-making process appears to be different (Devictor et al., 2004).

Many life-support decisions require applying the 'best interests' criteria, which involves balancing the benefits and drawbacks of life-sustaining medical therapy. Prolongation of life (with the awareness that biological existence without consciousness may not be a benefit), greater quality of life (including pain or disability reduction), higher physical pleasure, emotional happiness, and intellectual fulfilment are some of the advantages. According to Clinical Practice Guideline Malaysia in 2005, intractable pain, irreversible impairment or powerlessness, emotional, mental, and economic anguish, and invasive and/or inhumane interventions that severely detract from the patient's quality of life are example of predicaments from life-sustaining medical treatment (LSMT).

Intensive Care Unit Protocols in Malaysia on Withholding and Withdrawal of Treatment (Malaysian Society of Intensive Care, 2019: 67-73)

Intensive care aims to restore patients' quality of life and lessen impairment. If these goals are not achievable, and the patient's family understands and agrees that this is not in keeping with the patient's wishes, compassionate care should be established to allow for a dignified death. Life-sustaining treatment (LST) withholding and withdrawal is a procedure in which various medical interventions are either not initiated or stopped. There is no ethical or moral difference between withholding or withdrawing life-sustaining treatment.

Principles

1. Abide by the principles of medical ethics when making end-of-life decisions.
2. Assess patient's decision-making capacity on end-of-life decisions. In patients with limited or absent capacity, families become surrogate decision-makers.
3. Respect patient's autonomy except in cases of non-beneficial medical treatment.
4. Implement a palliative care plan once LST withholding or withdrawing is decided upon.
5. Clearly documenting all decisions on LST withholding or withdrawing in the clinical records.
6. Treat dying patients with respect, dignity and compassion.

Ethical Principles

1. The principles that underpin end-of-life (EOL) medical decisions are:
    a. Respect for autonomy: acting in accordance to what the patient wants
    b. Beneficence: acting to benefit the patient
    c. Non-maleficence: causing no harm to the patient
    d. Distributive justice: paying attention to fairness and equity.
2. These principles are either individually or collectively used to frame the discussion on EOL and one does not supersede the other.
3. The principles may be conflicting for example:
    a. between respect for autonomy and beneficence: a terminal cancer patient who insists all LST to be provided although of no benefit to him.
    b. between beneficence and justice: providing invasive mechanical ventilation in a patient with decompensated heart failure who has had multiple hospital admissions in the last 6 months and is dyspneic at rest versus allocation of ICU bed for a polytrauma patient.

Decision-Making Capacity

1. Patient's decision-making capacity should be assessed before having a discussion with him on EOL. This includes the patient's ability to comprehend, appreciate, rationalise and express choice of treatment.
2. Most ICU patients do not have decision-making capacity and hence families become the surrogate decision-maker.

3. The standards that may be used by surrogates in decision-making include: a. Substituted judgement: decision of the patient if he/she has the capacity b. Best interest: decision based on the potential benefits vs. burdens of treatment taking into consideration patient's values and beliefs
4. EOL decisions are shared medical decisions made by clinicians and concurred by family members.

Autonomy and Obligation to Treat

1. Once decision-making capacity is established, patient's autonomy must be respected even though survival may be implicated.
2. In cases of non-beneficial medical treatment, clinicians are not obliged to initiate or continue LST.
3. The MMA Code of Ethics 2001 states:

"*where death is deemed to be imminent and where curative or life-prolonging treatment appears to be futile, ensure that death occurs with dignity and comfort. Such futile therapy could be withheld, withdrawn or one may allow irreversible pathology to continue without active resuscitation. One should always take into consideration any advance directives and the wishes of the family in this regard. In any circumstance, if therapy is considered to be lifesaving, it should never be withheld*."

Respect for the Dying

1. All dying patients should be afforded the same standard of care as other patients.
2. They should be treated with dignity, respect and compassion.
3. Their privacy and confidentiality should be respected at all times.

Withholding and Withdrawal of Life-Sustaining Treatment

The following patients are to be considered for withholding and withdrawal of LST:

1. **Imminent death**
   Patient has a severe acute illness that is clearly not responding to therapy, and reversal or cure is unlikely, despite any continued optimal therapy e.g., septic shock with multiorgan failure.

2. **Terminal condition**:

   Patient has a progressive terminal disease incompatible with survival longer than 3-6 months. e.g.

   i. End stage respiratory disease on long term oxygen therapy with severe community acquired pneumonia
   ii. End stage cardiac, respiratory or liver disease with no options for transplant iii. metastatic cancer unresponsive to treatment

3. **Severe and irreversible condition impairing cognition and consciousness, but death may not occur in months**

In such cases, a patient is often planned to not receive CPR or other resuscitative measures in the event of deterioration e.g., persistent vegetative state post cardiac arrest, severe dementia or severe stroke with poor cognitive recovery.

4. **Advanced age with poor functional status due to chronic organic dysfunction** e.g., Multiple co-morbidities with deteriorating physical performance.

5. **Severe disability with poor quality of life** e.g.
   i. Stroke with minimal conscious state or dense paralysis
   ii. Decompensated heart failure with ongoing shortness of breath at rest despite optimal therapy

6. **Advanced diseases of progressive life-limiting conditions** e.g.
   i. Motor neuron disease with rapid decline in physical status

ii. Severe Parkinson's disease with reduced independence and needs assistance for activities of daily living (ADL)

7. **A patient who has stated his/her wish against initiation or continuation of life support therapy**.

This will include patients who have given clear advanced care directives.

Practical Issues of Withholding and Withdrawal of Life-Sustaining Treatment

1. Medical team consensus

The intensive care team and the primary team should agree on EOL decisions.

2. Communication with patient and relatives

a. The best practice is that the same clinician (specialist/consultant) who is involved in the active care of the patient, deals with the family. He/she should be someone who frequently communicates with the family and has established a rapport with them. A witness (nurse or doctor) should be present during these discussions.
b. Clinicians need to respect the fact that each patient and family will differ in how much input they wish to have in the decision-making process.
c. In the event of any disagreement, allow time for repeated discussions and negotiations. Failing this, consider either:
    1) Time-limited trial which is a goal-directed tries of any intervention, limited by predetermined outcomes that are evaluated at planned intervals.
    2) Second medical opinion from another clinician from a similar specialty
    3) Facilitation by a third party e.g., spiritual advisor
d. Patients and families must be given sufficient time to reach decisions on EOL.

3. Management plan for withdrawal of life-sustaining treatment

To guarantee that the withdrawal process goes well, a clear management plan is required. It should be communicated to the family, with a focus on the patient's comfort. The following elements should be incorporated in the strategy:

a. Maintain current support until the patient and family have had adequate time together.
b. Ensure other healthcare professionals e.g., primary team, physiotherapist, dietitian are aware of withdrawal plan. Cease all investigations e.g., blood taking and X-rays.
c. Ensure pain and other symptoms e.g., dyspnea is well controlled. Morphine is the most commonly used opioid for analgesia and comfort. There is no maximum dose. Large doses of opioids may be required for comfort and may unintentionally hasten death. This "double effect" of opioids is acceptable.
d. Manage airway secretions by using glycopyrrolate, positioning in lateral position and frequent suctioning.
e. All treatments that do not contribute towards comfort should be discontinued e.g., antibiotics, blood transfusions. Feeding and intravenous fluids may be discontinued unless specifically requested by family.
f. Maintain patient's personal hygiene and dignity at all times. e.g., diaper soiling is dealt with immediately.
g. Withdrawal of vasopressors may result in immediate death. Families should be aware and nearby.
h. Withdrawal of mechanical ventilation may be carried out either as:
    1) Terminal weaning where ventilator settings are reduced while leaving the endotracheal tube in-situ or
    2) Terminal extubation

i. Disable all monitor and ventilator alarms. Demedicalise the patient and allow family members to be close by.

4. Other considerations

a. Unrestricted access to the patient should be provided to the family.
b. Non-invasive ventilation can be utilised to reduce dyspnea in conscious patients as a palliative care approach.
c. Neuromuscular blocking makes it impossible to gauge comfort and should not be utilised in patients who are intubated.
d. Only using benzodiazepines for terminal sedation if high opiate doses are unable to relieve pain.

Documentation
Document all decisions regarding withdrawal and withholding of treatment, including the basis of the decision and amongst whom it was reached.

5. Notification of death

Death should be communicated in direct language, gently.

6. Bereavement

Provide bereavement support to the family and healthcare providers, if necessary.

Other Guidelines In Malaysia On Withholding And Withdrawal Of Treatment (Malaysian Society of Anaesthesiologist, 2004).

a) Consensus on Withdrawal and Withholding of Life Support in the Critically Ill 2004

The principles of withholding or withdrawal of life-support should be based on the basic principles of medical ethics. These are:

1. Preservation of life which is frequently tempered by the second principle.
2. Relief of suffering – This covers distressing symptoms such as pain, distress caused by anxiety, etc.
3. "First do no harm" – Non maleficence
4. Respect the autonomy of patients – Patients have the right to informed choices in treatment and have the right to refuse or accept any given mode of treatment.
5. Concept of a just allocation of medical resources – This is an idea that must benefit the vast majority of people in the society. Allocating limited and expensive resources such as intensive care to likely non-salvageable patients restricts the amount of money available for prospective survivors. Rationing will almost certainly be necessary as medical prices rise. Intensive care is very costly; thus, cost is a factor to consider.
6. To be truthful to the patients and family or surrogates as to the prognosis of their loved ones.

b) Steps in Decision-Making to Withdraw or Withhold Life Support

1. Medical consensus – It is essential that the primary physician and the intensive care team have agreed on a consensus before any decision is taken. In certain cases, more than one primary team may be involved and it is essential to have the consensus of all the caregivers. In the event of absence of medical consensus, active treatment is continued. Further period of active treatment is set and subsequent review of management plan. The primary physician in our context refers to the specialist or consultant under whose department the patient is admitted.

2. Nursing consensus – Nurses play a key role in intensive care and are in continuous contact with patients and relatives. The sense of sympathy for the patient is often stronger and it is essential that they also support the decision to withhold or withdraw therapy.

3. Communication – In the unfortunately rare event that the patient is fully rational, awake and competent, the communication should be with the patient. More often in the intensive care setting the discussion is with the relatives. A clear and honest medical opinion should always be given to the family. To avoid any seeming conflict of opinion, it is best that a single resource person deal with the family, while the others can be present. The physician orchestrating discussion with either the family or patient, must be someone who is involved in the active care of the patient. This key person must be someone who has been frequently communicating with the family and has a rapport with them. This task should be done by a senior medical staff and should never be left to the most junior doctor in the unit.

4. The family should be given time to come to terms with the impending loss of their loved ones. They should be allowed to ventilate their feelings and be as often as possible with the patient.

5. Time limited goals should be established by the clinical team and this must be based on clinical judgement and best medical evidence. Families will usually agree to discontinuation of life support systems after a reasonable trial of therapy has demonstrated failure.

Management Plan for Withdrawal of Life Support

There should be five main objectives for ensuring a good end of life care;

- Receiving adequate pain relief and relieved of any other distressing symptom such as dyspnoea.
- Avoid prolongation of dying.
- Active sense of control over events.
- Strengthen relationship among loved ones.
- Relief of "burden" amongst caregivers and the loved one.

The Plan for Withdrawal Will Generally Have the Following Components

- All basic support such as pain control, hydration and nutrition, patent airway and freedom from breathlessness, must be ensured to keep the patient comfortable.
- All life support must be continued until the patient and his family had enough time together.
- Removal of life sustaining therapy in escalating steps after ensuring the patient is both pain free and free from any form of discomfort.
- Support therapies such as inotropes and other medications are withdrawn first. Usually, in a patient with multi organ failure, this alone may sometimes result in death.
- Relief of pain and discomfort – At this stage, most ICU patients are already receiving some form of sedation and analgesia. These drugs are continued, often at higher doses.

Discontinuation Of Mechanical Ventilation

There are two strategies for the withdrawal of mechanical ventilation

1. Terminal weaning i.e., gradually reducing the ventilator rate, positive end-expiratory pressure, oxygen levels or tidal volume while leaving the endotracheal tube in place.

2. Extubation after appropriate suctioning.

In terms of patient comfort, there is no substantial difference between the two approaches. However, for patients who have difficulties emptying secretions or protecting their airways, the endotracheal tube should be retained in place while ventilatory assistance is lowered. Whatever approach is used, it is paramount to monitor the patient's comfort during and after the ventilator is removed. To relieve dyspnoea and associated pain, intravenous opioids and benzodiazepines should be given as often as possible. The alarms on the monitors should be disabled. The family should be allowed to be with the patient if they choose to. The physician should be present to ensure the patient's and family's comfort during withdrawal of mechanical ventilation.

Clinical Practice Guidelines Ministry of Health Malaysia 2005: 8-10

Withholding and Withdrawing of Life Support in Children.

In principle the decision on when to withdraw life support is made by the attending consultant paediatrician with the assistance of the whole team (colleagues, medical officers, nursing personnel) and in consultation with parents.

Pre-Withdrawal Preparation

1. It is important that the decision to withdraw life support is a team effort in which the parents are fully involved. The decision should first be discussed with personnel involved in the care of the child. It should then be discussed with the parents before a final decision is made.

2. If a parent (e.g., mother post Lower Caesarian Section Surgery) has not seen the child since admission, attempts should be made for that parent to see the child before the actual withdrawal is done.

3. For continuity and trust, it is important that the attending team - consultant paediatrician, medical officer and nurse be present to see the parents through the whole process: pre-withdrawal, withdrawal and post-withdrawal counseling.

4. The attending consultant pediatrician (or most senior member of the team), medical officer and nurse should discuss the following with the parents:
   a. The timing of the procedure - the date and time of the actual withdrawal should be decided by the parents (within reasonable limits).
   b. What the procedure entails - care should be taken to indicate how long the breathing might continue, that the child may have gasping respiration, that sedation may be used if the child in anyway appears to suffer.
   c. Who, if any, of the family members will be present with the child, during the preparation of the child, during the switching off, and after switching off. It may be meaningful in the grieving process for siblings and grandparents to be present.
   d. Religious needs - at times parents may request a religious person to be present to pray for the child, or this spiritual role can be undertaken by anyone else like a staff member.

5. Establish the parents' preferences for the following:
   - Naming the child.
   - Photographs - parents may wish to take photographs of the child (these can be taken at the time of withdrawal when the child is fully clothed or earlier).
   - Hand and footprints, hair clippings etc. (may be taken by the parents later if they prefer).
   - Holding the child during the dying process.
   - Clothing the child.
   - Post-mortem

Withdrawal Procedure

1. The attending nurse prepares an empty cot, child's clothes, any prescribed sedation or analgesia. Photograph child before stopping ventilator if desired.
2. Place screens around child and ask visitors to other babies to leave the ventilation area.
3. The attending nurse prepares the child in the following manner:
   a. Removing all invasive lines except the endotracheal tube. Just prior to this it may be wise to give sedation (e.g., a morphine purge to limit trauma of gasping). Alternatively, it is possible to keep one heparinised IV line in case of need for sedation.
   b. Cleaning any blood or fluid stains on the skin if necessary.
   c. Changing nappy and dress up the child in selected clothes.
4. Parents and designated family members can be present during this process or be waiting in a designated room.
5. Allow for time to pray – formal prayers by person chosen by parents or by ward staff.
6. Designated person (preferably attending paediatrician or medical officer) to stop ventilator and withdraw endotracheal tube.
7. The attending nurse to hand over the child to parents and family. At times it may be appropriate to wrap the newborn in a shawl so as to cover birth defects and present the child as best as possible. Place in cot and wheeled to a private room with family (this may be a designated "bereavement room", a counselling room or the room used for breast milk expression)
8. The attending nurse and doctor should do the following during the dying process:
   a. Encourage parents to hold the child.
   b. Standby with parents if requested but it is generally preferred to allow them to be alone with the child during the dying process.
   c. Check child and parents periodically.
   d. Leave family with the child for as long as they want but not for a too long period.
   e. Provide tissues and refreshments as necessary.

Post-Withdrawal Management (After Death)

1. The attending nurse and doctor should express sympathy to parents. Some physical contact may be meaningful (e.g., a hug or holding the hand).
2. The attending doctor to certify the death.
3. The attending nurse should explain the process of releasing the child's dead body.
4. Before the parents leave, the attending doctor should arrange a one-week appointment for parents with the attending consultant paediatrician (or neonatologist) to facilitate the grieving process. The primary focus of this follow-up is to help parents with the decision for withdrawal and assess/discuss any guilt feelings. In addition, there may be a need to re-discuss the diagnosis or provide more information from tests.

Fatwa in Malaysia Relating to Withholding and Withdrawal of Life-Sustaining Treatment

To the best of our knowledge, several Malaysian states have held discussions about the fatwa on ethical and legal challenges of end-of-life care. It includes fatwa from state of Terengganu, State of Federal Territory, The State of Sarawak, The National Fatwa Committee and The State of Selangor.

Fatwa from The State of Terengganu

The 8th Terengganu State Fatwa Committee Meeting of the 12th Term which held on 20 Syaaban 1439H equivalent to 6 May 2018 has decided regarding the issue to discontinue end-of-life care and related treatment either directly or indirectly for patients who have been confirmed to have no hope. It must be conditionally certified unanimously by three doctors who specialise in the disease. This requirement is also related to the following actions:

i. Achieving 'medical futility' results;
ii. Do not continue resuscitation and subsequent treatment;
iii. Stopping life support; and
iv. Execution of initial medical instructions.

However, it must ensure the patient's health to be better cared for, and the patient can still continue treatment as usual according to the Standard Operating Procedure (S.O.P.) set by the hospital. This decision was made based on *Kitab Fatawa Muasirah*, volume 2, pages 525-529 by Dr. Yusuf al-Qardhawi.

Fatwa from The State of Federal Territory

Resulted from the Islamic Law Consultative Committee Meeting 6/119/2019. The 119th / 2019 Federal Territory Islamic Law Consultative Committee meeting held on 27 July 2019 has decided that:

Discontinuing end-of-life care and related treatment either directly or indirectly to a patient who has been confirmed to have no hope of recovery is a MUST with the following conditions:

i. Certified by at least two (2) specialists in the disease.
ii. Achieving 'medical futility' results. Medical futility means primary or emergency treatment of cases that would be or would be almost futile;
iii. Do not continue resuscitation for patients who did not receive initial treatment at the scene. For example, a person who was in a coma due to a heart attack and did not get cardiopulmonary resuscitation (CPR) at that time at the scene.

Fatwa from The State of Sarawak

The 24th Sarawak State Fatwa Board Meeting on 10 Jamadilawal 1435H / 12 March 2014M unanimously accepted the following decision:

1) A person's life ends when the spirit leaves from his body. Medically, it is determined when the heart and / or brain have stopped functioning. Any action, using any name at all, that causes the heart and / or brain to stop functioning before it is supposed to occur for stopping life is a murderous act.

2) Euthanasia, in the sense of stopping the life of a person before a person is confirmed dead by using any means and relying on any reason is forbidden in Islam. Patients requesting that Euthanasia be performed on him orally, in writing or on any condition can be categorised as having committed suicide or doing something to commit suicide. A medical practitioner who takes action to end a patient's life by any means can be categorised as having killed someone. Representatives who request that the patient's life be terminated in any way may be categorised as the party who ordered the patient to be killed.

3) If treatment is stopped after the heart and / or brain is confirmed to stop essentially and only works with the help of support devices, it is out of the meaning of Euthanasia practice because the purpose of stopping life is no longer implemented. Such actions are permissible because the patient has been confirmed dead and does not require any treatment.

4) There is no space in Islam that allows a person to choose to die by stopping any form of treatment in order to end the misery experienced. Based on the hadith of 'Ata' bin Abi Rabah, the patient can choose not to be treated but it is not a reason to end life. The person needs to be patient to accept the allegations of Allah SWT. In addition, there is no provisions that allows a person's life to be stopped in order to reduce the cost of treatment.

Fatwa from The National Fatwa Committee

The 97th Muzakarah of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia (*Jawatankuasa Fatwa Kebangsan Malaysia*) which convened on 15-17 December 2011 discussed the Law of Euthanasia or Mercy Killing. Muzakarah has made the following decision:

After listening to briefings and expert explanations as well as examining the evidence, arguments and views put forward, Muzakarah is on the view that stopping the life of a person before the person is confirmed dead by using any means and based on any reason is illegal and forbidden by Islam. Accordingly, Muzakarah ruled that the act of speeding up death through the practice of euthanasia (whether Voluntary, Non-Voluntary or Involuntary Euthanasia) or mercy killing is illegal according to Islam because it equates to the act of killing and it is also contrary to Medical Ethics in Malaysia.

This decision is in line with the Word of Allah SWT:

وَمَا كَانَ لِمُؤْمِنٍ أَن يَقْتُلَ مُؤْمِنًا إِلَّا خَطَـًٔا

Translation: "And never is it for a believer to kill a believer except by mistake".

(Surah an-Nisa' 4: 92)

and the Hadith of the Prophet SAW narrated by an-Nasa'ie which means: Rasulullah SAW said, "Do not expect death, if a person is good, it may be that it adds good and if a person commits a sin it may be that he repents (and hopes the pleasure of Allah)".

Muzakarah also emphasises that the job of a doctor is to help patients in matters of goodness. Helping to hasten death is not included in matters of goodness but belongs to things that are forbidden and sinful. However, in cases where the physician has confirmed that the patient's heart and / or brain has stopped functioning properly and the patient is confirmed to have no hope of survival; relying only on respiratory support, Muzakarah decides that the action of stopping the respiratory aid is allowed by Islam because the patient has been confirmed dead by a physician and any treatment is no longer required.

Similarly, in cases where the physician has confirmed that the patient has no hope of recovery and the patient has been allowed to return, then the action of discontinuing primary treatment and only continuing treatment (conventional treatment) is allowed by Islam because such conditions are not included in euthanasia or forbidden mercy killing.

However, if the treatment or support aid is used for other purposes such as aids to remove fluid to facilitate breathing, then the action of removing or stopping it is not allowed. In cases where the physician is faced with a situation where the patient has to deal with two options, either to continue treatment even if it is likely to have side effects that can lead to death or to remain in constant pain, Muzakarah agrees to decide that it is necessary for the specialist medicine provide treatment or medication to the patient (such as painkillers) although it may affect the patient's life.

Accordingly, in line with the method of fiqh: that is, 'in an emergency, everything that is forbidden is allowed', the practice of Indirect Euthanasia or Double-Effect Medication can be implemented according to Islamic views to ensure that the suffering faced by patients can be controlled and its implementation is not directly aimed at accelerating death.

Muzakarah also decided that in medical methods, brain death is considered as death and when the death is confirmed by an expert, then it will involve all laws related to death prescribed by Islamic law. Therefore, it is necessary to discontinue supportive treatment (e.g., the use of ventilator machines) with the consent of the next of kin after being confirmed by two physicians who are not involved in organ donation matters.

Fatwa from The State of Selangor

The fatwa dated December 20, 2012

1) It is illegal to perform Euthanasia or Mercy Killing for trying to speed up death by stopping treatment or taking drugs at excessive doses to stop life and considered as a murderous act. The act of killing is an act contrary to the will of Allah S.W.T. and deprives Him of His rights.

2) The job of a doctor is to help patients in matters of goodness. Helping to accelerate death is not included in matters of goodness but belongs to matters of evil and sin.

3) In medical methods, brain death is considered as death. Therefore, one should stop supporting treatment with the consent of the next of kin, for example the use of a ventilator after being confirmed by two Muslim doctors who are not involved in organ donation matters.

Discussion

In our attempt to explore the relationship between ICU protocol and Fatwa in Malaysia relating to withholding and withdrawal of life-sustaining treatment, we found not much different gaps between both guidelines. As a result, we have arrived to the conclusion that both guidelines should be fulfilled simultaneously.

Intensive Care Unit Protocols in Malaysia	**Fatwa in Malaysia**
Ethical Principles When making end-of-life decisions, the principles follow medical ethics. Respect, dignity, and compassion should be shown to those who are dying. Respect for autonomy, working in the best interests of the patient, causing no harm to the patient, and observing justice and equity as distributive justice are all ethical principles.	**Ethical Principles** The fatwa underlines that the patient's health should be better cared for, and that the patient should be treated as usual according to the hospital's Standard Operating Procedure. It is illegal to perform Euthanasia or Mercy Killing because it is a murderous act to try to hasten death by ceasing therapy or taking medications in excessive dosages to end life. Killing is an act that goes against Allah S.W.T.'s will and deprives the rights.

Decision-Making Capacity The patient's decision-making capacity was tested when it came to end-of-life decisions. For patients with limited or complete absence in decision-making capacity, families serve as surrogate decision-makers. The autonomy of the patient must be respected, safe in the case of non-beneficial medical treatment. Because most ICU patients lack decision-making capacity, their families act as surrogate decision-makers. Surrogates may utilise substituted judgement as a decision of the patient if he or she has the capacity, as well as best interest as a decision maker based on the prospective benefits vs. burdens of therapy while taking into account the patient's values and beliefs. EOL decisions are shared medical decisions, reached by professionals with family members' approval.	**Decision-Making Capacity** The state of Terengganu issued a fatwa on the topic of discontinuing end-of-life care and related treatments for patients who have been confirmed to be without hope, either directly or indirectly. It must be conditionally certified by three doctors who specialise in the disease unanimously, but a fatwa from the State of Federal Territory stated that it must be conditionally certified by at least two (2) specialists. The National Fatwa Committee's fatwa underlines the importance of discontinuing supportive treatment (such as the use of ventilator equipment) with the approval of the next of kin and following confirmation by two physicians who are not involved in organ donation. The topic of brain death being viewed as death is highlighted in a fatwa issued by the state of Selangor. As a result, one should stop supporting treatment with the approval of the next of kin, such as the use of a ventilator when two Muslim doctors who are not involved in organ donation certify it.
Patients for Withholding and Withdrawal of Life-Sustaining Treatment The ICU Protocol Malaysia broadly listed the patient's condition: • Imminent death when the patient has a severe acute illness that is not responding to therapy and is unlikely to be reversed or cured despite continued excellent therapy, such as septic shock with multiorgan failure. • Terminal condition when the patient has a fatal illness that makes surviving longer than 3-6 months is impossible. • The illness is severe and irreversible, diminishing cognition and consciousness, yet death may not occur for months. In such instances, it is common practice to refuse CPR or other resuscitative measures if the patient's condition deteriorates, such as persistent vegetative state after cardiac arrest, severe dementia, or severe stroke with poor cognitive recovery. • Advanced age, poor functional status, and diminishing physical performance due to persistent organ dysfunction, such as several co-morbidities. • Severe disability with poor quality of life.	**Patients for Withholding and Withdrawal of Life-Sustaining Treatment** When obtaining 'medical futility' results, most fatwas in Malaysia stressed on end-of-life care and related treatment. It is aimed either directly or indirectly at individuals who have been told they have little hope after being certified by disease specialists. Medical futility refers to the primary or emergency treatment of cases that are or are nearly fruitless. In the context of euthanasia or mercy killing, a fatwa from Sarawak was discussed. If therapy is terminated after the heart and/or brain have been confirmed to have stopped functioning essentially and are only functioning with the assistance of assistive equipment, it is no longer considered Euthanasia because the goal of ending life has been achieved. Because the patient has been determined to be dead and does not require treatment, such measures are lawful. Similarly, if a physician confirms that the patient has little chance of recovery and the patient is allowed to return, Islam permits abandoning primary therapy and just continuing treatment

• Advanced diseases of progressive life-limiting conditions such as motor neuron disease, which causes rapid deterioration in physical status, and severe Parkinson's disease, which causes limited independence and necessitates assistance with activities of daily living (ADL). • A patient who has expressed that he or she does not want life support therapy to be started or continued. This will include patients who have given clear advanced care directives.	(conventional care) because such circumstances are not covered by euthanasia or mercy killing. When a physician is faced with a situation in which the patient must choose between continuing treatment even if it is likely to cause death or remaining in constant pain, the fatwa agrees that it is necessary for the medical specialist to provide treatment or medication to the patient (such as painkillers), even if it may affect the patient's health.

Conclusion

The present study revealed that there is no significant difference between decision made by medical professional in conjunction with the ICU protocol and fatwa in Malaysia. The medical provider should rationalise in a holistic approach to the care takers regarding critical care conditions. In order to avoid unnecessary dispute and miscommunication, the health care workers must have a better understanding regarding the nature of the views held by the general public and hence those of patients' relatives, their further expectations and preferences. Decisions concerning this issue are influenced by considerations related to religious or culture varieties, quality of life, and long-term disabilities. The provided protocol and fatwa in Malaysia can be taken as a guidance for Muslim health care workers as well as families in decision making for withholding and withdrawal life sustaining treatment in ICU.

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