

Breaking Bad News to A Terminally-diseased Physician in ICCU: A Case Study of Ethical and Cultural Dilemma

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Abstract

Background: Breaking bad news is one of the most problematic tasks for physician. Moreover, local guidelines or recommendations about this is not well established in Indonesia and its practice still varies between physicians.

Case Illustration: This paper presents a case of a fellow physician admitted to ICCU with terminal cardiac condition whose family wished to keep the bad news away from the patient. The physician team were in a difficult situation when the patient asked about his condition, but they decided to respect and commit to the family's decision to not giving information about his terminal state.

Conclusions: In performing such problematic task, balancing non-maleficence and autonomy principle is the key. Cultural background differences should also be considered when dealing with such cases. Other important factor that can affect this practice is lack of legal support in Indonesia. Combination of all those factors should always be considered for the best interest of both parties.

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Introduction

The physician-patient relationship used to be a one-way communication with a paternalistic characteristic.^{1,2} Physicians acted as the sole decision-makers for the medical treatment of the patients, while patients were not involved in the decision-making process.¹ They were also commonly concealed from the diagnosis and prognosis. Patient did not even bother trying to understand their disease because they believed that the physician was giving their best to cure them. Such a condition persisted worldwide until the advancement of bioethics. Methods of treating patients were finally shifted from a paternalistic approach to an individualistic approach.¹⁻³ Informing diagnosis and treatment planning is now a common practice worldwide, even in Eastern cultures. Patients are also encouraged to participate actively in choosing the treatment options for their disease. This progress aligns with the recognition of patients' right to information, which is part of the autonomy principle in modern bioethics.^{1,4}

The paradigm shift in truth-telling was evident in an older publication from 1979.⁵⁻⁶ It was observed from a survey conducted in the US between 1961 and 1979. In 1961, 88% of physicians did not routinely discuss the diagnosis of cancer with patients. Surprisingly, in 1979, 98% of physicians discussed the diagnosis of cancer with patients.⁵ However, telling the truth about life-threatening prognosis to patients is still a controversial topic, especially in the eastern part of the world.⁶⁻⁷ Despite the emerging trend to disclose important information regarding the patient's condition throughout the world, many countries still prefer the non-disclosure principle in their medical practice.^{3,6,8} A survey performed in 2000 declared that only 17% Japanese physicians agreed that a doctor should inform patients of a cancer diagnosis.⁶ From another perspective, in a different Asian country, only 48% hospitalized Iranian cancer patients were aware that they had cancer.^{1,9} Cultural aspects play an essential role in this area.³ In Asian perspectives, patients' family members are decision-makers. Therefore, information regarding the patient's disease and its prognosis is commonly given to them.^{3,8}

Indonesian culture regarding breaking bad news to patients is similar to that of Japan and Iran. Truth-telling had been encouraged since the development of palliative care medicine in Indonesia in 1992. However, the progress had been very slow and varied across the country. Communication between doctor and patient is still somewhat paternalistic. Patients

perceive doctors to be of higher status and avoid disrespect by not asking too many questions.¹⁰ This trend is gradually shifting towards modern bioethics principles in which the patients hold a significant role in deciding treatment options for themselves. On the other hand, unlike most developed countries, there were no local guidelines or recommendations for physicians on breaking bad news in Indonesia.¹¹ Therefore, the practice of telling the truth to patients varies greatly among physicians. Currently, the decision on whether to disclose comprehensive information about the disease to patients or their families primarily rests with the physician.

Case Illustration

Mr. NH, a 79-year-old male, presented to the emergency room in National Cardiovascular Center Harapan Kita (NCCHK) with chest pain in the last 3 days before admission. The patient, who was a physician in a local hospital, demonstrated signs and symptoms of shock with low cardiac output. Interventricular Septal (IVS) Rupture due to acute ST-Elevation Myocardial Infarct (STEMI) was confirmed by echocardiography (Figure 1). The defect was identified as a discontinuity of the apical ventricular septum. Color Doppler image revealed a turbulent jet at that specific region, consistent with left-to-right shunting. The ECG result is shown in Figure 2. ST-segment elevation was obvious on precordial leads (V1-V4). The subsequent evolution of the ECG was also observed, with the development of a pathological Q wave. Cardiogenic shock due to a mechanical complication was the initial main problem. An Intra-Aortic Balloon Pump (IABP) was applied, and the patient was admitted to the Intensive Cardiovascular Care Unit (ICCU) immediately. IABP gave a temporary solution for the hemodynamic problem. However, definitive treatment was needed. A multidisciplinary discussion with a cardiovascular surgeon decided that the patient required surgical closure of the IVS rupture with a synthetic patch. A synthetic patch for IVS rupture closure was not available at that time. An effort was made to provide the patch from various parts of the country, with no satisfying result. The neighboring country could also not help with patch availability. IABP could not be maintained for more than 13 days for the patient due to the development of Acute Limb Ischemia (ALI). IABP needed to be removed while no definitive treatment can be done. At this point, deterioration of the clinical condition and death were inevitable. This would be the appropriate time to deliver the bad news.

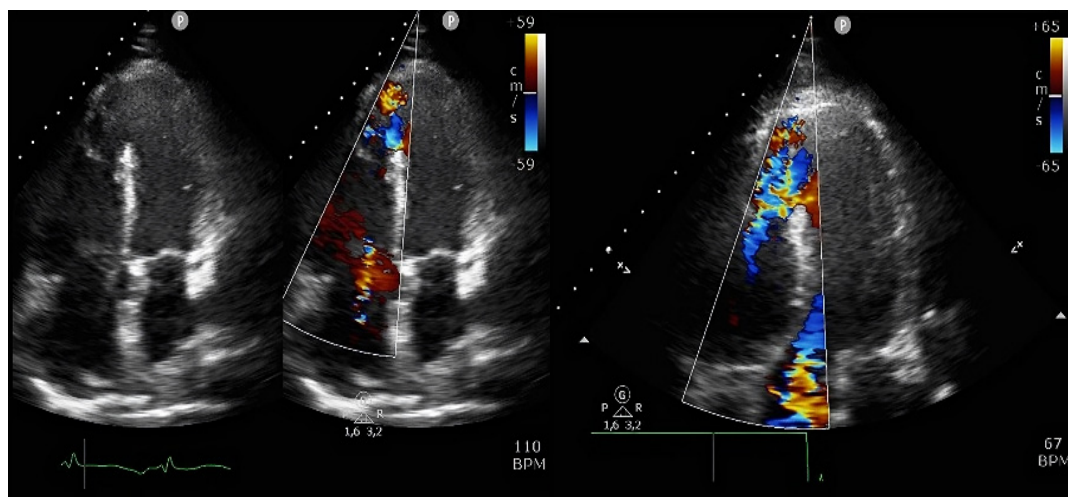


Figure 1. Echocardiographic image of IVS rupture.

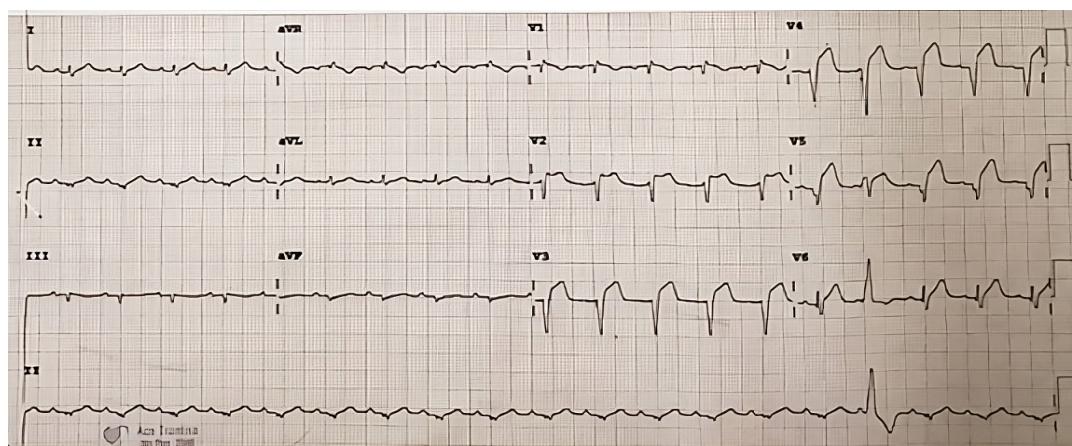


Figure 2. Patient's ECG.

The bad news was delivered not to the patient but to his family. A formal meeting with five family members was held. At this meeting, the family decided that the patient should not be informed of the poor prognosis. The patient remained conscious until several hours before death. The patient tried to understand his condition by asking some doctors and medical staff, but no one answered directly. Most medical staff were comforting the patient, assuring them that they were making their best effort. Considering the poor prognosis and unavailability of a definite treatment, the Do Not Resuscitate (DNR) option was offered to the family. The patient later died under DNR status.

Discussion

The development of modern bioethics principles in recent decades, especially autonomy, has changed both physicians' and patients' perceptions of communication in medicine. The patient's role is getting bigger and more balanced with the physician's

role. Physicians' dominance is no longer acceptable in medical practice, even in Eastern countries.¹ Despite such progress in all parts of the world, physicians' attitude towards information disclosure still varies greatly among different cultures.^{1,3} Research about truth-telling practice was numerous in various parts of the world. It is well established that different cultures influence this practice. The difference between Western countries and Eastern cultures regarding this issue is conspicuous. Western countries uphold the value of the individual, while Eastern cultures place more emphasis on the important role of the family.^{1,7-8} Indonesia is a large country in Southeast Asia whose culture resembles most eastern civilizations.

The most common topic in reviews and research regarding truth-telling is about cancer patients.^{3,5,7,9} However, breaking bad news is not limited only to such a diagnosis. The scope is much bigger. Any news related to permanent changes of an individual is actually considered bad news. Some diagnoses considered as bad news are cancer, coronary artery

disease, diabetes, mental illness, genetic disease, and incurable fatal disease.¹⁰⁻¹² The worst kind of news involves information about imminent death. The ethical aspect of truth-telling about imminent death is similar for both cancer and other incurable fatal diseases.¹² Therefore, ethical analysis of truth-telling in cancer patients applies to other fatal diseases.

Modern Bioethic Principle and Truth Telling

The principles of modern bioethics were initially described by Beauchamp and Childress in 1979.¹³ It recently passed its fortieth anniversary, with numerous research and reviews polishing the concept of modern bioethics.¹⁴ Those principles, as depicted in Figure 3, are beneficence, non-maleficence, autonomy, and justice.^{3,4} Beneficence obliges to promote the well-being of patients, which must always be encouraged. Non-maleficence is the fundamental principle of avoiding harm and not inflicting further harm on patients. Justice means that every action planned for patients is impartial and fair. Autonomy entails respecting and appreciating the rights of patients as individuals to determine what course of action is best for themselves.^{3,4} Balancing all these aspects is the key to implementing the ideal practice of modern bioethics. All those principles are valuable tools for analyzing ethical problems in medical practice, including breaking bad news. Beneficence and justice play a minor role in truth-telling. Non-maleficence and autonomy are essential

aspects in analyzing ethical issues in breaking bad news.³

Respecting the patient's autonomy means respecting their right to know what is wrong with their body and their right to decide which course of treatment they are willing to undergo. Applying autonomy means telling the truth to the patients, including an explanation of the disease and its terminal nature.^{4,8,13} Patient's characteristics are an important part of applying the autonomy principle. Both internal and external factors influence it. Internal factors are mental capacity, stress, and the capability to understand medical information. External factors are culture and socioeconomic class.^{1,8} Considering all internal factors in upholding the autonomy principle, physicians need to be certain that the patient is lucid and has the capacity to receive bad news and make decisions based on this condition.² However, one can argue whether, once the patient knows his terminal state, he will be depressed and no longer have the ability to decide the next course of action. All those factors influence a physician's reasoning to determine how deeply they respect the patient's autonomy. A physician might give full disclosure of all information, reveal the diagnosis but not the terminal nature, or conceal both the diagnosis and the prognosis.^{3,7}

Upholding the non-maleficence principle is what keeps physicians away from revealing the disease

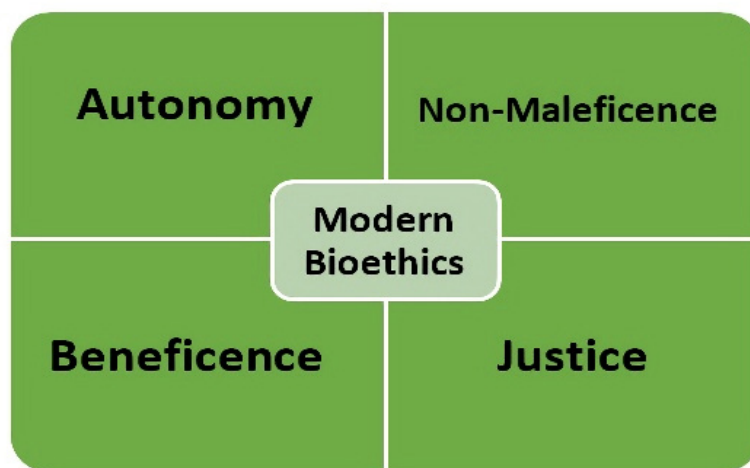


Figure 3. The four pillars of modern bioethics.^{4,13}

and its terminal nature to the patients.⁸ The most important justified reason not to disclose important information regarding terminal disease was the fear of causing new psychological morbidity to the patients.³ Psychological comorbidity is not a rare finding in terminal patients. It usually comes as depression, and it can be as advanced as suicidal thoughts or the intention to hasten death.¹⁵ The prevalence of

depression among cancer patients is 5-20%.¹⁵⁻¹⁶ This prevalence increases with more advanced stages of cancer, which resembles a more imminent death.¹⁵ A study in 2013 recorded that more than half of terminally ill patients in the Netherlands (50.4%) were taking psychotropic medication to cope with psychological morbidity.¹⁶ A comparison of the quality of life between patients who knew their cancer di-

agnosis and those who did not revealed that the first group had a significantly lower degree of emotional and social functioning.⁹

Despite the obviously higher number of psychological morbidities in terminal patients, a direct correlation between breaking bad news and depressive symptoms has not yet been established.²⁻³ Furthermore, it is still debatable whether concealing the truth can serve as an effort to prevent depression in terminal disease patients.²

Not telling the truth to patients may harm them in many ways. It may not harm patients medically, but it may do so from a holistic point of view. Patients who do not know what their disease is might ignore important symptoms and are reluctant to seek medical attention.^{1,17} They may make major decisions about their lives that they would not make if they knew the truth. They can be frustrated to be the one kept out of a big secret.¹⁻² Their trust in doctors and their families will dissipate.¹⁷ Patients with terminal disease may miss the opportunity to say goodbye and leave a meaningful farewell for their loved ones. Moreover, for a religious person, the opportunity to make peace with God in the face of imminent death can provide a significant sense of closure if they know they do not have much time left.¹ These consequences are often ignored and neglected by both physicians and families. When considering breaking bad news, these factors should be acknowledged.

Physician's Point of View

Analysis suggests that physicians' reluctance to tell the truth to terminally ill patients is mainly influenced by their attempt to balance autonomy and non-maleficence.³ Multiple factors from the physician's point of view also influence the practice of information disclosure to terminally ill patients. Both internal and external factors can drive it.^{1,12} These factors have been reviewed in multiple publications, and several solutions have already been established.

Breaking bad news is not an easy task for physicians. It places a significant burden on physicians, as if they were taking hope away from patients' minds.^{3,11} Moreover, breaking bad news is a stressful action where patients and families might respond negatively and blame the doctors for any dissatisfaction.¹¹ A survey conducted in 2002 analyzed how patients perceived the event of having bad news broken to them. Among 106 participants, 26% were dissatisfied with how their doctors told them the truth.¹⁸ Another survey in 2018 in Poland explored that a bad experience in

receiving bad news often stems from the doctor's attitude and lack of emotional support during the truth-telling event. This issue comes from the physician's lack of skill in delivering bad news.¹² It has been addressed recently, and physicians are recommended to acquire this specific skill to manage such a stressful environment. The modern curriculum of medicine has been integrating skills of communication and how to perform breaking bad news with empathy.^{3,11-12} This effort might reduce physicians' worry and prevent them from concealing information out of fear.¹¹

Feedback from patients who received bad news also indicated that their unpleasant experience was due to an insufficient amount of time given for communication.¹² Physicians at the hospital are always busy. Most of their time in the hospital is spent on appointments with numerous patients in the outpatient clinic and on visits to many patients in the ward.³ A survey of patients receiving bad news in Poland described that 42% patients felt that physicians did not devote enough time to communication.¹² A survey of physicians revealed that the average time for a physician to perform good-quality breaking bad news is 27 minutes.¹⁹ Although it is understandable that sparing more than 15 minutes of a physician's time exclusively for meetings with patients and families is difficult, sufficient time allocated for breaking bad news is crucial for the patients and families.

Medical practice is vulnerable to lawsuits. A simple miscommunication or minor dissatisfaction from either patients or families might end up in court. This drives physicians to be very careful in handling communication with both patients and families. Breaking bad news is a grey area that is not regulated by law. A lack of legal and ethical guidelines can also be why many physicians are confused about what action to take. Some countries have addressed this problem and published formal recommendations for use.^{3,7,12,20-21} However, Indonesia still lacks of guidelines.¹¹ This put Indonesian physicians in a difficult situation, resulting in their hesitation to give full information disclosure for patients.¹⁰⁻¹¹

Lack of skill, lack of time, and lack of legal support are obstacles, from the physician's perspective, to deciding whether to deliver bad news to patients.^{1,12} These internal and external factors create doubt in the minds of physicians. Considering Indonesian culture as an eastern culture, physicians prefer to defer the decision to families to clear their doubts.

Family's Role in Deciding Truth Telling

In contrast to Western culture, which respects an individual's values in full, Eastern culture emphasizes the family's role.^{1,8} Family plays a vital part in deciding which treatment options should be selected for the patient. As a country in the eastern hemisphere with a similar culture, disease is considered a family matter in Indonesia. Hence, the decision-making process is made by family discussion.¹⁰⁻¹¹ Patients tend to comply with the family's decision, even when it contradicts their own wishes. With that much role of the family, family is frequently the first part being informed about the disease and the nature of the disease in this part of the world.^{1,7-8}

In most Asian countries, the family is given the privilege to decide to what extent the patients should be informed of their disease and its prognosis.^{3,8} The most common practice is informing the patient's family of both the diagnosis and the prognosis first, and then letting them decide whether the physician should also inform the patient or not.¹ On some occasions, the bad news was delivered to the patient by a family member without the physician's presence.³ Resistance to disclose information might come from the family. Usually, this decision is taken because they believe it will only cause psychological trouble for the patient without any benefit.^{3,8} Families tend to believe that a poor prognosis would extinguish the patient's hope and generate depression. Therefore, families prefer to protect their beloved member from the truth of the illness.^{7-8,10}

Family members often state multiple other reasons to conceal the information from patients. First, the family did not know how to tell the truth. Second, the family did not think it necessary to say to the patient the truth. Third, they believe that the patients would be better or happier if they didn't know the truth.¹ The first reason is based on a lack of skill to perform such an action. This lack of skill can be covered by the physician, who was trained to deliver bad news.¹¹⁻¹² The second and third reason is based on assumptions and feelings.

The significant role of the family in deciding whether the patient should be informed does not always align with the patient's desire. Patients' preferences toward full disclosure differ from one culture to another.¹ Survey of patients revealed that 83-99% patients would like to be informed of their diagnosis in Western countries.² The numbers were lower in non-Western countries (24-74%).^{2,6-8} Survey of Japanese patients revealed that only 65%

patients agreed that physicians should inform the family first about their patient's terminal disease and let them decide whether the patient should be told or not.⁶ Although this number represents the majority of Asian patients whose desire is to let the family decide, the minority is not small in proportion. The same survey elaborated more by describing that 24% Japanese patients preferred that physicians should inform the patients about their terminal state, even if their family decided not to tell.⁶ The same contradictory phenomenon was also observed in Hong Kong, affirming that there was no academic evidence to support that breaking bad news should be performed to the family instead of the patient.⁸ Whether the family's interest represents what the patient really wants or not needs to be questioned and researched.

ICCU Setting

ICCU settings are known as battlegrounds in the fight against numerous medical emergencies. Spaces for comfortable discussion with families are usually nonexistent. Such discussions usually take place in the aisle between beds. Moreover, information is conveyed in a limited time due to the physician's rush to attend to another medical emergency for other patients.²¹ This setting does not encourage full disclosure of terminal disease. Lack of time and an appropriate place to deliver bad news are also essential factors in breaking bad news.^{3,19}

A poor environment for breaking bad news should not be an excuse not to do so. No matter how busy the physician was during emergency procedures, they should always make time for communication after the storm passed. When a comfortable, private room for breaking bad news is unavailable in ICCU, cooperation with other units that have such a meeting place is urged. Hospital management should be encouraged to understand that patients' beds and medical equipment are not the only infrastructure needed in ICCU.²¹ Meeting room or conference room is also essential.

Case Analysis

There were no problems in the diagnostic process of the disease. The diagnostic process, from anamnesis to supportive examination, was thorough and timely. Problems arose when the ideal solution for the patient could not be put into practice. The main problem discussed in this paper is the consequences of this condition: Should we tell the patient?

Modern bioethics encourages thorough analysis in dealing with various problems of ethics. The four main pillars represent multiple perspectives in

analyzing such a condition. Balancing the principles of non-maleficence and autonomy is key to telling patients the truth.³ Should we uphold the autonomy principle as most Western countries do, we need to tell the patient about his condition and his terminal state.¹ Our patient explicitly asked about how his disease is progressing. Our medical staff decided to respect and commit to the family's decision not to give him information about his terminal state. Arguably, our medical staff neglected the autonomy principle of the patient. However, the autonomy principle is complicated. Internal and external factors influence it.^{1,4} Cultures and social relations in particular render autonomy not only limited to "always tell everything to the patients."⁴ It has been suggested that notifying unprepared patients of a bad prognosis, whose cultural practice is to avoid painful medical truth, is actually not respectful to their autonomy.^{1,2} Forcing the truth on unprepared patients can also damage the trust the patient has placed in the physician and break the relationship.² This notion of cultural sensitivity is important to discuss.

Formal breaking bad news was performed in a conference room to family members. This practice is common in Indonesia. In such a conference, some decisions are made. It often involves selecting the course of treatment for the patient. In difficult cases, the conference also decides whether the physician should tell the patient about his imminent death.⁷ Respecting the family's preference is the main characteristic of medical practice in Eastern cultures.^{1,3,6,8} However, this decision should be made only after the physician explains both the consequences of revealing and concealing the truth to the family.³ The family decided that the patient should not be told about his terminal state. The family requested that all medical staff comply. This is a common but difficult situation for a physician. Western and Eastern cultures reacted differently in this situation. A survey from 2000 comparing Japanese and US physicians exhibits such a phenomenon. When the family requested that no information be given to the patient, 79% of US physicians still gave it anyway. Only 8% Japanese physicians agreed to do the same thing.⁶ We reacted the same way in accordance with our Eastern cultures.

The objective of ethical practice in this condition is to discern the patient's preference without conflicting with the family's interests. Asking whether the patient wants to be told about the truth of their disease is the best course of action.^{1,8} It is

common for patients in Western countries to have a surrogate decision maker. Such patients do not wish to hear or receive information about their disease, so they choose someone they trust to perform that important task.^{1,2} This option is legally supported as long as the patients' wishes and chosen surrogates are well documented in the medical record. Should the patient choose no surrogate, what the patient wanted trumps what the family wishes for. Whatever options the patient chooses, his autonomy is maximized.¹ The important issue is when we ask the question. Asking whether the patients want to choose someone as their surrogate when their condition deteriorates might imply that their disease is terminal. This consequence contradicts the family's desire that the patient feel everything will be fine. Family might be against such action and blame doctors afterwards. The hardest part is knowing the patient's preference without asking them at an improper time.

Lack of legal support in Indonesia is an important negative factor in breaking bad news to patients.¹⁰ This condition causes physicians to be too careful because of the fear of legal lawsuits. When physicians tell the truth to patients and respect their wishes, they might incur the family's rage for not complying with their wishes. Local ethical guidelines might serve as a benchmark for physicians nationwide in deciding how to handle difficult ethical issues in breaking bad news.^{7,20} This guideline will be the standard for physicians on when to tell the patients directly or when to tell the family first.²⁰ This legal support can also cover the issue of a surrogate decision maker, which is currently uncommon in Indonesia.

Conclusion

Breaking bad news is one of the most problematic tasks for physicians. While many factors played a role in analyzing ethical problems in breaking bad news, balancing beneficence, non-maleficence, autonomy, and the principle of justice is the key. Carefully handling communication with both patients and families is essential; forcing the truth may cause psychological morbidity, but withholding the truth may also harm them in many ways. A step-by-step approach in a controlled and comfortable environment is needed to prepare patients and families for breaking bad news. It is encouraged for physicians to perform good-quality breaking bad news in sufficient amounts of time, and to respect the patient's right to know and the patient's right

not to know about their condition. Legal support from local ethical guidelines is needed, as it will serve as the standard of care for physicians when dealing with ethical cases. This legal support will provide guidance on when and how to disclose the true situation to the patient, address the issue of the surrogate decision-maker, and serve as strong grounds and protection for the physicians.

List of Abbreviations

ALI	Acute Limb Ischemia
DNR	Do Not Resuscitate
ECG	Electrocardiography
IABP	Intra-aortic Balloon Pump
ICCU	Intensive Cardiovascular Care Unit
IVS	Interventricular Septal
NCCHK	National Cardiovascular Center Harapan Kita
STEMI	ST-Elevation Myocardial Infarction

Ethical Clearance

Not Applicable.

Publication Approval

All authors consent to the publication of this manuscript.

Authors Contributions

Conception and the framework of the manuscript was initiated by TMHP and DAJ. Manuscript was drafted by TMHP, FPA, WF, and FT. TMHP, BEP, and DAJ critically revised the manuscript. All authors contributed to the article and approved the submitted version.

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There is no AI tools involved in the writing process of this manuscript. Manuscript were drafted manually. Proofread and spell-check were also performed manually by authors.

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