

# ABCDE assessment for palliative care truth-telling dilemmas: a case study

Rismia Agustina, Susan Jane Fetzter, Wei-Shu Lai, Kennedy Diema Konlan, Pradana Zaky Romadhon and Mei-Feng Lin

Rismia Agustina  
Department of Nursing,  
College of Medicine,  
National Cheng Kung  
University, Taiwan; School  
of Nursing, Faculty of  
Medicine, Lambung  
Mangkurat  
University, Indonesia

Susan Jane Fetzter  
Department of Nursing,  
College of Health and  
Human Services,  
University of New  
Hampshire, USA

Wei-Shu Lai  
Department of Nursing,  
College of Medicine,  
National Cheng Kung  
University, Taiwan

Kennedy Diema Konlan  
College of Nursing,  
Mo-Im Kim Nursing  
Research Institute, Yonsei  
University, Korea;  
Department of Public  
Health Nursing, School of  
Nursing and Midwifery,  
University of Health and  
Allied Sciences, Ghana

Pradana Zaky Romadhon  
Hematology-Medical  
Oncology Division,  
Department of Internal  
Medicine, Airlangga  
University, Indonesia

Mei-Feng Lin  
Department of Nursing,  
College of Medicine,  
National Cheng Kung  
University, Taiwan

Correspondence to:  
l30mf@mail.ncku.edu.tw

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## Abstract

**Background:** In Indonesia, the diagnosis of a serious illness is often mediated through the patient's family, reflecting the cultural importance of family involvement in the patient's care and collective decision-making. **Aim:** To use a case study to show the difficulty that healthcare professionals face telling the patient the truth about their condition in Indonesia. **Method:** The Kagawa-Singer and Blackhall ABCDE framework was used during truth-telling dilemmas to assess patients' and families' attitudes (A), beliefs (B), contexts (C), decision-making styles (D) and environments (E). **Findings:** Studies have shown that family involvement in health-related communications can alleviate the stress associated with the disclosure of a serious illness. Palliative care nurses must acknowledge the importance of family in the patient's cultural context, by involving them in the disclosure of a diagnosis and disease trajectory by integrating every element of the ABCDE model in palliative care.

**Key words:** ● ABCDE model ● family ● health-related communication ● Indonesia  
● palliative care

Palliative care provides a comprehensive and multidisciplinary approach to improving the quality of life of people with a life-threatening illness (Rigney, 2022). Nurses practicing in palliative care settings can find the nature and depth of information provided to patients during the terminal stage of their illness and at the end of life challenging (De Brasi et al, 2021). Truth-telling becomes an important aspect of a nurse's role when providing palliative care.

The impact of truth-telling varies depending on the individual and the culture (Park et al, 2018). Asians frequently hide the truth out of fear of destroying hope for the patient or causing emotional anguish (Zhu et al, 2021). In Indonesia, healthcare professionals first inform family members about a patient's terminal prognosis to let them decide if they want to inform the patient (Martina et al, 2022).

Indonesian nurses are expected to provide nursing care with professional veracity (Indonesian National Nurses Association, 1989). However, within the context of Indonesian culture, ethical guidelines related to truth-telling have not been developed. A case study is presented to examine the ethical dilemma shared by Indonesian nurses and an approach for the resolution proposed.

## Case study

Mrs A is a 36 years old, married mother of four children. Her breast cancer has metastasised to her brain. She is terminally ill. The responsibility for her care depends on her husband, who has been designated as the next of kin. The family is devoutly Muslim and Javanese. Consistent with family bonds in Indonesia, Mrs A's father, mother and siblings, help with Mrs A's daily treatment and the care of her children. Her siblings also provide care. All of Mrs A's immediate and extended family participate in making treatment decisions for Mrs A.

Her condition has steadily deteriorated. The physician informed the family about her prognosis. During the consultation, the family remained silent and seemed to be in denial, common behaviour among those of Javanese ethnicity. The family indicated that they believe death is God's secret, regardless of the doctor's perspective. They pray that God will bring a miracle. As the patient's legal guardian, Mrs A's husband asks the doctors and nurses to keep the patient's prognosis secret. The extended family also agrees to conceal the prognosis. However, with the decline in health, Mrs. A seems gloomy and unmotivated to undergo treatment.

Mrs A asks the doctor directly about her

condition and prognosis. In an attempt to satisfy the family's wish and maintain an ethical responsibility to be truthful at all times, the doctor responds:

**'From the MRI results, cancer has spread to other regions. But we will do our best; if we continue praying, nothing is impossible. So, you also have to stay hopeful.'**

When Mrs A's condition continues to decline, she asked Nurse F, whom she has known during her treatments:

**'Am I dying, and am I going to die?'**

Nurse F is confused about how to respond to her inquiry.

### Significance of the problem

Culture shapes how people perceive diseases and mortality, which also significantly influence communication patterns, particularly nurse-patient communications regarding unpleasant news (Cain et al, 2018). There is compelling evidence that a good palliative care outcome is associated with the quality of support systems available (Milberg et al, 2020). In societies where interpersonal family cohesion is valued and regarded as paramount in decision-making, especially during poor health, healthcare professionals telling the truth becomes problematic (Ling et al, 2019).

Truth-telling strategies in palliative care settings within the cultural context of Indonesia have not been identified in the literature. Given the divergent cultural perspective, the influence of family, cultural ties related to illness, and the multifaceted hierarchical nature of communication in Indonesian cultures, truth-telling remains a clinical dilemma among healthcare service providers, especially nurses in palliative care units. Nine million Indonesians have emigrated, from Asia, Australia, Europe, to America (Tiwa et al, 2021). Truth-telling strategies within a cultural context will be potentially applicable to those who live in Indonesia, as well as around the world.

### Case review

Truth-telling is a process that requires pre- and post-assessment, preparation and continuation of care plans aimed at improving patients' and families' awareness of critical information, essential to the patient's condition (Watson et al, 2019). Nurses have a vital role in diagnosing a patient or their prognosis. Although most

patients get information regarding their illness from the physician, numerous patients in palliative care still use need support from nurses to understand their condition (Flidner et al, 2021). The challenge of truth-telling intensifies when 'bad news' is to be delivered to the patient, or when the nurse has to be supportive when the patient's condition is declining (Hinshaw, 2022). Truth-telling can make nurses struggle to manage their feelings of guilt, sadness and frustration while giving such news (Testoni et al, 2020).

Nurses worry about patients' negative emotions, potential suicide, family requests to hide the truth, fear of disagreeing with physicians, and inadequate time to discuss the prognosis (Cheng et al, 2021). Many informal family caregivers believe truth concealment will benefit the patient and maintain their hope (Zhu et al, 2021). If the truth was told, the family fears the patient will refuse further treatment or become non-compliant with treatment (Wu et al, 2021).

### ABCDE assessment as an approach

The ABCDE (Attitudes, beliefs, context, decision-making style and environment) assessment framework was developed by Kagawa-Singer and Blackhall to avoid cultural stereotyping or dismissing the cultural effect in palliative care settings (Kagawa-Singer and Blackhall, 2001). The mnemonic, adapted from Koenig and Gates-William's work, was originally aimed to assess cultural variations in end-of-life care (Koenig, 1995). The ABCDE framework can be used during truth-telling dilemmas to assess patients' and families' attitudes (A), beliefs (B), contexts (C), decision-making styles (D), and environments (E).

The case of Mrs A requires Nurse F to assess the patient's and family's attitudes. Nurses must recognise the views of the ethnic group, and the unique characteristics of each patient and their family. Consideration must be given to cultural traditions, and the attitudes they foster towards healthcare. These attitudes significantly influence care-seeking behaviour and use of health services (Kagawa-Singer and Blackhall, 2001).

The Javanese ethnic group's philosophy, reflected in Mrs. A's family's attitude toward her diagnosis and prognosis, is 'nerimo ing pandum', which means 'accept each situation that God has given with grateful feeling' (Farmawati and Wiroko, 2022). This philosophy strongly influences the Javanese people's reception of 'bad news' and other medical information, including diagnosis and prognosis (Kuswaya and Ma'mun, 2020).

Beyond the Javanese, other Indonesian ethnic groups also display unique attitudes that influence healthcare interactions. For example, the Batak people of North Sumatra often emphasise resilience, a fighting spirit and encouraging patients to confront illness with determination (Siregar et al, 2020). Among the Minangkabau of West Sumatra, there is a strong sense of communal support where extended family play a crucial role in providing emotional and pragmatic help to the patient (Rhandyka Rafli et al, 2021). In Bali, the Balinese Hindu philosophy of 'Tri Hita Karana', which focuses on harmony among people, nature and the divine, influenced the approach to healthcare by fostering a holistic view of wellbeing and encouraging practices that maintain balance in all aspects of life (Laksmi et al, 2021).

These diverse cultural attitudes across Indonesia highlight the importance of understanding and integrating patients' and families' attitudes into palliative care, ensuring that healthcare delivery is respectful and effective (Givler et al, 2024). Nurse F should approach Mrs A and her family with sensitivity to their cultural attitudes, fostering open communication that respects their values, and involving the family in discussions about care in a way that denotes cultural acceptance and gratitude.

The second element of ABCDE involves understanding the patient's and family's beliefs about religion and spirituality. Since 1945, the ideology of Indonesia has been rooted in 'Pancasila', the five principles. The first principle, 'Belief in the Almighty God (Pheoney, 2019), impacts every aspect of Indonesian lives, including palliative care. The principle focuses all intentions and wishes on God as the sole controller of all events and happenings in human life (Susongko et al, 2021). Even a discussion about death and dying, commonly discussed in palliative care, is considered taboo among Indonesians (Kristanti et al, 2019).

Such decisions regarding death and dying are God's sole prerogative (Martina et al, 2022). A recent study found that while most Indonesians were interested in learning about their medical diagnosis, few were interested in their prognosis (Eng et al, 2022). Indonesian culture believes death is in God's hand, not in human prediction (Dewi et al, 2021). Therefore, 'try our best, let God do the rest' is a common proverb in Indonesia which is interpreted that, people need to do their best in any situation, regardless of the prognosis (Aksa 2020).

More than 90% of Indonesian people follow monotheistic religions, with nearly 87%

practicing Islam (Statista Research Department, 2021). Islam values honesty. Believers follow Muhammad, the prophet:

**'Truthfulness leads to righteousness, and righteousness leads to Paradise' (Al-Bukhari 6094 846 CE).**

Islam also believes that God, not humans, predetermines death. As stated in the Holy Quran: 'Allah takes the souls at the time of their death' (Verse 39:42). Muslims believe that death is not the end of the story. A strong belief in the afterlife is held among Muslims. The concept of death is then seen as a journey, that all Muslims must sojourn in anticipation of meeting the ultimate God, and gaining rewards for their good deeds. Muslims view life as a test, and therefore strive to do as many good actions as possible during their lifetime (Oualaalou, 2018). Given the strong Islamic values in Mrs. A's family, they anticipated that she would receive a good reward from the maker after death. Nurse F should assess what is considered important about Mrs. A's and her family's faith and spiritual needs. Spiritual strength can sustain the patient and family at the end of life.

The third element of ABCDE concerns the patient's and family's contexts. The historical and political context of the patient's and family's lives is investigated. Information should include where they were born, their economic status, any experiences with discrimination, access to healthcare, languages they speak, and how integrated they are into their ethnic community (Kagawa-Singer and Blackhall, 2001). Nearly 1100 different languages are spoken in Indonesia, one of the world's most linguistically varied nations (Zein, 2020). Nurses should inquire as to the patient preferred language for communicating with them about their health problems (Kwame and Petrucka, 2021). Nurse F may need to access an interpreter to best care for Mrs. A and her family. Nurse F also can get insight into Mrs. A and her family's lives by conducting a life history assessment, which can help Nurse F better understand the patient and the family's context of caring (Johnsson et al, 2018).

The fourth assessment is the patient's and family's decision-making style. Nurses are encouraged to learn about the decision-making patterns of ethnic groups, patients and their families. They should note whether the patient is making decisions independently, or the family is involved (Kagawa-Singer and Blackhall, 2001). Independence is highly valued in Western cultures

(Brant and Silberman, 2021). Palliative care can be provided in the home, long-term care or acute care facility.

In contrast, Indonesian culture emphasises caring for one's family members as an integral aspect of palliative care (Werdhani, 2019). Indonesia is a family-centered society, that culturally emphasises collectivism, mutual obligations and harmonious interpersonal relationships (Maulana et al, 2018). Due to Indonesian norms, caring and making decisions, including truth-telling is not an individual matter, but instead a collective family obligation (Silberman and Berger, 2022). Care of the family, especially parents, is one of the ways that Indonesians learn to appreciate life and the legacy of their ancestors (Kristanti et al, 2021).

Patriarchy also plays a significant role in Indonesian decision-making processes (Azizah, 2023). Traditionally, the Indonesian society is patriarchal, meaning that the oldest male family member, often the father or eldest son, holds primary responsibility for important decisions. This includes financial decisions, healthcare choices and the disclosure of medical information (Rizkianti et al, 2020). The patriarch's authority is respected and seldom challenged within the family hierarchy. His role is not only to make decisions but also to protect and provide for the family (Najmah et al, 2020).

In Mrs. A's case, this patriarchal structure was evident in the family's attitude toward her diagnosis and prognosis. They collectively decided that the reality of her situation should not be disclosed to her directly. This decision aligns with the cultural norm where the patriarch determines what is best for the family and the patient (Sutarsa, 2022). Nurse F should assess who will be paying for Mrs. A's treatment, which is likely the responsibility of the oldest male family member. Understanding and respecting this hierarchy is crucial for effective communication and care planning. Nurse F should engage with the appropriate family member, typically the patriarch, to discuss relevant issues and ensure that the family's values and cultural practices are honored in the care process.

The fifth ABCDE assessment is the patient's and family's environment. At this point, the emphasis on seeking various properties to help understand patient cultures is emphasised. Indonesian people in each political district are clustered into neighbourhood communities or 'Rukun Tetangga' (RT) (Kushandajani, 2020). In many islands of Indonesia, neighbourhood community leaders are influential in people's

daily lives, especially those living in rural areas (Padmawati et al, 2019). By being aware of the family's environment, resources can be accessed by Nurse F. Nurses' understanding of the cultural aspects relevant to a family, can be obtained from local interpreters, health care personnel from the same community, community leaders, and religious organisations (Kagawa-Singer and Blackhall, 2001). Resources can enhance nurses' understanding, which can be beneficial in addressing truth-telling issues.

During the assessment, nurses must also be aware of their own nonverbal communication (Wanko Keutchafo et al, 2020). Offering patient information may be one way of dealing with the situation (Kagawa-Singer and Blackhall, 2001). For example, Nurse F could reply to Mrs. A:

**'Some patients choose to hear about their current prognosis, while others wish that the physicians and nurses mostly communicate to their families first. Is there a way you'd like to get this information?'**

Nurse F could offer a hypothetical example. This approach considers the patient's and family's values in a way that allows for indirect dialogue, subtly prompts and encourages more inquiries (Kagawa-Singer and Blackhall, 2001). For example:

**'Others who suffer from the same condition as yours, have found that considering a variety of choices for care, such as taking opioids as a painkiller, has helped them maintain their quality of life.'**

## Discussion

Hospital and home care patients come from a wide range of ethnic and spiritual backgrounds, representing the diversity of Indonesia. A single truth-telling approach in all situations is no longer enough for healthcare institutions (Zolkefli, 2018). As a result, the idea that the best approach is to communicate openly and honestly during palliative care treatment in the context of the cultural complexity of Indonesia has generated considerable debate. A person's cultural and personal values will influence the importance they place on speaking the truth (Ilkic, 2020). The truth-telling challenge deserves awareness by palliative care nurses. By integrating the religious and cultural traditions of Indonesia into the healthcare assessment, truth-telling difficulties can be satisfactorily resolved.



## Conclusion

In this case study, the usefulness of the ABCDE assessment was useful in deciphering the culturally complex Indonesian setting. Nurses can use the ABCDE approach to obtain healthcare information as part of the palliative care plan. Truth-telling in palliative care settings must be anchored in the nurse's ability to adequately assess the attitude, beliefs, context, decision-making, and environment of the patient and family.

## Implications for practice

The patient's and family's views are considered the basic tenet of the truth-telling process in Indonesia. Palliative care nurses must acknowledge the importance of family in the patient's cultural context and involve them in all deliberations. As palliative care is a continuum of care, truth-telling is not a one-time event. The ABCDE assessment approach in revealing the truth can be applied by nurses not only in the diagnosis disclosure, but in the disease trajectory. Integrating every element can provide a truth-telling map for nurses in palliative care. Further study is recommended to comprehend and evaluate the ABCDE approach across the Indonesian archipelago and other cultural backgrounds. *IJPN*

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### CPD reflective questions

- Why are families an important part of a patient's care in Indonesia?
- Why is it difficult for healthcare professionals to tell patients the truth about their condition?
- How can palliative care professionals judge how much information to share with a patient?

### Key points

- An ABCDE assessment is useful to decipher the culturally complex Indonesian setting
- Truth-telling in palliative care settings must be anchored in the nurse's ability to adequately assess the attitude, beliefs, context, decision-making and environment of the patient and family
- Palliative care nurses must acknowledge the importance of family in the patient's cultural context and involve them in all deliberations

### Correspondence

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