SHOULD INFORMATION BE WITHHELD FROM A PATIENT?

CLINICAL CASE

Pedro, 77, has been living in a nursing home since suffering a stroke. The physical aftermath of the stroke has limited his mobility, requiring assistance with basic daily activities. Consequently, he was admitted to a residential center because his wife, with whom he lived, was unable to help him out of bed or assist with bathing on her own. He has strong family support; his wife visits him daily and spends the afternoon with him at the center, taking walks with him in a wheelchair.

In recent months, Pedro has experienced increased forgetfulness and episodes of disorientation. He has been diagnosed with "age-associated cognitive impairment, mild/early degenerative VS." Since this diagnosis, he has shown signs of low mood and increased dependence on his wife. He is notably more restless in the mornings when she is not present but becomes more cheerful, calm, and cooperative in the afternoons when she is with him.

A couple of weeks ago, Pedro's wife was admitted to the ICU for severe pneumonia, which ultimately led to her passing. Since her absence, Pedro has become much more nervous, and his routine has been disrupted. He now spends most afternoons alone and does not go outside the center, except on weekends when his two daughters, who live in another city, visit him. He barely socializes. The staff at the center have informed the daughters of his worsening mood and increased nervousness in the afternoons. Pedro repeatedly asks about his wife in a circular manner.

However, the daughters have instructed that Pedro should not be informed of his wife's death, as they believe it would cause him unnecessary suffering: "He has enough with his illness, not to add my mother's mourning to it. He would not get over it." Dr. Suárez, the physician at the center, is uncertain if withholding this information is truly benefiting Pedro. Should Dr. Suárez inform Pedro about his wife's death, or should she respect the daughters' decision?

ETHICAL ANALYSIS OF THE CASE

In this case, truthfulness and the right to information conflict with respect for the daughters' decision, who may be Pedro's guardians, as it is unclear if he is competent.

The clinical relationship is established primarily with the patient, but the immediate family is also involved and must be considered in certain situations, especially when patients lose cognitive abilities and are no longer competent to make decisions. In these cases, the family becomes part of the clinical relationship and must be integrated into the decision-making process. Regardless, although the family's input is important, the care team's primary commitment is to the patient's well-being and determining what is in the patient's best interest.

Sometimes, conflicts arise between relatives and the healthcare team due to disagreements about what each thinks is best for the patient. In this case, the discrepancy stems from the family's desire to protect Pedro from the pain of his wife's death, while the care team believes it is preferable to inform him so he can say goodbye and mourn. The daughters fear their father would suffer from the news, but the center's experience suggests that residents eventually accept the death of their family members and are able to move on. Furthermore, the lack of information seems to be causing Pedro increased agitation.

POSSIBLE COURSES OF ACTION

- Deceive Pedro by telling him his wife is in another residence each time he asks, in order to prevent him from suffering from the news
- Ask the daughters that if they are not going to tell him the truth, taking Pedro out of the center would be preferable, as they believe it is inappropriate to deprive him of this information.
- Have a meeting with the daughters to explain Pedro's worsening agitation and suffering by continually asking about his wife.
- Assess his cognitive ability to determine whether he will be able to comprehend and remember the news of his wife's death once he is told about it.
- If it is determined that he will be able to understand the news, explain that to the family, and assure them that once informed, he will be able to say goodbye to her and in time will come to accept it.
- Explain that Pedro has the right to receive information about his wife and that it is preferable for them to be the ones to give him the news.
- Regardless of whether you tell him the news, as he will probably still be agitated, prescribe an antipsychotic to keep him somewhat more sedated in the center.
- Inform Pedro of his wife's death in secret from the daughters.
- Notify the guardianship court to inform Pedro of the news against the daughters' wishes.

RECOMMENDED COURSES OF ACTION

- If possible, make a joint decision with the daughters. This requires a conversation between the daughters and the healthcare team, allowing both parties to express their arguments and points of view.
- In the conversation, explain to them the worsening of Pedro's agitation and suffering from continually asking about his wife. Also, inform them that Pedro, as a husband, has the right to receive information about his wife, and it would be preferable for them to be the ones to give him the news.
- If it is determined that Pedro can digest such news, explain to the daughters that once he is informed, he will be able to say goodbye to her and that he will surely end up accepting it. Moreover, it should be stated that her absence generates a clinical worsening, with important psychological suffering for Pedro.

- In case of continued refusal, continue working on the importance of truthfulness with the daughters.
- If the daughters refuse to give him the information and the cognitive assessment concludes that he would not be able to comprehend nor remember the news, respect the daughters' decision.

DISCUSSION

When caring for a patient with cognitive issues, it is important to involve the family, always seeking what is in the best interest of the patient. In cases where there is a disagreement between the family and the care team, deliberations should be opened where each party may express their wishes and explain their reasons. The care team should listen to the family without prejudice which will help them to better understand their motives. Usually, after opening such discussions a consensual decision can be reached, because, at the end of the day, everyone wants what's best for the patient. In exceptional cases, where a joint decision is unable to be reached and the care team believes a decision by proxy is not in the best interest of the patient, then the case should be referred to the courts, with the assumption that this action will likely break the clinical relationship and trust between the care team and family members.

Sgd.: ASISA-Lavinia Bioethics and Health Law Committee
27th of June, 2024