

SUPPLEMENTARY MATERIAL

Description of data: three situations of a case scenario involving a patient with advanced dementia

The first situation of the scenario of a patient with advanced dementia

Seven years ago, 85-year-old Si-young Lee (pseudonym) was diagnosed with dementia and moved to a nursing facility after living at home for 3 years. At the time of their admission, they had difficulty urinating and evacuating, and he/she frequently failed to recognize her children. He/She had difficulty walking, so they used a wheelchair, spent most of their life in bed, and required assistance with eating.

He/She was treated in the intensive care unit for 1 month for pneumonia during the previous winter. Since then, his/her strength has declined, and he/she has been immobile this year. A pressure ulcer developed on their buttocks, and he/she no longer identified their children and could not have meaningful dialogues with others. Even when they scooped up food, they did not consume it and instead spat it out; consequently, he/she frequently experienced choking. Due to the risk of aspiration, he/she was required to receive nutrition through a nasogastric tube after undergoing a swallowing function test at the hospital. Consequently, nutrition was administered through a nasogastric tube, but they had to repeatedly remove and reinsert the nasogastric tube.

The family was distressed whenever Si-young Lee was restrained forcibly, and a nasogastric tube was inserted.

The second situation of the scenario in the acute exacerbation stage

Si-young Lee went to the emergency ward for low blood pressure, loss of consciousness, and fever. Despite numerous emergency interventions, the patient's blood pressure and oxygen saturation decreased, prompting the doctor to recommend tracheal intubation and mechanical ventilation to save the patient's life.

The patient's family, however, refused artificial intubation and ventilator treatment, stating, "They have suffered enough, and we wish to send them off in comfort."

When Si-Young Lee was diagnosed with dementia, they repeatedly told her children, "If it's time for me to die without recognizing people, I don't want to die while causing suffering to those around me, so please let me live comfortably." He/She did not complete an advance directive regarding life-sustaining treatment.

The third situation of the scenario 3 months after the acute exacerbation stage

Si-young Lee underwent a tracheotomy and was transferred to a nursing hospital while dependent on a home ventilator, as determined by the medical team. He/She has lost their voice since being placed on a ventilator, rendering the communication impossible. The caregiver and the children had to take turns tying the patient's wrists and ensuring that the ventilator tube and nasogastric tube did not become dislodged whenever the patient moved. In addition, they frequently administered airway suction to remove sputum, altered the patient's position to prevent bedsores, and administered intranasal feeding through a nasogastric tube.

Three months have since passed. Si-young Lee spends a great deal of time sleeping, and when they are conscious, they spend most of the time staring into nothingness. If the ventilator is turned off at this juncture, Si-young Lee will die. On a ventilator, it is possible for them to remain alive, but it cannot prevent the progression of dementia.