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Case Report

A narrative study of unforgettable dying stories of Chinese patients in the intensive care unit: an eight-year experience

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Abstract: To describe individual perspectives and reflections on unforgettable stories about dying over an eight-year period, in a mixed surgical and general intensive care unit (ICU) in China. The study was carried out at the Second Affiliated Hospital of Soochow University. The research was based on personal experience and reflection. Narrative and experiential reflection synthesis were performed for the data analysis. This was done to understand the current situation regarding dying, then to identify and analyze, and finally to put forward some suggestions regarding the experience. The discussion and preparation for death in the ICU may still require further discussion. For a better acceptance of hospice care and high quality and dignity of death and even the donation of organs, it is important that health care providers learn to talk about death with their patients, and to encourage the patients to participate in the decision-making process.

Keywords: China, death, intensive care, end of life, narrative

Introduction

In the Chinese culture, the word death connotes a misfortune, although it is inevitable that all mankind experience death. Sometimes it is a taboo to talk about death even in front of the dying in the hospitals, because it may be deemed as a curse; instead, people are advised to offer a wish for an early recovery.

In China, there are no annual data on death in the intensive care unit (ICU); however, in the United States, one out of every five decedents is admitted to an ICU before death [1]. The quality of death is not a new research focus in the West and many studies show that the majority of family members are satisfied with the quality of end-of-life (EOL) care and quality of dying and death [2]. Although our government always emphasizes that the construction of a spiritual civilization is as important as the development of economy, the quality of EOL care in China may be inconsistent with the nation's remarkable achievements in economy, even among the lowest ranked individuals [3-6]. When entering the ICU, patients and their families are prone to fear and anxiety [7]. The quality of death in the ICUs has rarely been reported in Asian countries [8].

In our institution, many dying patients hospitalized in ICUs may be sent home urgently while taking their last breath, without any prior communication on death with the patient. In fact, most of such patients may be in coma during the last minute before death. With the spread of coronavirus disease 2019 (COVID-19) and the development of civilization, talk about death has become more open. However, it is still uncommon in the ICU to communicate with the patient about their impending death in China. Based on our traditional belief, they should be sent home because of the saying that "the leaves should go back to the root", which means, everyone should revert to their origin. Although several deaths have occurred in the ICU, the experience of some are really unforget-

table. Therefore, we aimed to reflect on the quality and dignity of death and hospice care and identify currently existing problems on death in ICUs in China.

In the Chinese culture, the body should be kept intact after death. This may explain why organ donation was seldom practiced in the past. However, the situation has now changed with the development of society, and many people have understood the importance of organ donation. Furthermore, to encourage organ donation, it is important is to talk about death firstly. On the other hand, the quality of life and quality of death concepts are being understood gradually by the public. Therefore, these unforgettable stories of death in the ICU may provide meaningful reflections. Moreover, the last journey of life in the ICU is not just a personal thing. Deaths in the ICU affects the family and even the whole society to some extent and may relate to policies on the medical insurance/euthanasia/distribution of medical resources, at the national level.

China has achieved remarkable economic success; however, our humanistic model of care may produce less success compared to the economic accomplishments. Recently, many doctors were killed in their workplaces and the killers were usually the patients' family members [9-13]. Medical violence is a serious problem. Therefore, we also aimed to identify solutions to address this.

Methods

Study setting

The study was carried out at the Second Affiliated Hospital of Soochow University. The hospital has over 2000 beds and more than 3000 medical staff. The hospital has been established for more than 30 years and in 2021, about 100,000 patients were admitted; moreover, we had the first organ donation last month (31 January 2022). The hospital's intensive care center has five ICUs. This study was carried out in one of these ICUs, a mixed surgical and general ICU, established in 2014, with 9 beds in the first 5 years and 10 beds afterwards. More than 500 patients are admitted here annually. Generally, patients are admitted after cardiac/gastrointestinal/macrovascular or orthopedic surgery at advanced age. The study was approved by the Ethics Committee of the Second Affiliated Hospital of Soochow University. The ethics review decision number is JD-HG-2023-06.

Ethical considerations: All the participants were assured that the data collected would only be reported in this study, and a written confidentiality agreement was provided. This study was approved by the ethics committee of the hospital, and the entire study process followed appropriate ethical principles.

Data sources: The stories come from the real experience of dying patients in our ICU. Patient data were obtained from communication and medical records. All patients were real existence. They came and died here left unforgettable stories about dying. We extracted data which gave us a lot of reflection to share in this article.

Unforgettable dying stories in the ICU

Story 1: "I am not afraid of death but afraid of lots of tubes in my body": A patient was admitted after stomach cancer surgery as usual, and the endotracheal intubation was removed two days later. We knew that this patient had graduated from Tsinghua University (top three in China) 50 years ago based on our discussion with him and had thought that he would be transferred to the general ward one week later. However, things did not go as planned. He experienced a second endotracheal intubation for deterioration of health and became silent after the extubation. He was still in the ICU one month later, but the doctors were not optimistic about his condition and had talked with his family on several occasions. His family asked us to cover up the truth for they did not want to discourage him. They told him that he would recover later and should just be patient.

One night, during my shift, the old man suddenly told me that he was not afraid of death but afraid of lots of tubes in his body and he knew that he would die soon, and that he wants to go home. I was surprised and encouraged him to communicate with his doctor and family. However, he failed to do so and when his family visited him, they advocated that he would recover later and he would be transferred to the general ward. Finally, this patient died in the ICU and never spoke about death with his fam-

ily during the stay in the ICU while he was conscious.

Story 2: "Please do not commit suicide because your wife needs you": He was a public servant in the local government, which is presently a well-coveted job in China, and had a tumor for 3 years. Before the admission, he had said goodbye to everyone including his family members, friends, and colleagues and had arranged his posthumous affairs beforehand. In other words, he was ready for death. Moreover, people around him except his wife were also ready.

The tumor was huge and compressed his airway; thus, he needed tracheotomy. Furthermore, because the tumor had metastasized into the lungs, he required ventilation. Thus, he was admitted in the ICU. His mind was alert, despite the presence of high-risk catheters, he was not restrained. One night, after about 5 months stay in the ICU, after hearing the ventilator alarm and quickly correcting the problem, we looked at the surveillance camera. Indeed, in our ICUs, every bed has a HD camera. To our surprise, it was not an accident, the patient had pulled out the ventilator line which had caused the alarm. He had tried to commit suicide. We told him that we understood that he had suffered enough and was ready, but his wife was not ready and that he should not commit suicide because his wife needed him. He nodded his head and finally died after 8 months in our ICU.

Story 3: "Do you remember your family"?: He was a homeless and was sent to hospital by the policeman at midnight. After the first surgery, he was awake and seemed well and his friend who was also homeless came to visit him. They were happy and talked a lot. Nobody paid their medical expenses. That was always the responsibility of the hospital.

"Do you remember your family"? We asked him several times, but he just smiled and never answered. We did not even know his real name. He talked to us but never provided the real information about himself. He died a day after the second surgery; the policeman failed to find his family and his body was stored in the mortuary at our hospital for half a year. With economic development, many people leave their hometown to live in the big city. They may hope someday to go back with wealth. This dream may come true; however, some may die in a foreign city.

Story 4: "Did he leave any word for me"?: He was a young boss and a father of two lovely children. He had had a dissection surgery in Shanghai 5 years ago, and this time, it was aortic aneurysm again. He came to the hospital due to pain and was immediately admitted to the ICU. Although he could have died at any time, no surgeon dared operate on him because his disease was very serious this time. On the second day, he communicated first with his family by WeChat application and later told the doctor that he felt better and wanted to sleep. Suddenly he was drowsy for about five minutes, then he was in coma and died less than 10 minutes later. His family grieved because of the bereavement.

Two days later, his wife came back for discharge procedures and asked whether her husband had left any word for her. However, his death was sudden, and without suffering. In talking we got to know that he liked socializing, did not take his medicines regularly, and because COVID-19 had exerted a toll, it caused their business to be sluggish.

Results

Reflections of the unforgettable dying stories

Case 1: talk about death: Studies showed that the word or feeling of death and dying changed over time and patients in ICUs are now more open to talk about death than with their family [14]. It is not useful to avoid discussing death because it is inevitable. We regret not having played the role of a communication bridge between the patient and his family as a nurse in story one; however, we also consider it best that we did not do that. The family visited him many times and he had the opportunity to talk about death to them but after his death his family said that he never did.

Today, medical violence is not new in China, and in this circumstance, for a nurse, it is better to talk less. It is true that we do not like to talk about death with our patients, but we are not alone in this. White et al. [15] reported that more than one-third of respondents rarely or never discuss EOL wishes with their patients in her study in two urban academic medical cen-

ters of USA. If the family asks that the doctor and nurse not tell the patient the truth, we will help to hide the fact that the patient may die soon even if the patient was conscious at that moment. On the other hand, some patients believe that they may die during ICU admission, even if their disease can be cured. Therefore, we really need to talk about death with the patient.

Case 2: we need a better place than the ICU for the dying: With the advances in medicine and economic development, the stay of many dying people may be prolonged in the ICU since such patients' lives can be sustained by medical equipment [16-18]. The patients then lie in bed 24 hours every day and may sometime be constrained. As nurses in the ICU, we encounter many dying patients whose last journey of life occurs here. It is not only the patients who feel bad but the nurses also suffer and are frustrated. It seemed that our job 'tortures them and fails to save them' and prolongs their life with low quality. Furthermore, medical resources appear to have been wasted. For these dying patients, we need a better place than the ICU where they can be comfortable and have family company outside of invasive medical operations, in order to spend their last time in peace.

Case 3: something more important than death: The patient in story 3 remained anonymous and he died alone in the hospital without any family member. Under the wave of economic development, many people leave their hometown to implement their "American dream" but hope to return after being successful, but some may die in foreign lands. We could not explain why the patient in story 3 was unwilling to identify himself. We talked about death with him when he was conscious; however, it seemed that he was ready for death and had no care about it. It is sad that he died alone, having lost the bond of family and relatives.

In our culture, our belief is that there is always something more important in the world than death. In English, we said nothing matters except life and death. In Chinese, we say "Let me but leave a loyal heart shining in the pages of history". A Chinese proverb says, "Though death befalls all men alike, it may be weightier than Mount Tai or lighter than a feather". Which means, no one can escape death, but the meaning of death can differ.

As a hospital in a developed area, we experience many terminally ill patients whose hometown is outside the city or province. Usually, their family would spend hugely on transportation to take the patient home for their last breath. We do not know why this anonymous patient refused to provide information about his family. However, one thing that was sure was that if we had contacted his family, they would have been asked to pay the medical expense. Maybe this patient thought there was something more important than a lonely death.

Case 4: preparation for death: Death may happen at any time. Some people may put the thought of death aside. However, sometimes, that fact death occur in the hospital may be unacceptable, even if it is reasonable. Medical violence may be perpetuated by the family or the patient may also take revenge. In Beijing, the son of a 95-year-old patient murdered his mother's doctor because he was not satisfied with the therapeutic effect in a hospital in 2019. The patient in story 4 must have been told many times about how close he was near to death, which was confirmed by his wife, but he still died without leaving any word, and with little awareness of the seriousness of the problem. His wife told us that he thought his disease was cured and had stopped taking his medicines for two years. It seemed that he had not prepared for death. Death education, an important aspect of nursing, involves a gradually growing concern [19, 20]. Death is inevitable, and the timing is uncertain, in my opinion, we need to prepare for death, to some extent, beforehand.

The fast-growing gross domestic product in China and technological developmental advances may make us feel prosperous, we can "fly in the sky and sail on the sea" and forget the truth that we are unable to live forever. Many patients' lives may be sustained painfully by advanced medical equipment in ICUs. To some extent, the quality of death is the embodiment of national civilization. The strong advocacy for scientific and technological development may mislead some people with extreme ideas that death occurring in hospitals is wrong and that the doctors should be blamed for that. Perhaps popular education about death may help us to prepare for death, which may improve the doctor-patient relationship to some extent.

Discussion

Strengths

The reflections reported in this study come from our real 8-year experience in the ICU in China, a country with a different culture about death compared to that of Western countries. The reflections express the understanding of the current situation firstly, attempted to identify and analyze the problems secondly, and suggested the way forward by providing some suggestions finally.

Limitations

We did not conduct a deep discussion about death with the patients or their family members. The refection mostly came from our experience of what we had seen. In the current medical environment, it is better for the nurse in ICU to talk less to avoid a contradiction based on a misunderstanding. However, the families we had contact with may be a microcosm of families of those in ICU in the general society, and our findings has practical significance.

Implications for nursing practice

As populations age, the chances of dying in ICUs has grown more. Euthanasia is illegal because of the ethical issues in China. Thus, the patients can only passively wait for death to arrive. Although the older generation may have heavy traditional ideas, studies [7] have shown that they are more open to discuss death than their descendants most of the time. The wisdom of age helps them to become increasingly philosophical about life. Regardless, it is still not that easy to discuss death with their families. When patients are likely to die in the coming hours or days, families often want prognostic information. Prognostic uncertainty and a lack of EOL communication training make these conversations challenging [21].

The correct understanding of death may start with life education, death education, and popularization of science. The Disney movie "COCO" that I watched previously had a good theme. We never know which comes first, tomorrow or accident. Almost all patients sign informed consent and power of attorney after entering the ICU the first time. Basically, all medical decisions are discussed and made by authorized persons. Sometimes, the patient may know nothing about their real situation because the authorized persons asked for concealment. Disconcertingly, some may be informed about the real situation but show distrust.

It is the medical staff who navigate the tension between autonomy and authority when engaging in life and death decision-making [22]. In contemporary Western health-care practice, it is generally accepted that parents will make or at least be involved in making EOL decisions (ELDs) for their children [23]. This is also true in this instance. Moreover, adult children may make decisions on behalf of their parents who are in ICUs. Traditional Chinese culture emphasizes the role of the family. Personal interests are generally secondary, and the affairs of family members are often determined by the family [24].

We believe that all patients and their family members should be helped to effectively establish death preparedness. Learning to face death and preparing for it can help us make reflections on building a better place for dying, so that the society may accept hospice better. Besides, there is always something more important.

As a nurse in the ICU, the experience of watching dying people struggling through invasive medical procedures in vain may make us feel hopeless. We are routinely exposed to pain, trauma, and the suffering we witness by nature of ongoing symptom management, which may make us feel compassion fatigue [25]. At the same time, unrealistic family expectations on behalf of the patient may be a source of nurse emotional distress.

Improving patients' quality of death, including enhancing their dignity, reducing their suffering and promoting acceptance of an impending death among family members may improve the emotional health of nurses [26]. The job of encouraging organ donations and giving back to the community may be more challenging and fulfilling and may also improve the emotional health of nurses to some extent. As some studies reported, a positive statistically significant correlation was found between the nurses' status of approaching emotions and subscales of Death Attitude Profile ($P<0.05$) [27].

In research, nurses reported that 40.9% of patients in ICUs suffer severely and 33.1% experience severe loss of dignity [28]. Another study indicated that the nurses' level of knowledge of law at the EOL would help patients receive adequate pain and symptom relief [29]. Moreover, we really need to improve our skill of communication and palliative care. A study proved that a 30-minute educational intervention improves internal medicine residents' self-reported comfort and preparation in talking about death and dying in the ICU [30].

However, the misperception of critical care and palliative care as sequential processes rather than complementary and simultaneous approaches, unrealistic expectations, and concerns that palliative care may hasten death, may lead to insufficient training in communication and palliative care skills [31]. As nurses, we do not have the ability to change the large environment, but we can improve our ability of death competence [32, 33]. At the same time, a study suggested that future research that targets unit-level variation in the successes of higher-performing units for achieving optimal care for patients who die in an ICU should be disseminated [1]. A study suggested that through graded diagnosis and referral systems in medical institutions, medical resources can be integrated and expanded to a range of hospice care services [24].

Conclusion

The discussion and preparation for death in the ICUs may still be insufficient in China. We really need to talk about death with the patient. Furthermore, if we want better acceptance of hospice care and organ donation and high quality and dignity of death, the first step is to learn to talk about death with the patient. Also, if we want to better establish a doctor-patient trust and doctor authority, we may need to eliminate concealment and deception and avoid asking the doctor to 'cheat' by giving the patient the excuse that it is "for your good". Some people may die alone in a foreign land despite the economic development; this requires further attention.

Nobody can escape death and we need to face it bravely. It is common that several patients may die in ICUs and they need to be encouraged to talk about it and prepare for it. For a good quality of death, the dying need a better place than an ICU.

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Disclosure of conflict of interest

None.

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