

## When Hanging on at All Costs is the Only Option

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### Article abstract

Having hope that a terminally ill patient may recover is not an unfamiliar sight in intensive care units across the globe. However, cultural heritage may make it even tougher. This fictional case study, which is a collection of years of experience, addresses decision-making within the Chinese Immigrant culture and focusses on how this may influence the care team. A new initiative, the Goals of Care (GOC) team, is also described.

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ÉTUDE DE CAS / CASE STUDY

## When Hanging on at All Costs is the Only Option

Laura Walther-Broussard<sup>a</sup>, Tiffany Meyer<sup>a</sup>, Nico Nortjé<sup>b,c,d</sup>

### Résumé

Avoir l'espoir qu'un patient en phase terminale puisse se rétablir n'est pas un spectacle inhabituel dans les unités de soins intensifs du monde entier. Cependant, l'héritage culturel peut rendre la tâche encore plus difficile. Cette étude de cas fictive, qui est un recueil d'années d'expérience, traite de la prise de décision dans la culture des immigrants chinois et se concentre sur la façon dont cela peut influencer l'équipe de soins. Une nouvelle initiative, l'équipe Goals of Care (GOC), est également décrite.

### Mots-clés

immigrés chinois, prise de décision, objectifs des soins

### Abstract

Having hope that a terminally ill patient may recover is not an unfamiliar sight in intensive care units across the globe. However, cultural heritage may make it even tougher. This fictional case study, which is a collection of years of experience, addresses decision-making within the Chinese Immigrant culture and focusses on how this may influence the care team. A new initiative, the Goals of Care (GOC) team, is also described.

### Keywords

Chinese Immigrants, decision-making, Goals of Care

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*"People don't want to hear the truth because they don't want their illusions destroyed."*

Frederick Nietzsche

## INTRODUCTION

Critical care providers are familiar with helping families navigate the difficult reality of a loved one's terminal illness. Encountering a family that will "not let go" occurs with a fair amount of regularity in all hospital settings. However, this is especially true now in the era of COVID where visitation of the patient is, more often than not, restricted. Allowing for a family member at the bedside in an Intensive Care Unit (ICU) serves many functions. It can bring emotional and physical comfort to the sick, communicate the loved one's wishes to the medical team, provide updates to other members of the family, and begin the family member's own anticipatory grief journey. Seeing is believing. But what if this is not true in all cases?

One such example is the following fictional case study of the Li family, which is based on the collective experiences of the authors over many years.

## CASE STUDY

Mr. Li was an elderly man in his late 80's. He met his spouse while living in China and they immigrated to America in search of a better life. Mr. Li and his spouse were married for fifty-six years. Sadly, he would experience his last wedding anniversary as an inpatient in the ICU.

Mr. and Mrs. Li have three grown and successful children, a son and two daughters, who live at opposite ends of the country. They are a traditional, close-knit Chinese family. When Mr. Li was diagnosed with an aggressive lymphoma blood cancer, the family unanimously decided to take him to another center for a second opinion as their local oncologist had suggested that given their father's advanced age and comorbidities, he would be best served by hospice care to promote quality of life and time spent with his loved ones.

When he was transferred, Mr. Li was beginning to be less active yet he still walked into the building without assistance. After a week of diagnostic testing, the Lymphoma team met with the Li family to offer their treatment plan recommendations. The team informed them that the chance of Mr. Li receiving treatment was nominal at best due to his age, advanced cancer, and other health concerns. This was difficult information for the Li family to hear, yet their sense of hope was bolstered at the slight chance that Mr. Li might receive therapy instead of the hospice referral they had already received. The family decided to proceed with the risky treatment plan despite advice from the Lymphoma team to focus on quality vs quantity of life. Unfortunately, Mr. Li grew gravely ill before he could begin his first round of treatment. He grew weaker and was taken to the Emergency Center by his family. Soon after, he was transferred to the ICU as he was growing increasingly more hemodynamically unstable. He would remain in the ICU for almost 2 months until his death.

Time spent by patients in the ICU is often precarious and touch-and-go. At one point early into his hospital stay, multiple medical teams (ICU, Lymphoma, and Supportive Care) met with Mrs. Li to recommend that her husband be made DNR (Do Not Resuscitate) and transitioned to end-of-life care. The family reluctantly agreed. Later that day, Mrs. Li and their son, Mike, were by Mr. Li's side as they were granted compassionate allowance to be present for his death.

Mr. Li, although gravely ill, seemed to have other ideas about the timeline of his death. He made small improvements the next day to the degree that his family reversed his DNR code status and withdrew comfort care orders. His family stated that although he could not communicate, Mr. Li was making progress and this was proof that he was not ready to "give up". The family shared their unrealistic hope that their octogenarian patriarch would get well enough to receive chemo and return home to them. The medical teams knew this was very unlikely but wanted to continue to support the Li family, especially Mike, who was unwavering in his conviction that his father would improve. Mike spent hours in long conversations with the medical team and focused on changes in all of Mr. Li's failing systems.

As is common in Chinese culture, the patient's oldest son was identified as the spokesperson for his family and Mrs. Li deferred medical discussions and decisions to her son. In Confucian teaching, men (grandfather, father, or eldest son) have absolute authority and are the primary decision makers (1). Among traditional Chinese American families, the eldest son most commonly serves as the spokesperson for the family (2). The eldest son holds the power to screen medical information, disclose terminal illnesses, and make final treatment decisions for his dying parents. On the other hand, wives, daughters, or daughters-in-law usually do not assume the role of medical decision makers, although they generally provide the physical care (2).

Taking direction from the son in this case, despite Mrs. Li still being recognized as the legal medical power of attorney, is an example of respecting cultural norms and values. Patients are not void of their heritage, healthcare providers have an obligation to be respectful of their customs, in as much as is allowed by the legal frameworks in force.

Despite frequent reinforcement by the medical teams that Mr. Li's frail condition and grave prognosis made him no longer a candidate to receive first line chemotherapy, the family adamantly stated their wish for Full Code with the hopes that Mr. Li would make enough improvements to receive treatment. After a week in the hospital with no change in Mr. Li's condition, it was time to enlist the help of the Goals of Care (GOC) team.

## **GOALS OF CARE TEAM**

The purpose of the GOC team, which is unique in this format in the USA, is to meet with a patient (if they are able to participate) and their family to offer support while delivering news the family may not want to hear or be ready to accept. This resource is an initiative to assist the physicians in navigating complex cases. Members of the GOC team include a Palliative Care physician, social worker, and clinical ethicist. Focusing on more than just the medical information, the aim of the GOC team is to try and decrease stress levels of families and let the attending physicians not bear the brunt of anger/aggression. The GOC team is there to "soften the blow", especially if a patient is acutely decompensating.

Another function of GOC meetings is to help all providers be on the same page with their recommendations. Complicating matters in this case was that prior to the GOC meeting, a member of the medical team offered Mr. Li's family treatment if he were able to improve enough to leave the ICU. The Li family desperately clung to this statement and seemed incapable of accepting the patient's decline.

Over time, the GOC team held at least eight different hour+ long family meetings with the Li family, conducted via Zoom due to COVID visitor restrictions. During this time, the Social Work Counselors worked closely with Mike and Mr. Li's spouse to help coordinate the meetings with them and the medical team. Multiple attempts were made by the GOC team to build rapport, explore the family's concerns, reservations, hopes, and wishes, while offering emotional support. Each attempt to join with the Li family was met with a polite decline.

Given the fact that during this COVID pandemic most healthcare institutions have a visitor restrictions in place, the outcome was that the family was not able to be at bedside for a few weeks. The GOC team was of the opinion that assisting the family to get access to see the patient might be beneficial in their decision-making. The Social Work Counselor was able to seek an exception to COVID visitation restrictions and an allowance was given to the patient's son to be at his father's side for 4 hours, while also participating in another GOC meeting.

When Mike first saw his father, he gasped and said, "Wow, he is really suffering". Yet, the outcome at that days' GOC meeting remained status quo. Mr. Li was still Full Code and the family continued to focus on small improvements in his vital signs, rather than seeing the big picture of multi-organ failure and general decline in his vitals. The concept of making life-sustaining treatment decisions in advance is not generally promoted in Chinese countries such as China, Taiwan, and Hong Kong (3,4). Consequently, Chinese immigrants are frequently unprepared to make these decisions at the end of life, which according to Hsiung and Ferrans (2) has resulted in additional distress and prolonged suffering, hindering appropriate care.

Eventually, Mr. Li declined further and died in the ICU despite remaining Full Code and not embarking on comfort care to the end of life. The institution's visitation policy dictates that patients can be granted compassionate visitation when they are actively dying. To this end, two of Mr. Li's family members were able to make it in time to be by his side for his last breaths.

It is common for medical team members to experience moral distress when they see their patients “needlessly” suffering. As medical providers, it can be difficult to remember that the person the family “sees” is the person they have known their entire lives. More often than not, this is the case when an advanced cancer causes a rapid decline in a short amount of time making it extremely difficult for families to process, reconcile, and accept this new reality. Although the medical team can initiate legal recourse to review the case, when families are demanding care provision that is not aligned with the medical team’s opinion, it often negatively affects the physician-patient-family relationship, and so should be a last resort. What was helpful in Mr. Li’s case is that there was shared responsibility of moral distress by various members of the teams, including those trained in psychosocial sciences, to not only support the family, but also the other team members.

After Goals of Care meetings, it is encouraged that the team members stay behind and debrief to share their frustrations and support each other. This is also an important opportunity to reflect on what worked/did not work and coach less experienced members of the team. The implementation of this approach has greatly reduced the moral distress within the ICU where the authors work.

## DISCUSSION QUESTIONS

- Do you think visitor restriction creates delays in processing of an acceptance for family members of their loved one’s critical condition?
- Are there similarities between other cultural views on doing everything until the end?
- What mechanisms exist in your local healthcare system to assist in goals of care conversations?
- How can one lower moral distress among the care team?

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