

CHAPTER 17



Supportive Relationships

Caring for Our Loved Ones in Chinese Culture

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The following stories reflect experiences of the first author, who is an exchange student from Zhejiang Province, China.

STORY I: LEAVING A LOVED ONE BEHIND

My best friend, Huang, died of acute myeloid leukemia. Today is the 468th day since she passed away.

When I first met her 5 years ago in Jingcai Junior High School, I felt an immediate connection. Talking to her was always a delight. She was smart and full of life, with a genuine curiosity and optimism of what tomorrow may bring. Huang's most endearing qualities were her willingness to help others unconditionally and to look out for those in need.

Fate strikes when you least expect it. Huang suffered a terrible and persistent fever 10 days before the College Entrance Examination. While she was frustrated with her sudden illness, no one expected anything devastating. However, she soon began to experience vomiting, oral ulcers, and bleeding gums. After a series of diagnostic tests, the attending physician and her health care team found that she had an excessive amount of white blood cells, an indication of acute myeloid leukemia.

When I got the news, I rushed to the hospital. I was heartbroken and overwhelmed. She did not look like herself. Her face was swollen and pale. Her eyes were haunted with despair. She looked so fragile in bed. After consulting with Huang's parents and our school, we decided to hold a fundraiser. We were deeply touched by the outpouring of support from our community. Many also volunteered to donate blood for Huang.

I will never forget Huang's boyfriend, Kai, who looked so affectionate and yet deeply troubled. He recognized the seriousness of her illness and the heavy burden of caregiving. Kai was quiet and withdrawn. He refused to donate blood, which surprised many of our close friends. The vast majority of our classmates and teachers had donated blood and money for Huang. Why did he refuse to "give" when everyone else was doing everything they could? Because I knew that he loved Huang, it was startling to me that he would refuse to do what so many others had done for her.

One day, on our way to visit Huang, Kai stopped me before we reached the medical ward.

"Tell her I will never be back," he said as he anxiously wrung his hands.

"What do you mean?" I frowned.

"Hmm . . . well, eh . . . I- I cannot . . ." Kai struggled to find words, "Tell her, 'Forget that we were ever together, I do not love her anymore.'"

I looked at him, bursting into tears. "How can you even say that? How can you choose to leave her when she needs you the most?"

Kai said nothing. He just walked away and did not even look back, ever. I was in complete shock. Nevertheless, I gathered myself and put on a smile before walking into Huang's room. With mannered optimism, I assured Huang that Kai would visit her later. After a few days, Huang received a text message from Kai informing her that they were no longer a couple.

"It shattered my heart and destroyed my spirit," said Huang, with tears swelling in her eyes.

I hugged her as tightly as I could, patting her back gently. She trembled and clung to me like a child, as if it was the only way to feel safe and loved.

Huang's family later transferred her to a hospital that specializes in leukemia treatment in Beijing, a city almost 1,000 miles away from our town. After a few sessions of chemotherapy, Huang developed drug resistance. The treatment also made her nauseous and she fainted often. "Damn it, I miss him so much!" This is the last text message I received from Huang.

Huang fought valiantly for her life for more than a year. In the end, she passed away during an episode of a severe rejection after a bone marrow transplant. In her last moment, she still called out for Kai, waiting for his return.

To this day, I cannot say that I understand why Kai chose to break up with Huang at the most difficult moment in her life. I felt that he should have stayed. But looking back, I knew he carried a heavy burden that I could not have fully understood. Maybe caring for Huang was so taxing and demanding that he could no longer bear it.

My time in the United States makes me think that Kai's experience and struggles are probably more universal than I first realized. After learning about this story, an American friend told me that she was once engaged, but her fiancé's parents begged her to break off her engagement after her fiancé sustained a severe brain trauma in a car accident. "You have a whole life ahead of you. We love you too much to let you take on this burden," they told her. My friend's tears never stopped as she shared her story. We all want to do the best for our loved ones.

However, when we cannot change a regretful situation such as a health crisis, when the burden of caring for our loved ones becomes unrelenting and overwhelming, we may feel that we have failed others and even ourselves. Maybe the pressure of doing what he thought a “good” boyfriend should do was just too overwhelming and unfair to Kai, a kid who was barely 18.

STORY II: DO YOU REALLY CARE ABOUT ME?

My Uncle Jie is more than 60 years old. He has a tough life, which is evident from his shaggy silver hair, wrinkled face, and darkened skin. He has always said that his love for his kids pushes him to work as hard as he can. His decades of hard work have built him a great fortune. However, he was recently diagnosed with lung cancer, a condition made worse by his status as a lifelong smoker and the poor air quality in China.

Jie’s family became distraught when he was first diagnosed. Ling and Matt, Jie’s daughter and son, were already married, building their own families and working hard to raise their children. They were not sure how they could best take care of their father and manage the situation. Nevertheless, they were determined to work together to ensure that their father had a smooth recovery.

Because Jie’s cancer is at an advanced stage, the treatment regimen is complicated and has presented many challenges. Dr. Lee, a surgical oncologist, ordered multiple scans and tests to identify the location and size of the tumor. Jie and his family were told that the lump in his lung was probably benign. Nevertheless, chemotherapy was needed to destroy abnormal cells. During the first round of chemotherapy, every family member was confident that Jie would beat the cancer. The whole family was ready to band together and do whatever was needed. With Jie’s medical insurance, 80% of the medical expenses were covered (except for the cost of imported drugs). However, the invasive treatment took a toll on Jie’s health. He was unable to exercise and move around as he used to, which further worsened his health. Soon, he needed constant care.

In the months following the treatment, Ling and Matt had several somber talks (and sometimes intense fights) about their proper share of inheritance and their responsibilities for Jie. At first, they fought with each other behind Jie’s back. Later, they argued in front of him. On several occasions, Jie became so angry that he passed out. Dr. Lee warned the family that their behaviors might compromise Jie’s health, so they should be calm and give their father some peace and quiet. Nevertheless, the family feud never stopped. Jie often cried in bed at night. He felt alone, even though he lived with his children.

To understand Jie’s experience, one must first learn about the parent-child relationship in Chinese culture. In the United States, children are expected to be independent and self-sufficient when they turn 18 or finish college, and their parents are expected to save for their own retirement and mostly pay for their own living and medical expenses, including accommodations in assisted living facilities. However, in China, parents offer care and financial support to their children well into their adult lives, often purchasing their first home, helping to raise their

grandchildren, and cooking meals for them. In return, when the parents become old and sick, it is often expected that a child (or a daughter-in-law) will quit his or her job to take care of the parents as a full-time caregiver. The child's home essentially becomes an assisted-living care facility, with him or her as the care staff. This means that the ill parent's funds (e.g., financial savings and properties) are expected to be given to the child (or children) as substitute income or at least as future inheritance.

Knowing this, I realize that the fights between Ling and Matt are about much more than money. Their discussions about their inheritance and their responsibilities and obligations to care for their father reflect their potentially disproportionate burden of that care. While it is easy to think that it is distasteful for children to fight over inheritance, Ling's and Matt's struggles to support their own families while managing lost income (and career opportunities) due to caring for Jie are not easy. I know that Ling and Matt are fighting for their own families too.

I always thought that people age gradually. However, I saw Jie age in a flash. He was discouraged and worried that he would never recover and that he would never have another trip with his old buddies, or have a normal, independent life again. It is still a long road for Jie to be cancer-free. He is currently undergoing radiation treatment. The journey will affect him and his family members in powerful ways.

RELEVANT CONCEPTS

Burden of care	Collectivistic cultures	Shared decision making
Caregiving	Individualistic cultures	Social network
Collaborative coping	Relationship maintenance	

DISCUSSION QUESTIONS

- Sometimes, we are tempted to distance ourselves from an ill loved one for the sake of our own survival and sanity.
 - In cultures to which you belong, how are people expected to behave when a friend becomes seriously ill? When a family member needs extensive care?
 - Is it considered selfish to walk away or to expect something in return?
- Management of health and illness is often a collaborative, coordinated activity between the patient and his or her support network.
 - How can a person's support network help a patient cope with a health crisis? What are some examples from the stories shared here?
 - What have you done to help a friend or family member to cope with a health crisis?
 - Do you think there are times when a patient chooses not to share illness information with his or her support network? Why? What are the benefits? Are there any negative consequences?
 - What are the benefits of sharing illness information with loved ones? Are there any negative consequences?

- In your experience, do a patient's friends sometimes respond differently than family members do in terms of emotional response, favors, and coping assistance? Explain and reflect on how the following factors may shape such differences: types of illness, relational closeness, cultural norms, and available resources.
3. Do you think people from collectivistic and individualistic cultures have different expectations and obligations about supporting loved ones during health crises? If so, what might those differences be and why?