A Lonely Farewell

I. Introduction

I sanitized my hands and walked into a stuffily warm room with only one bed in it to discover a frail elderly woman named Joan with gray hair and a dark yellow complexion, making me suspect jaundice. A stuffed cat sat on her chest as she laid in bed. I introduced myself and pulled up a chair to sit beside her. Going into the room, I had not known what to expect. While I had seen many other patients before, I had never sat down with a patient who was dying. The volunteer coordinator had asked me to make Joan as happy as possible. Trying to follow my coordinator's directions, I asked Joan about her stuffed animal.

"Maxine is her name." Joan smiled as she told me more about her new stuffed pet that had replaced her cats that she was not allowed to bring with her to the hospital. We talked about her two cats, Gus and Max, and how she lived alone with both of them. Slowly, I gleaned her life story. Born into a dysfunctional family with an abusive and cold father, she escaped when she was young. She went on to marry and had two sons, but her husband was also prone to violence, leading her to leave him and raise her two children alone. Her two sons had now moved across the country and had not visited her in many years. As we approached the end of her story, she looked up to me and I will never forget what she asked me.

"I've never told anyone all of this, I don't know why I told you all of this. Why are you doing this, why did you listen to me?"

For a moment, I was speechless; I did not know how to respond to her. Perhaps it was because I felt it would be impolite to leave halfway through her story with an excuse that I had to see other patients. Perhaps it was because she reminded me so much of my own grandmother.

Perhaps it was because I was trying to empathize with her and understand what dying was like. She was just so alone. Joan knew that she was going to die in the coming days and all she had was her stuffed cat and a quiet college boy listening to her story.

The solitude of the experience stuck with me. There was no one to accompany her in her final moments and journey. As someone who is interested in medicine, I had hoped that being a physician would allow me to accompany people at their most vulnerable moments. I had always pictured my own final moments to be shared with my loved ones, feeling some semblance of comfort before passing into the unknown, but this experience changed how I thought about dying. No matter what occurs during my life, whom I meet or what connections I make, death will be something that I experience alone.

Quarantined at home this past spring, my parents and I watched the 2019 film, *The Farewell,* written and directed by Lulu Wang. The film is based upon the director's own real-life experience and is centered on a Chinese American family going back to China to see their terminally ill grandmother, Nai Nai, who does not know she is dying. The family hides the truth from the grandmother, because they believe it is best if she does not know her own diagnosis. Watching the film, I was delighted to discover a piece of myself in the protagonist, Billi, a Chinese American in her twenties who immigrated with her family to the United States when she was still a child. I found myself in Billi's shoes, as a Westerner trying to understand the main conflict in the film: whether to tell Nai Nai that she had terminal lung cancer.

Like Billi, my gut reaction was that there was a moral responsibility for the physician and family to tell Nai Nai the truth about her diagnosis. Not only did it seem unethical to lie to the

grandmother, but she also had a right to know about her own health so that she could play a role in determining her care. The act of lying to Nai Nai about her condition violated Western informed consent laws and more importantly, our respect for patient autonomy. When confronted by Billi, the family justifies their decision, arguing that telling Nai Nai of her medical condition would only cause fear and more suffering. A physician in the film even tells Billi that it is common for families in China to choose not to inform one of their members about their illness if they believe that is what is best. Where does this divide between East and West come from over patient autonomy and end-of-life decision-making? How would I approach this situation myself if I were a physician? Why did Joan's experience seem so much lonelier than Nai Nai's experience?

II. Western Individual Autonomy

Western medical ethics is founded on four fundamental ideas, as expounded upon by biomedical ethicists Thomas Beauchamp and James Childress, of beneficence, non-malfeasance, and justice with a heavy emphasis on respect for individual autonomy.[1] Our basis of individual autonomy is supported by terms of self-determination, independency, self-interest, and self-reliance grounded in Western and Christian roots.[2] This forms our definition of autonomy to be a sufficient and rational individual who, free from external influence, makes self-intended decisions.

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[1] Saad, T. (2017). The history of autonomy in medicine from antiquity to principlism. *Medicine, Health Care and Philosophy, 21*, 125-137. doi:10.1007/s11019-017-9781-2

[2] Gomez-Virseda, C., Maeseneer, Y., & Gastmans, C. (2019). Relational autonomy: What does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Medical Ethics, 20*(76)

The extent of individual autonomy and self-determination is exemplified in the United States Supreme Court case, *Cruzan v. Director, Missouri Department of Health.*[3] In this case, Nancy Beth Cruzan was reliant on life support following an automobile accident. Her parents sought to remove her from life support citing her having no chance of recovering. In its decision, the Supreme Court recognized that without clear and convincing evidence, Cruzan's life support could not be removed by her parents' request:

> We do not think the Due Process Clause requires the State to repose judgment on these matters with anyone but the patient herself…there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent.[4]

The United States Supreme Court's ruling reaffirmed the right to refuse medical treatment as protected by the Due Process Clause, but it also noted that this right to refuse medical treatment does not apply to family members making the decision for an incapacitated patient. This case shows how the ideas of self-determination separate the family and the individual in the decision-making process.

Separation of family and individual leaves less room for the family of patients to play a role in deciding the course of treatment. For example, once while shadowing a geriatrician, Dr. M, I observed an older woman come in for a routine checkup accompanied by her daughter. The daughter brought up her mother's lack of ability to continue living on her own and worried that her mother would injure herself in her daily living. Already stressed with her and her own child's medical issues, the daughter wanted the mother to either move in with another family member or to an assisted living facility. The older woman refused to be moved out of her house, however,

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[3] Cruzan v Director, Missouri Department of Health, 497, U.S. 261 (1990)
[4] Cruzan, 286

desiring independence. Dr. M, unsure how to navigate this difficult social situation, focused on merely treating the patient's symptoms and shied away from taking part in the conversation surrounding the mother's living situation. I was distraught over the situation, wishing that Dr. M would help unravel some of their social issues rather than focusing only on the clinical. I empathized with the older mother for wanting to remain in her own house and have independence, but I could not help but side with the daughter, believing that it was self-centered for the mother to not see the stress and pain she was causing her loved ones.

This is in stark contrast to the situation in *The Farewell,* where Nai Nai's care is decided upon by the family and physician in accordance with what was believed to be the best for the whole family. Like Billi and most other people who grew up in the West, my first instinct was to brand the family's deceit and action without the approval of the grandmother as paternalistic and a violation of the grandmother's autonomy. However, I now recognize that their actions were not only justified within the context of Chinese philosophical and cultural thoughts, but also elucidate some of the deficiencies created by Western ideas of individual autonomy and self-determination.

III. Chinese Views on Autonomy and Ethics

Compared to Western societies where death is viewed as being experienced by the individual, Chinese societies view death from the perspective of the family, where the family is the central unit of existence.[5] Chinese understanding of the importance of family and society is

[5] Lee, S. (2009). East Asian Attitudes toward Death— A search for the ways to help East Asian elderly dying in contemporary America. *The Permanente Journal, 13*(3), 55-60. doi:10.7812/tpp/08-068

founded in its respect for filial piety, also known as *xiao.*[6] *Xiao's* Chinese character, 孝, is comprised of two ideograms that illustrate a "father" over a "son". Filial piety implies a continuity between generations from parents to descendants as well as a respect for elders and parents. It is a fundamental moral principle within Chinese culture, shaping parent-child relationships, family dynamics, and interdependency among members. Community and family play a large role in decisions where they may act as aides, interpreters, and advisors. Autonomy does not solely belong to an individual; the individual is a part of a larger-self where familial autonomy trumps individual autonomy.[7]

An example of filial piety within Chinese culture is the mourning of deceased family members and ancestors. Whenever I would travel back to China, one of the defining features of every trip was a visit to the graves of our passed relatives and ancestors (*sao mu*). *Sao mu* translates to the sweeping of the tomb, a ritual used to express and promote people's feelings of filial piety, convey respect for our ancestors, and to reunite the family.[8] Accompanied by many distant relatives, we would clean the tomb, lay out many different foods and snacks, stick incense in the pots that had been placed around the tombs, and burn fake money and clothes in the hope that they will be used by those who have passed on. Afterwards, the family would gather for a large meal together, joking and enjoying each other's company as it was a rare occurrence for so many of the family to be together in one place.

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[6] Canda, E. (2013). Filial piety and care for elders: A contested Confucian virtue reexamined. *Journal of Ethnic & Cultural Diversity in Social Work, 22*, 213-234.
[7] Min, M. (2017). Beyond a Western Bioethics in Asia and its implication on autonomy. *The New Bioethics, 23*, 154-164.
[8] Chen, B. (2012). Coping with death and loss: Confucian perspectives and the use of rituals. *Pastoral Psychology, 61*, 1037-1049. doi:10.1007/s11089-012-0476-6

In *The Farewell*, the diagnosis of Billi's grandmother with lung cancer brings together the family like the process of *sao mu*. As an expression of their family unity and *xiao*, the family returns from foreign countries to gather together to spend time with Nai Nai. This aligns with their decision to not tell Nai Nai of her illness. It is the belief that what she is going through is not something she must face alone, but rather a family experience. To Chinese, Nai Nai's life and illness affect all those around her. However, the communal experience brought by filial piety was not something that Joan was able to experience. Left alone in the hospital, her sons had not been at her death bed, sharing their own mother's final moments.

IV. Balancing the Individual and Relational

In criticism of Western individualistic autonomy, scholars argue that the individualistic understanding of autonomy is insufficient as people are rarely, if ever, fully independent individuals.[9] Gomez-Virseda highlights several shortcomings of individualistic autonomy within end-of-life care. This includes the misconception of the individual self, since end-of-life care is a relational process rather than an individual one. Many families play a central role and patients often consider their families when choosing to enter hospice care.[10] There is also a failure to accurately portray the decision-making process, as models of individual autonomy depict a calm and rational individual, when in reality patients may have fluctuating cognitive states charged with emotion. The final failure noted by Gomez-Virseda is in the lack of incorporating a social reality where the decision-making process is made in consultations with and in consideration of

[9] Dove, E., Kelly, S., & Lucivero, F. (2017). Beyond individualism: Is there a place for relational autonomy in clinical practice and research? *Clinical Ethics, 12*(3), 150-165.
[10] Broom, A., & Kirby, E. (2012). The end of life and the family: Hospice patients' views on dying as relational. *Sociology of Health and Illness, 35*(4), 499-513. doi:10.1111/j.1467-9566.2012.01497.x

others, including the family and the physician. Fully realized individual autonomy would distance the physician and family from the decision-making process when in reality they both play a large role in the patient's final decision.

These factors make a convincing case against complete individual autonomy and its inability to allow the patients to consider others in their thought process. A more realistic and better paradigm for medical decision-making proposed by Gomez-Virseda is relational autonomy, which is founded on the idea that people are socially embedded, with their identities shaped in relation to social determinants surrounding them, such as gender, race, class, and ethnicity. With this model, autonomy is not mutually exclusive from thinking of others, recognizing that decisions of individuals are made in conjunction with others.[11] Therefore, relational autonomy allows for a shared decision-making process where patients, relatives, and healthcare professionals act as partners.

The Chinese view of autonomy and end-of-life decision-making most approaches relational autonomy due to their belief in filial piety. In *The Farewell*, when Billi continues to express guilt over hiding the terminal diagnosis from their grandmother, Billi's uncle responds:

> You think one's life belongs to oneself. But that's the difference between the East and West. In the East, a person's life is part of a whole. Family. Society. You want to tell Nai Nai the truth because you're afraid to take responsibility for her. Because it's too big of a burden. If you tell her then you don't have to feel guilty. We're not telling Nai Nai because it's our duty to carry this emotional burden for her.

His response highlights the difference between Billi's two cultures and identities. Billi's desire to tell Nai Nai about her condition is based upon the Western ethical views she has regarding respect for autonomy. She sees Nai Nai as an individual who has a right to know about her

[11] Walter, J., & Ross, L. (2014). Relational autonomy: Moving beyond the limits of isolated individualism. *Pediatrics, 133*(1) doi:https://doi.org/10.1542/peds.2013-3608D

diagnosis and to determine the course of her medical care. Billi's uncle, however, echoes ideas of relational autonomy noting that one's life is not independent and is rather a part of a larger network which includes family and society.

Chinese similarities to relational autonomy are reflected in their patient-physician relationship. One summer, in my family's hometown of Guangzhou, I shadowed physicians in the local hospital. On one of the final days, an attending physician pulled me aside and asked me if I knew the differences between the medicine practiced in the United States and the medicine I had just observed. He explained to me that the patient-physician relationship in the East was very different to what I may see at home. Doctors in China take into account many factors when determining their next steps of care. He explained that, of course, they consider the diagnosis and the prognosis, but they also had to take into account the family's economic and social circumstances, something that their American counterparts did not usually need to consider.

The extension of filial piety, a duty to consider the family's resources and the interdependency among generations, directly impacts the Chinese patient-physician relationship. The physician is charged with taking care of both the individual patient and the family unit as a whole, considering the circumstances that surround their values and relationships. In China, the doctor-patient relationship model actually becomes the doctor-family-patient relationship. The family plays a large role in decision-making, signing informed consent forms and patients who were interviewed agreed that it was in their best interest for their family members to play an increased part in their care.[12] This resembles relational autonomy and the differences that it leads to in the patient-physician relationship. The cultural and philosophical differences in China have

[12] Cong, Y. (2004). Doctor-family-patient relationship: The Chinese paradigm of informed consent. *Journal of Medicine and Philosophy, 29*(2), 149-178. doi:10.1076/jmep.29.2.149.31506

led to a more involved role for both the physician and family in determining an individual patient's care.

In contrast, the Western patient-physician relationship leaves less room for the input of the physician due to dedication to individual autonomy. In Dr. Atul Gawande's *Being Mortal*, he highlights the shortcomings of both the paternalistic and informative patient-physician relationship. In the paternalistic model, the physician acts as a patient's guardian and determines the best course of treatment for the patient. In the informative model, the physician provides the patient with all relevant information and allows the patient to select the medical intervention they want. In this model, patients have complete autonomy, and the ball is entirely in their court, "In truth, neither type (the paternalistic and informative model) is quite what people desire. We want information and control, but we also want guidance."[13] Dr. Gawande stresses that the physician's role is not to take a step back and hand over complete control to the patient. When physicians only play the informative role, the patient-physician relationship is reduced to a retail relationship where the physician is hired to supply knowledge and skills in place of working to understand what their patients truly want.

Instead, Dr. Gawande and the medical ethicists Ezekiel Emanuel and Linda Emanuel[14] advocate for a more deliberative model. In the deliberative model, the physician adds an element of moral persuasion as they discuss health-related values that may affect the patient's disease or treatments. Emanuel and Emanuel describe the deliberative model as having the physician act in the role of a teacher or friend who plays a more involved role in the patient's decision-making

[13] Gawande, 201
[14] Emanuel, E., & Emanuel, L. (1992). Four models of the physician-patient relationship. *Jama, 267*(16), 2221-2226. doi:10.1001/jama.1992.03480160079038

process. The shared decision-making process emphasizes that patients are not individuals who are self-sufficient and isolated from the influences of others.

If individual autonomy fails to account for essential values and goals of patients, families, and physicians within the healthcare decision-making process, why is there such a heavy emphasis on its importance? Toni Saad claims that it is due to lack of clear guidance from ethics defining what is a good life:

> Ethics…is greatly impoverished if there is no shared, concrete, conception of what is good; that is the suggestion here. Hence, in the absence of a shared conception of the good life, of what is good and evil, the only remainder is individual self-determination (autonomy). This is the lowest common denominator of modern morality, and probably the main reason for the current dominance of autonomy.[15]

This absence of a clear consensus on what is good leads to the overemphasis on respect for individual autonomy, sacrificing valuable and worthwhile parts of the medical experience, leaving it to being extremely isolating and lonely.

As someone who hopes to work in the medical field, I want to be able to be there for my patients so that they do not feel alone. I do not think that unwavering respect for individual autonomy is the answer to all questions surrounding the decision-making process. Physicians should not shy away from helping their patients beyond diagnosing their illnesses and prescribing them medicines. They must play an active role in understanding their patients' values and desires to better aid them in choosing the right care. If the geriatrician I shadowed, Dr. M, had used the deliberative model, he would have inquired more about the mother and daughter's concerns and helped guide them towards a plan that was mutually beneficial. This might have

[15] Saad, 2017

included understanding the social dynamic between the mother and daughter along with their respective values, so that he could better serve as a mediator and friend.

In addition, individual autonomy should not take away our friends and family, as our lives would not be worth living without them. Why then, should we proceed to isolate ourselves from others during our final days? The individual autonomy decision-making process erects walls around the patient, disconnecting them from the world around them and fails to let anyone in to help bear an extreme emotional burden during dying. Family, friends, and the physician must be allowed to cross over to extend a helping and guiding hand to let the patient know they are not alone.

V. Conclusion

Reflecting ideas of individual autonomy, the Western philosophical perspective of death is also lonely and focuses on the individual with it being conceived as "I will die." As Olberding explains, Chinese philosophers perceive the issue not as "I shall die," but rather "other people die." The story I told at the beginning following Joan with her stuffed cat named Maxine was about a dying individual cut off from those around her. I perceived the issue to be "Joan will die." There were no strands attached to her story, just one person left in her room with no one to care or think about her. However, the Chinese view of death would not have painted the story I told in the same way. Death and loss are communal events in China, as depicted by Confucius's loss of his beloved student Yan Hui. Following the death of his pupil and friend, Confucius is

forever changed, he is no longer able to share a mutual understanding with a student who fully understands his mentor. “Without the student who loves learning, the teacher is changed, lost.”[16]

Like how the illness of Nai Nai affected the whole family, the death of a person does not belong only to her. The death of Confucius’s student is told through the perspective of Confucius as his passing changes Confucius forever. Confucius is no longer able to be the teacher he was before, a part of him has passed away forever with Yan Hui. This is because death is not an individual experience. A part of the living dies with the deceased, never to be the same again. “We do not die alone. Rather, our dead take us out when they go.”[17]

Through reflection of my own experiences and on the film *The Farewell*, death to me is not as lonely and isolating as I had perceived it to be before. Respect for autonomy is important, but we need a model of autonomy where it does not isolate our patients and loved ones, for death is something that no one should have to face alone. If I could go back into the warm room with the stuffed cats and Joan bundled underneath the covers, I would tell her that I listened to her because I was with her. I had listened to her story and now her story was a part of mine. I listened because of the human connection I felt and my desire to show solidarity with her. For when I left the room and she passed, a part of me was gone as well.

[16] Olberding, 214
[17] Olberding, 222

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