

# Asano Humanities & Health Certificate

## 2019-2020

### Reflection Examples

---

**Who Decides What's Best?:** Using your experience of an Asano event as an example, please discuss the following: Who determines what is best for a person? For a family? For a community? What factors must be weighed to make such life-changing decisions?

David Bales  
Event: Tangles in Time

### Tangles in Time

*Who determines what is best for a person?* Before realizing that this was a prompt from which we were able to use as a springboard to reflect on our experience, it was a question that followed me out of the Tangles in Time performance. Having the agency to make our own decisions is a quintessential aspect of our humanity. That autonomy can be infringed upon by any number of outside forces, but the idea that it can be obstructed by the decay of the brain, stealing memories and eroding abilities, makes for a much different conversation. When the issue is easily discernible as external the solution is often to condemn the oppressor and fight for liberation. However, when the oppressor is the very thing that gives us the ability to make decisions in the first place -- let alone the ability to communicate, to make sense of our surroundings, to live -- who does that leave in control?

Life, and I'm learning, medicine, doesn't always follow a straight line. You die when your heart ceases to provide your tissues with necessary oxygen, but what about when your mind breaks down? That's not black and white by any means. There's a process of degradation that is variable person to person and even a waxing and waning of cognition within the individual. We can all agree that in the most severe cases of dementia, people are no longer able to make their own decisions, but determining when that deficit manifests is a more difficult task. As we learned in the performance, the burden of caretaking is typically thrust upon the closest family members willing and able to accept the weighty responsibility that is presented to them. The burden though goes beyond that of just caring for a partner or parent with a significant disease -- the front row seat to the mind's slow demise can be a brutally complex emotional experience. It isn't fair, but it seems to be the only option available to us.

In thinking about that initial question of how we can better determine what's best for a person, both from a societal standpoint and from a more specific perspective as a future physician, it's unequivocally clear to me that there is no right answer beyond providing support. Societally, that support

can look financial in providing access to resources like home health services and even more basically, adequate and affordable care. As physicians, I think that support requires an understanding of the wide reach of memory illnesses as it pertains to the lives touched by the individual affected. The responsibility requires advocating for change outlined above, but more importantly it requires treating the patient and their support system as one. It is not the physician's responsibility to decide what is right for a person, but to respectfully present their opinion and support the decision-making process, whether that is in someone competent to make their own decision or someone whose process has been deferred to another.

E. Reilly Scott  
Event: Health Humanities Reading Group

### Who Decides What's Best for COVID-19?

In the past week, choices have been made at every level to deal with the COVID-19 pandemic problem. Schools and companies have closed their doors to opt for online-learning and working instead. Governments around the world have shut their borders and forced lockdowns within communities. Individuals are self-quarantining and practicing better hygiene to prevent the spread of disease. However, some people are still traveling, going on cruises, and having gatherings with friends and family. As a result of this ongoing problem, the Health Humanities Reading Group appropriately chose to cover the reading "A Brief History of Love: A Rationale for the History of Epidemics" from the Health Humanities Reader this week.

The article talks about the previous pandemics that have happened around the world and how that influenced the actions we take today. According to the article, because science and medicine lags behind the spread of the virus, the only actions that really prevent outbreak are public health measures. The plague represented one of the first public health acts by quarantining ships in harbors before allowing people to disembark. If a town experienced cases, its doors would close so that no one could enter or leave. During the Spanish influenza pandemic of 1916-1918, the most significant decline in flu cases in the United States was in St. Louis because they closed all public gatherings, schools, theatres, and libraries.

Do we need these lockdowns and mandates or can we trust people to isolate themselves? The plague pandemic of 1348-1350 showed people may not follow the restrictions. People hired to dispose of the dead bodies took the clothes they were supposed to burn to wear instead because of their poverty, thus bringing the disease back to the community again. During the

Spanish flu, Philadelphia imposed rules about the disposal of the dead, their clothes, and their belongings to prevent these same effects. For COVID-19, schools across the country have closed. However, instead of students isolating themselves and staying home to prevent the spread of disease as the closing was meant to accomplish, multiple universities, such as West Virginia University and University of Dayton, threw parties so large they had to be broken up by police. Unfortunately, this shows that people will still do as they please during a pandemic, and there does need to be reinforcement to ensure public safety. While China's lockdowns and mandates that people must stay inside seems extreme, it could be the only way to enforce "self"-quarantine of those potentially infected.

Public health measures will be the most effective way to combat the spread of the disease. At an individual level, there is misinformation on the extent of the disease, lack of knowledge on practicing health safety, and people who do not realize their impact on society. As a result, I believe public health and government officials will have to decide what is best for the public.

Madeleine Kilimnik

Event: Moment to Moment Film Screening

### Who Decides What's Best?

Who ultimately decides what is best? Or rather, is it a who or a what? When a disease so debilitating as Alzheimer's comes into play, is the patient, the family, or the disease truly deciding the course of action? Though the disease decides who it affects, when, and how, I believe that the will of a patient can outweigh the power of a disease. From the short snippet I saw of Carl's life in *Moment to Moment*, he proved that he was still deciding what was best.

Though he could no longer work as a teacher or build contraptions to highlight physics principles, he established a new job for himself: that of a copper-extractor. Taking copper out of old computers and televisions may not seem like a noble feat, yet when combined with Susan's artistic abilities, true art was created from the simple manipulation of wires. Carl is deciding what is best for himself-- he is making a conscious effort to continue to work and analyze his abilities. Also, Susan is deciding what is best by working with Carl through activities to help his stimulation and brain function. Susan is also deciding what is best for herself; she is not fleeing from a difficult situation, rather finding solace in Carl's continual engagement with life.

When the movie showed the turnout to Susan and Carl's copper art show, I felt a sense of relief that their community did not neglect them. I saw neighbors and friends engaging with Carl, asking him about his art, and the pride Carl exuded from his abilities to still produce something of value. In this instance, the community is deciding what is best. They are deciding that it is best to support Carl and his newfound talents of copper extraction, but moreover, support two people who find emotional comfort in an activity that serves as an escape from their traumatic situation.

'Who decides?' is a loaded question. Everyone decides. As portrayed in *Moment to Moment*, it is not solely one person's decision of what is best, rather a collective effort by the

person, the community, and the family. And as mentioned previously, diseases can decide as well. Carl did not decide to suffer from Alzheimer's. He did not decide to stop understanding how a clock works. However, this disease never defined him because it did not decide for him. Carl decided to sit and draw clocks for hours, Susan decided to make Carl's copper into art, and their community decided to celebrate their courageous battle against a disease...a disease losing the battle to decide.

Dunia Tonob

Event: Moment to Moment film screening

### Who Decides What is Best?

I was struck by the meticulous attention Carl paid to his daily activities. He would spend hours tracing draw by number sheets or tinkering with mechanical appliances. Perhaps most heartbreaking but also most impressive was his effort to recreate a clock. He knew he was missing something and painstakingly drew and measured out his representation. But also striking were his interactions with his spouse and care partner. She demonstrated an incredible patience, love, and encouragement of her husband, going so far as to organize an art show to honor his work. However, she also expressed her frustration and grief at the situation and it made me think about what is the best way to care for a loved one with advanced dementia.

Of course, in its early stages, dementia is frightening and frustrating, but overall manageable without too much assistance. But as the disease progresses and your loved one grows more likely to wander at odd hours or even becomes distressed and violent, what then? One option, and often the only option for many families struggling to care for a patient requiring 24/7, is to place their loved one in a care home. This decision is incredibly difficult and yet there is very little most families can do to mitigate the sense of abandonment and shame that comes with leaving a loved one in a care facility. There are improvements to traditional care environments like dementia villages or the Green Houses Project, but they are not available for the majority of people. Choices are limited by cost, distance, insurance status, and level of community support. The burden of choice often falls to partners and family members who are ill prepared for the emotional toll. For many people, there is no good choice.



I was reminded of Annemarie Mol's 2008 text, "The Logic of Care: Health and the Problem of Patient Choice," where she argues that person centered care and patient choice centers patients as expert consumers in situations where more opportunities instead create greater burdens. Instead she argues for a "logic of care" where providers enter a partnership with their patient, managing care options through shared work and experience. This is the goal of most patient interactions today, but it also calls into question how to maintain a patient's autonomy when we traditionally understand dementia as a loss of personhood. I believe that Carl's partner and care circle did an incredible job of demonstrating how to move past person centered care to an understanding of embodied selfhood, offering persons with dementia care that respects and fosters their inner lives, emphasizing their capacity to build and enjoy relations, albeit through non-traditional methods like art.

I believe that in optimal circumstances, "who" decides what's best is everyone – that is, just as I imagine care to be a coming together of society, decisions must also be made as a partnership. Ideally, persons with dementia will discuss their desires with loved ones and providers before they are no longer able to speak for themselves.