

Asian American Community Contexts and Voices

***a sampling of “real life real stories” shared by students in the Asian American Studies course,
Asian American Cultures and Health Practices” (AsAmSt 345)
at UMass Boston in Spring 2009 to inform***



Health Issues, Voices, and Visions in Massachusetts Asian American Communities

***a cross-community sharing of stories and strategies with invited service providers, clinicians,
advocates, policy-makers, researchers, and funders***

**co-convended by the Joslin Center Asian American Diabetes Initiative, the Massachusetts Asian
American Commission, and UMass Boston’s Asian American Studies Program.**

Saturday, May 9th, 2009 from 1:00-5:00pm

UMass Boston campus – Venture Development Center



Poverty/Cost Stories

My parents currently do not have health insurance because they can't afford it. My mom is a seamstress and my dad is a chef. They are both currently unemployed. I have helped them apply for Masshealth but still haven't gotten a response from them in over a month. I wonder what my parents would do if I weren't around to help them. Perhaps they would just have to do without health insurance? Of course not, now with the added stress that the state law imposes on everyone to be insured or penalized. I don't have anything against the "insurance for all" law but I do have a problem with how the law determines whether you can or cannot afford health insurance. I don't think that the poverty levels that the government uses to determine eligibility are fair. Given my parents' insurance-less and poor financial situation, they will not see a health care professional unless it means life or death whether or not one of their children pays for services. This is a perfect example of disparities facing APIAs in getting assistance when needed...

My mother does not speak English, so she is afraid of going to see a doctor. If one of us does not go with my mom for her doctor's appointment, this means she will be afraid to go by herself if there is no translator there. Besides, my mom hesitates to pay for health care insurance every month and for every service plus fees for medication that we can not handle. Sometimes, she refuses to have medications because of the cost. Living at the poverty line just above \$20,000/year and with children going to college block my mother to seek health care herself. She thought that we can not handle extra costs or expenses; and we should otherwise save money for needs such as food and shelter...

I know a friend who was working in a supermarket a couple years back. This friend was a fish-monger and he cleans fish for a living in the supermarket. One day he accidentally slit his hand with the knife while cleaning the fish. He almost used the whole roll of paper towel and it really didn't stop the bleeding. So he took a week off from work to get that taken care of. Surprisingly, a week later when I saw him, he told me he still hasn't seen a doctor yet about his cut. The reason he told me is that his insurance isn't ready yet so he didn't think he can go...



Translation/Language Stories

I remember in middle school (or maybe younger), I have to accompany my mother to the doctor. My mom has a lot of trust in me. She knows that I will be able to explain to the doctor about her sickness. She was more confident in me than I was in myself. When we were at the doctor's office, the doctor asks my mom first how she is feeling. My mom asks me to translate that she wasn't feeling well. She suffered some pain from her legs. I translate what my mom told me to. The conversation gets more detailed as I am struggling with my translation between the doctor and my mom. It was hard to use medical terms when I don't know much. At times, I have to ask the doctor to explain to me some of the terms in detail and then I translate to my mom. My mom gets a little concerned when she sees that I am struggling, though. As I get older, I see how much my mom has suffered with the English language. I feel that I am struggling, too, but compared to her, she suffered much more. Therefore, with experience of being a translator for my parents, especially my mom, I realize how important language is...

For many low-income Asian families, especially Chinese families, the health clinics they usually go to are South Cove Community Health Center in North Quincy or the one in Boston's Chinatown. Another health facility is Tufts Medical Center. My grandmother probably attends one of these places about 2-3 times a month. She is 89 years old this year and is still going strong. Although, my grandmother has a lot of health problems and takes a lot of

different types of medications, she still manages to do a lot of things for her age. But now as she gets older and health problems became more severe, she needs a lot more attention and help in doing certain things like bringing her to her doctor's appointments. If someone doesn't bring her to the doctor's, she would usually go alone. Then there would be a translator at one of these facilities. I took my grandmother once to Tufts Medical Center for one of her checkups. I did this to try to understand her health problems better. I feel that there is always a miscommunication between the doctors, translators, and my family...

Last week, I took my wife to the Dorchester House. We were almost finished talking to a nurse who was taking our information. There was an elder Vietnamese woman asking me if I can I wait for her when I am done. I said yes. She needed my help to translate something for her. She looked worried before and after she asked because of her language problem. She needed to fill up some of her medicines, but there was no Vietnamese nurse around at that time. I believed that the elder Vietnamese woman has children, but they might be at work. After helping her, I was leaving and I wondered are there any more elder women or men who need help like this woman? I am sure the answer is "yes", not only one. Could be hundreds, thousands or more. I wish hospitals have someone hanging around to help translate for the patients. Some nurses can speak the patient's language, but they have to work...



This happened about 2 weeks ago. My dad was a heavy smoker for about 40+ years now and he smokes about 2-3 packs a day. The smoking finally caught up to him and he was diagnosed with having cancer inside his bladder. The doctor found something weird inside his cell of the urine when they were examining it. Through x-ray, we found out that he had a small tumor right outside the bladder. So the only solution the doctor said was to have open surgery and remove the tumor from the bladder and he will be all set. There were two kinds of surgery

offered by the doctor. He told my dad that he can just have one incision which he goes in to do it. The other option would be to have 5 small incisions all around his whole stomach. After translating it to my dad about the whole situation and consideration, he wanted to have the option of just having one long incision instead of the 5 small incisions. He figured having 5 incisions around the stomach means the whole stomach is going to hurt afterward, so why not just have one incision and have one spot hurt. And on top of that, he worries that infection might occur. If he just has that one incision, only one spot would get infected if it happens. If there were 5 incisions, what if some healed but some are infected? Then there are going to be more problems. So after the consideration and talking with the doctor, we made the appointment for the surgery. I went to the surgery with my dad that day and I wanted to double-check with the nurses on what kind of surgery that he was going to get because I don't want them to perform the surgery option that my dad doesn't want. I asked 5 nurses handling the case and none of them could answer me! So when it comes time to bring my dad into the pre-operation room, they told me I couldn't go with him because it one of their rules. I kept insisting that my dad doesn't speak English that well and none of you could verify what kind of surgery my dad is going to get. So I wasn't willing to let my dad go off by himself without me. So I ended up having to talk to the head nurse of the pre-operating room to see if I can just go inside with him and do the translation with the anesthesiologist and verify that the right operation is going to be performed on my dad with the doctor when he arrives. The doctor did verify that he was going to do the option my dad had chosen. After hearing his word, I was more relieved because I don't want my dad to be in a situation that he doesn't want...

Addiction/Abuse Stories

When I was between the ages of five and ten, my father had a gambling problem. Not only did he gamble, he also drank too much and hit my mom. I remember one specific incident when I was about eight years old and my father and mother were screaming at each other. My father had gambled all the money that both my parents were saving for years to buy a house. It escalated to the point when my father struck my mom. I remember crying and trying to stop him along with my three siblings. The fight ended when my parents decided at the spur of the moment to get a divorce. They both asked me individually whom did I want to follow and of course I answered my mom. I felt torn because my family would no longer be a whole. My mom has always taken care of me since birth and I felt that she has never done any wrong. Of course my loyalty is with her. They did not follow through with the divorce and are still together to this day probably because they actually managed to save up enough to buy the apartment building that we currently reside in now. My father has calmed down with the gambling and violence but the memories will stay in my mind. I witnessed this growing up and I feel as though it has negatively affected me. I've always held a grudge against my father for striking my mother; I can never really look him in the eyes. There is always a vivid image of what happened and what could possibly happen again in my mind...

I started smoking when I was around 16 years old. I think I started smoking due to peer pressure and the other important factor is that my dad smoked. As a kid, my dad smoked a lot. When we go out, while driving he would open the car window and smoke. At a young age, I hated the smell of cigarettes. I would always complain how bad it smelled and it was unhealthy. But at the age 16, I started smoking myself. I thought that if it was ok for my dad to smoke, it wouldn't be too bad. Then, a couple of my friends started smoking and I got into it. Because of this addiction my dad had, it affected the well-being of my whole family. My older brother started smoking at a young age too. Not sure if it was because of my dad, but I'm sure it is related. The only one in my family who doesn't smoke is my mom, but over the years she experience second hand smoke, so it will affect her health as well. Because my dad smoked, it seems normal for me to smoke. One person affects the whole family. Recently my dad tries quitting, only to go back smoking after 4 months. The same goes for my brother and me. We all have tried, but eventually we start smoking again. I feel like this is an addiction that my whole family needs to quit...

One of my brothers used to be a bartender. He had a good job and he made a lot of money on that job. Everyday he made different kind of wines, so he had to taste them. Everything seemed okay with him. My family did not say anything. People thought it was a part of the job he had to do, but one day he realized that he had an alcohol addiction. The business went down and he lost his job. Instead looking for another job, he felt sad, and drank more. He drank at work, at home, everywhere and anytime. He was out-of-control every time he got drunk. My

family was in despair. Everyone in our house gave him the advice. We tried to convince him to stop drinking and we would try to help him find another job. He said he would. But the next day, nothing changed. He could not sleep without drinking alcohol. He was an alcoholic. My mom said he was a slave of alcohol addiction. We tried to search for an answer for how to stop, but I couldn't find an answer that worked. He almost gave up and lost all hope...



On my friend's twenty-first birthday, me and my other friends took him to Foxwoods for some gambling. We pitched in and gave him some money to play poker. We were planning to stay just for a few hours. When it was getting really late, I told my friend it's time to go home but he said he wants to stay for another hour. I told him everyone is really tired and they all want to go home. He was losing the whole night and I tried to tell him there is always another time to come back. He told me with an angry tone that he wants to stay for another hour and I finally gave him his wish. An hour later, I came back and told him everyone is waiting for him and they all really want to go home. He wanted to stay a little bit longer and I told him "no". I was so outraged that I yelled at him to cash his chips and leave. He finally left the poker table and he was really angry at me during the ride home. One week later, I called him to go hang out and he never picked up the phone. An hour later, he called me and I asked him where he was. He told me he was at Foxwoods. I asked him if he was up or down with his winnings and he told me that up a couple of thousands. I told him that he should leave the casino. From the sound of his voice, he was angry and hung up the phone. A couple of hours later, he called back and was extremely angry. He lost all of his winnings and blamed me for giving him bad karma. At that point, I knew I needed to tell his parents about his problems...

Stigma/Shame Stories

Everyone in the family was very happy to celebrate for the one-month baby boy. His parents named him "K", meaning "intelligence". He grew up and showed that he was a smart boy when he played blocks with other cousins in the family. For instance, he made a house with toy blocks and drew pictures. When K reached to 3 years old, his parents seemed to worry about him because K did not talk. His parents took him to see a doctor even though he was not sick at all. The doctor told his parents that K was a healthy kid and he could tell why K talked slower than other children. But K would talk soon as the doctor said. K's parents were worried about him when K turned five years old. K was still healthy, but K still did not talk at all. Someone told them that K had a strange disease. K's parents would not believe that because they really loved him. After K was 7 years olds, K still did not talk except babble sounds like papa. That was how K could talk. His parents seemed to believe what people told them about the strange disease. They felt shame about K's disease. People said that if the child cannot talk, it is because his/her parents did a lot of bad things in the past, so that this will affect the child. K's parents were ashamed. They did not want anyone to know their child does not talk because this implied that they were bad people. They kept K at home all the time and would not let K go to school. K was very sad and wanted to play outside with other kids. Everyday K looked at the window to see other children playing or going home from school. K wished that he could go to school and talk to everyone. K's parents gradually hated him because K was a shame for the family and they could not take K outside...



Throughout high school, I had a best friend whose name was Johnny. We always tell each other everything and never hide secrets from each other. In our senior year, we apply to many colleges together in hopes we can still hang out together in the same school. Both of us got accepted into UMass Amherst and we were going to plan on

dorming together. But due to my financial crisis in my family, I couldn't go to UMass Amherst. So he went and I just stayed back here and went to Quincy College. I really wanted to go to Amherst but dorming cost a fortune and I didn't want to spend that kind of money. While he was there at Amherst, I guess he got a little too promiscuous. After his sophomore year, he found out that he had HIV from a regular body checkup. He didn't know what to do, so he came and talked to me about it. I was very sad when he told me about the news. I told him that no matter how bad it seems right now, he has to tell his family about this. He kept on insisting and pleading for me not to leak this out because he wants to maintain his image to his parents that he is a nice son and the thought of him having HIV will bring shame to the family from friends and relatives. He told me that everything in the medical field is so advanced now, maybe there will be hope in the future that there will be some kind of medicine that can cure him. After a few years, his condition worsened and every time I look at him, he looks very anorexic. He still kept insisting that I shouldn't tell his family about his disease. At this point, I feel like whatever he wants, I'll try to help him out. He likes the fact that his parents tell everyone how good of a son he is and he's going to become successful one day. He doesn't want to let everyone know that he is a freak with the HIV virus and he got it because he was being promiscuous. Then, a few months after that, the HIV virus became AIDS. His T-cell count had dropped enormously and you can just tell by looking at him because he is always sick. He doesn't have enough T-cells in his immune system anymore to fight off any infection or sickness. Finally he collapsed and went into the hospital. I notified his parents and they came to the hospital and found out what happened to their son. After a couple of weeks, Johnny passed away. So from all this, I think Johnny should have never hid this from his parents. Even though there may not be a cure, he should let his parents know so they can spend the rest of the time with him. But he wants his parents to maintain this good image of him and not this promiscuous boy that got HIV from having sex. So all in all, though, I think Johnny was very brave for hiding all of this to himself and he was one of the best friends that I ever had. I hope he is resting in peace in heaven...

The first time I ever had to face my depression was in middle school. I was writing in my composition book, something I did often as a means of relief. I wrote the same thing over and over for as long as I needed for that feeling to go away. I wrote, "I want to die. I want to die. I want to die." That day, sitting in the cafeteria alone, I continued adding to the list. I wrote the line several times, until a teacher came up from behind me and took the notebook from me. I was frightened. She flipped through the pages and told me to come with her. I stood outside the main office as she spoke to the guidance counselor and gave him my notebook. I thought I would die of panic just standing there, imagining what might happen in the aftermath, what my parents would say or do, the lies I would have to tell. I imagined myself running and hiding somewhere. But they would find me eventually. And I would never disobey my teachers. I stood there and waited to be called into the office. The guidance counselor tried to speak to me, asking me questions about why I wrote "I want to die." I thought it was a stupid question. Isn't the answer obvious? Because today, I want to die. I couldn't answer though. I just sat there, crying, sobbing, knowing that soon my mother would be called, and I would have to make up an elaborate lie. It turned out, all I needed was a simple lie. My mother had to leave work and come get me at school. I was so ashamed and scared. I was causing my mother so much trouble and worry from getting a call from school in the middle of the day, for taking my mother away from work to deal with her stupid daughter, and for putting her in a helpless position in front of my teachers. I should have done a better job of hiding it. How dare I burden my parents with something stupid like feeling sad about nothing in particular? I couldn't say anything to my mother in front of the guidance counselor. I was too embarrassed, or too distracted. As my mother and I walked home, I told her that kids just do stupid things sometimes, and that my teachers took it too seriously. You know how white people are, so sensitive about everything. I told her I was sorry, and that I wouldn't do anything that stupid again. I had imagined that my mother would be angry with me and yell at me, but she was a little worried. She asked me why I had been sad. I told her it was the usual things: stressed out with school, sad about being fat and ugly, and that I felt lonely sometimes. Those things were true, but they were not the reasons for why I didn't want to live most days. That lie would come back to haunt me years later. My mother would believe that those simple things were the cause of all of my sad days for years and years, and I never told her otherwise. I never told her that the real reasons eluded me, and that it tormented me that I didn't have the answers, that I couldn't fix myself. The next day, I went to see the guidance counselor to get my notebook back. I told him something similar to what I told my mother. I told him that I didn't really mean what I wrote, that I was being melodramatic. I think he was somewhat skeptical, but he gave me back the notebook. He asked that I come to see him if I ever wanted to talk or had any problems. I said OK. Then he said, "You're not going to come to me, are you?" I answered truthfully,

"No." He shook his head, and I left the office. Everything went back to the way it was, except I stopped writing in that notebook. I stopped writing those kinds of things. I think I started writing poetry after that in a clean, new book with a pretty cover.



Treatment/Care Stories

As a child, I hated coining, because it felt painful and ticklish. If I were sick, my mother would use coining practice for me. I asked her why. She answered that not every disease would be treated with coining method. However, when you were sick, for instance, with headache, dizziness, sweat, and not feeling good, coining could be utilized. This helps you feel better. I was curious to know how was coining helpful. As I grew up, I understood more. My mother always uses oil and a coin to rub the back and front of the body. Sometimes, people rub their shoulder or forehead. Coining helps to promote circulation and to relieve muscle tension. After coining, the skin will be red but I feel warm and good. When my family came to America, we did not use coining method often. Instead, there was Tylenol. We heard many stories that coining makes parents get punished 1-2 days in a jail because people think that they abuse their children. This prevents people to use coining or other traditional cultural practices. However, my family still keeps utilizing coining method and herbal medicine. My mother often buys herbal medicine and oil for coining in Chinatown or Vietnamese markets in Dorchester. I think I will pass these traditional cultural practices to the next generation because, believe or not, these are helpful to treat for specific diseases...

A couple of years ago, my dad was experiencing pain in his stomach area. So he went to have an x-ray. Later we found out that he had a gallstone stuck in his gallbladder. The doctors recommended that he perform a surgery to remove the stone. My dad tries asking the doctor to see if there is any medicine he could take to remove the stone, but the doctor said surgery is the only option. But my dad would rather drink herbal medicine than to go

under the knife. He asked some relative in China to send him some herbal medicine that was supposed to help dissolve these stones. After half a year of drinking the herbal medicine, my dad went back to the hospital for an x-ray to see if the stone have been dissolved. But the x-ray showed that nothing has changed and the doctor recommended my dad to perform the surgery. When my dad told the doctor that he was taking some herbal medicine, the doctor replied that herbal medicine wouldn't help. In my dad's point of view, herbal medicine is better than surgery. I agree with the doctor that surgery would be better, but he insist that herbal medicine would help him...



My grandpa is at the age of 80. He lives in the retirement center in Wollaston and gets up early every morning to go exercise. Although he can't exercise as much as before, he still has to do it for the sake of his health. When he was young, he had to go up to the mountain and gather wood for the family to use on a daily basis for cooking and boiling water. One day, he accidentally fell and bruised his knee. He went to a doctor and it was fixed at the time. But I guess as age progresses, it comes back to haunt you with arthritis. He says his knees are the worst when the weather rains, and sometimes it would get to the point where his knees are inflamed. There is no cure for it and the doctor would only prescribe pain medication for him. There is a strange way for him to ease the pain though. Every week when I bring him for his grocery shopping, he would buy at least half a gallon of vinegar. I thought it was kind of weird for him to buy so much vinegar all the time but I just assumed he uses it in his cooking. Then one day, I asked him why does he buy all that vinegar all the time. He told me it is for him to use on his knee to cure the pain and arthritis. Every few days, he would soak up a towel with vinegar and apply it to his knee. He states that, this will not only kill all the germs and bacteria on the knee, but it will help cure arthritis. He said he feels a bit better afterward. But the thing is, I know for a fact he had probably been doing this for many years,

because he had asked me to buy vinegar for him on a weekly basis for so long. He is still doing it to this day because probably he heard it from China...



My mother's friend is over the age of 65. She usually walks 30 minutes every day outside in a park, around her neighborhood during summer. Sometimes, her friends walk with her when it is warm. When it is cold, she does exercise at home. She uses a treadmill to walk for 30 minutes and sometimes does bicycling about 10-15 minutes. She has exercised for 5 years because her doctor tells her to. She is hypertensive and overweight. She had knee pain before so she could not do exercise. Now she tries to maintain regular exercise in order to lose weight and to be healthy. It is not easy for her because she often has to exercise alone. She also has to do housework such as cooking and cleaning up a house for her family. After five years of regular exercise, she feels much better. She is able to lose some weight and feel more relaxed. She mentions when she moved to the United States, her lifestyle changed. She was so busy working and doing housework that she had no time to exercise. When she was in her country, she did farming and walked a long distance from her house to a farm. She was able to do exercise by walking to the farm...

My concern is my mom. She was diagnosed with type two diabetes. Sometime I'm very worried and always try to be there for her. She's very cautious with the things she eats. She never drinks soda because she knows it's bad for your body. Every time she cooks, she tried not to put too much sugar in the food. She eats a lot of whole wheat and egg whites. Everyday she drinks this bean tea to reduce her diabetes. But I'm still worried because I don't want to see her go through the same thing that my grandmother went through. I want to see her live her life to the fullest...

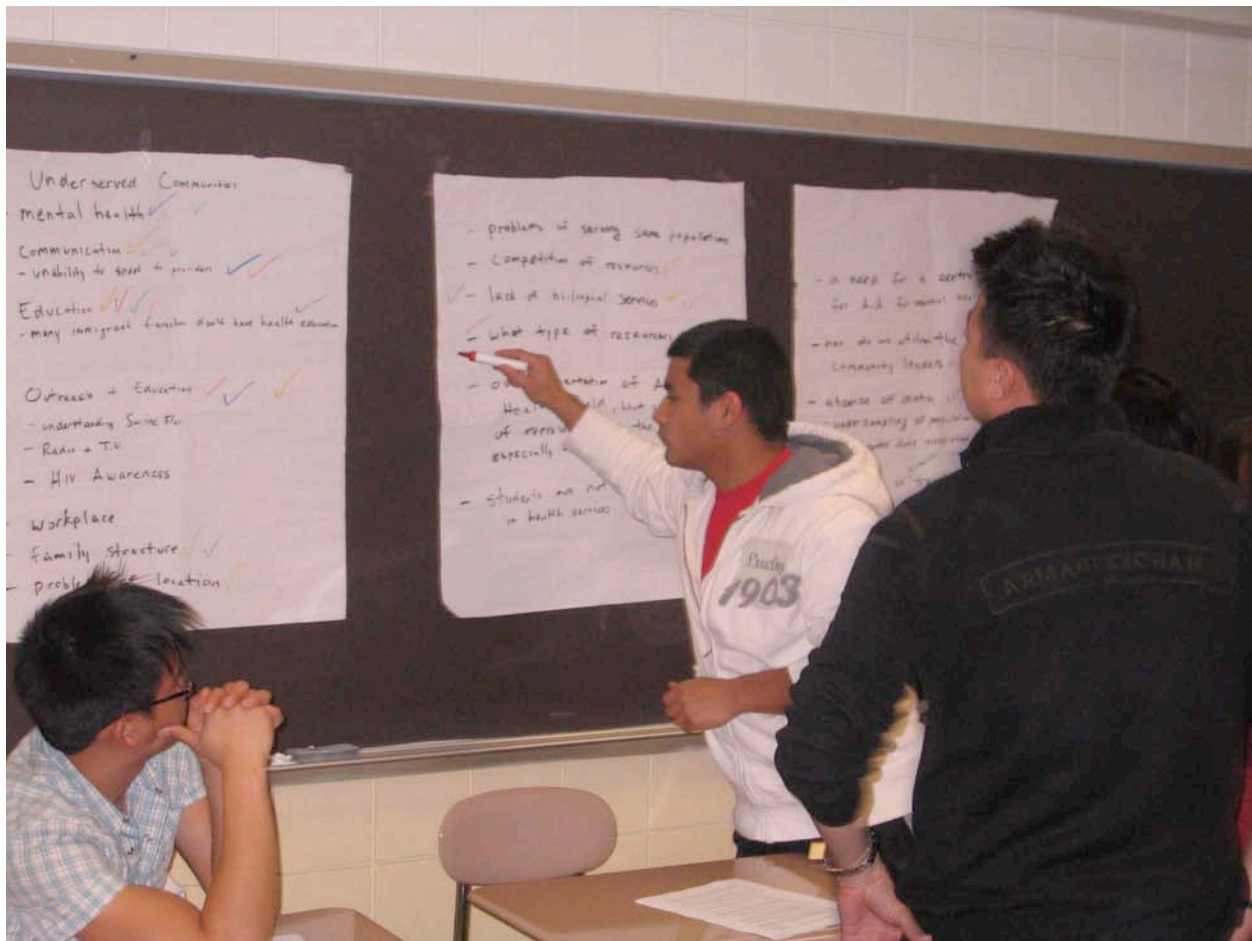
For about 3 months now, my mother started to make brown rice daily. Her friend has diabetes and she told my mom that brown rice is better and healthier for you; she has also heard about brown rice on the Vietnamese radio. She is trying to get my older brothers to start eating the brown rice but still they do not like it. In school and taking health classes I always knew that brown rice is healthier for you, but I just never really liked the taste, and I have always felt that you can't compare it to white rice. My mother started cooking it on a daily basis, but I never ate it until one day I just ate a little because we had no white rice and since then brown rice has grown on me. I do eat brown rice a lot more now and for people that have says that brown rice takes a lot more time to cook, it's really not true. My mother cooks it just like white rice in our rice cooker and it is done in 20 minutes...



Sometime on a sunny day, my father would go to the back yard and do some form of Tai Chi. I laughed at him and asked him how he knew about tai chi which he learns from watching television. Since my dad had a stroke a year after we came to the United State, he does not work. His doctor told him to walk and exercise once his surgery is healed. I remember one time he brought home an upright exercise bike that someone threw away. The exercise bike was old and not in perfect condition but he really love pedaling on it. On rainy days and on days when he is lazy, he would paddle on his bike for thirty minutes. For some reason, my dad only exercises in the morning and not at night. I don't recall ever seeing him workout at night. Other routines that I see him perform are Western style, such as jumping jacks and sit-ups. He also stretches his body and uses my dumbbells. When lifting dumbbells, my dad takes off all the weight and only works with ten pounds. He usually does curls or holds the weight for two minutes. My father always works out by himself which surprises me because it can get pretty boring. On second thought, I think I should ask him to work out with me next time...

Why/How Stories

I was thinking about how my parents one day would need those kinds of professional help. It is getting harder for my parents to see now, due to old age. I'm worried one day that their eyes would go so bad, that they couldn't see. It is always a worry I have since I moved away from my parents. I think that it is very important that more resources are put into funds and services for disability use. There need to be more bilingual students in the field who would help the patients. My recent Joslin Center Asian Clinic visit, for example, really changed my view of doctor-patient connections. That day, Sophia was talking to a patient in Chinese. During my time there, the interaction between Sophia and the patient was friendlier, closer, and in a way, like a family. There was actually doctor-patient interaction that I haven't seemed much before. The point I want to make is that, for programs to be successful, it requires more open minded staff — someone who likes interaction between patients and doctors to create a trust and understanding. By filling this staffing gap, it would help the patient in feeling more comfortable with their doctor. If the doctor can have the trust of their patients, it would create a family-like relationship with the patient...



Most immigrant parents when they come to this country, they would like to work hard so they would have the money to send their kids to school and have a bright future. Asian Americans often would like to work in the health field because many other Asian Americans had success in it. Going into that field would bring them closer and help make a good income for their future. When I graduated high school, my intention was to major in computer science. After a year of college, my parents convince me that I should go into the health industry because that's where the money is at. You will never be unemployed because there are jobs everywhere. Computer jobs were at a low back then. So I stopped taking computer courses and just took random classes at my

college. Out of all the classes I took, none was in the health field because I really had no interest in it. I have tried many classes, accounting, business, paralegal, etc. You name it, I probably tried it. I nearly spent two extra years trying to find my dream. This is why I'm 24 now and still at school when I was already going to school full time at 18. I see most of my friends already graduated and have nice jobs and it feels kind of depressing. So I finally gave in and tried to go into a class call Phlebotomy. This is just a fancy name of people taking blood and doing blood work in a blood lab. It is almost like being a medical assistant at the same time. I really got into it and I got certified and am now working at Quincy Hospital. Hence, this is why I'm trying to go into the nursing program now. I found something I really like to do and my parents would be proud of me. Nursing is on the rise now and needed badly everywhere. When I do become a nurse, my parents would have a big relief because then they would know I have a great job and the income for me to start my own family and my future...

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