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A Case Study in Assurance

"If I Die, You Will Eat Me"
Public Health Challenges Related to a Hmong Refugee TB Case

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Abstract

In October 2004, a 66 year-old Hmong female was hospitalized with symptoms of pneumonia unresponsive to conventional treatment. The family requested a second opinion and an infectious disease physician suspected tuberculosis (TB). The patient was placed in a negative pressure isolation room. Sputa were obtained and cultures revealed the presence of acid-fast staining bacilli. The presumptive diagnosis of active *Mycobacterium tuberculosis* infection was made.

After discharge from the hospital, the health department was notified by phone. A communicable disease report was completed. The client began directly observed therapy (DOT) for treatment of TB. Compliance became an issue within one week of discharge. Cultural factors impacted noncompliance issues, so an understanding of these factors became vital to managing her case. The patient was rehospitalized on several occasions in relation to her TB.

Due to issues of noncompliance, the legal counsel and health officer for the county had to make decisions related to the protection of the public, resulting in an isolation order for hospitalization signed by a judge. Noncompliance related to refusal of medication and nutrition continued during the hospitalization. The hospital ethics committee reviewed the case and requested administration of a competency test. This resulted in the placement of intravenous lines for medication and nutrition.

The patient had immigrated to the United States from Laos in 1996. She participated in the local health department's refugee screening program upon arrival and had a positive purified protein derivative (PPD) test. In 1996, she was prescribed a 6-month course of INH for latent tuberculosis, was placed under the supervision of her family, and received monthly supervisory visits from the local health department nurse. Directly observed therapy was not performed at this time. She speaks no English, depends on her extended family to translate for her, seldom ventures outside the home, relies on her family for all information, and has no community contacts. She is not a U.S. citizen and is not eligible for Medicare and Medicaid. This raises issues concerning access to primary and preventive health services. One of her daughter-in-laws, who is pregnant, performs the primary care. Trust of western medicine may be an issue, given that she was originally treated preventively and now she is being treated again (only she knows if she completed the course of therapy in 1997). Due to cultural differences, she has no understanding of bacteria and viruses and western medicine. She only knows the use of a shaman, who treats the soul of the person and works with spirits. She is an elder and is treated with respect and regard. Her children are conflicted because they want to respect her decisions, but also have a greater understanding of western medicine and a desire to be compliant. She believes she is being poisoned by the medicine and that when she dies people will eat her.

The case demonstrates many challenges to the public health system regarding resettlement: understanding social, cultural, and economic factors related to assuring access to health services; establishing links to health care; evaluation of effectiveness of those health care interventions; and enforcing laws (e.g., isolation orders).

Introduction[1]

Hmong refugees began arriving in Wisconsin in 1975. Resettlement began following Hmong service in the United States sponsored "Secret Army" during the Vietnam War. After the war was over, the Hmong found their lives were in danger were they to remain in their homeland of Laos. Nearly 45,000 Hmong moved to refugee camps in Thailand by the end of 1975. Since many Hmong believed the U. S. had promised aid to clan leaders in the event the war was not successful, many were encouraged to leave the camps and resettle in the U.S. This first wave of resettlement (and subsequent waves in later years) found the Hmong concentrated largely in three states: California, Minnesota, and Wisconsin.

Throughout the 1980s and 1990s, waves of resettlement activity continued. Some of those who chose not to resettle to the U.S. moved to the grounds of a Buddhist temple, Wat Tham Krabok. Prior to 2004, the last major wave of Hmong immigration occurred in 1996. Recent changes in the Thai government, once again, forced the issue of resettlement for the Hmong from Wat Tham Krabok. Hmong Refugees basically have three options: (1) return to Laos where their safety continues to be in question; (2) stay in Thailand, but without any rights or claim to citizenship; or (3) move to other countries. This latest wave of resettlement has again seen the Hmong concentrate in areas where prior generations have settled, including a high rate of immigration into north central Wisconsin.

Because sanitation and medical care at the camps is not equivalent to that in the U.S., the Hmong refugees have a higher rate of tuberculosis (TB) than the general population of Wisconsin. Over the 10-year period from 1994 - 2004, the average rate of TB cases in Wisconsin Hmong was 16.6 per 100,000 population (pop.). The rate in 2004 was 24 cases per 100,000 pop. Over the same time period, the average rate of TB cases in all Wisconsin residents was 2.1 per 100,000 with a rate of 1.8 per 100,000 in 2004.

Another important background issue pertinent to this case study involves the traditional Hmong family unit. In Hmong families, it is not uncommon for the parents to live with their extended families, including children and grandchildren. Second and third generation Hmong are more likely to integrate into Western culture and are more open to ideas of Western medicine than those immigrants who were the first in their family to come to the U.S.

This case study is a fictionalized account based on an actual TB case in an elderly Wisconsin Hmong refugee. The main subject of this case study is an elderly Hmong woman, named Felin Lo. She lives with one of her sons and his family and spends a significant amount of time in the household of her other son and his family.

She has few interactions outside of her family circle. Although her sons and their families have both adopted Western culture and are open to Western medicine, her belief system is still strongly rooted in traditional Hmong cultural values. The case demonstrates many challenges to the public health system regarding resettlement issues: understanding social, cultural, and economic factors related to assuring access to health services; establishing links to health care; evaluation of effectiveness of those health care interventions; and enforcing laws (e.g., isolation orders).

Episode I: The Phantom Microbe Menace

In December 1996, Felin Lo, a 66 year-old Hmong refugee from Laos, arrived in Wisconsin with her two sons and their families. Felin Lo is a traditional Hmong elder. She does not speak or understand the English language. She is completely reliant on her extended family. She does not have her own home but rather resides between the homes of her two sons.

As a new refugee, Felin Lo received refugee screening at the local health department (LHD). Her knowledge of the American health care system is limited to information filtered throughout the refugee camps in Thailand[2]. Some of the questions that resonate throughout the camps included[2]:

1. Why do American doctors take so much blood from their patients?
2. Do American doctors eat the livers, kidneys, and brains of Hmong patients?
3. When Hmong people die in the United States, are they cut into pieces and put in tin cans and sold as food?

Felin Lo received her health care in Thailand through a shaman. The shaman typically treated the soul of a person and worked with that person's spirits. The shaman would visit an individual in his or her home, sometimes spending many hours with the person. The shaman never asked questions, never asked the patient to undress, and would provide an immediate diagnosis[2].

Upon arrival in the U.S., Felin Lo received a variety of tests at the health department to diagnose potential communicable diseases. The screening for TB is a skin test called the purified protein derivative (PPD). Her PPD test was positive with an induration of 20 mm. Subsequently, a chest x-ray was ordered and was ultimately read as "inconclusive." Sputa were obtained, which were negative for *M. tuberculosis*. After a consultation with the infectious disease physician, Dr. Michael Bacterium, a decision was made to start Felin Lo on a 6-month course of isoniazid (INH) for latent TB.

Because of the positive PPD and the 6-month course of INH, a referral was made to the local health department's communicable disease public health nurse, Ms. Ress Purator, (RN '95) for health teaching and case management. Due to the language barrier, Nurse Ress Purator requested that the Hmong bilingual health aide accompany her on the visits to the home(s) of Felin Lo's immediate and extended families.

Nurse Ress Purator and the bilingual health aide made monthly home visits. During these visits, the family received education regarding the etiology, transmission, control, and signs and symptoms of TB. Felin Lo completed the 6-month course of INH without incident. With the INH therapy complete, Nurse Ress Purator discharged Felin Lo from the health department caseload and sent a letter to her primary care physician, S. Putum, M.D., informing him of the above information.

Episode II: Attack of the Latent Infection

Felin Lo remained healthy, living with her sons in Wisconsin for the next seven years. In October 2004, Felin Lo began experiencing lethargy, fever, weight loss, and coughing. She was taken by her family to the local Federally Qualified Health Center (FQHC) to see her primary care physician, Dr. S. Putum. A chest x-ray was completed and revealed probable bacterial pneumonia. Dr. Putum ordered admission to the local hospital for antibiotic therapy and rehydration.

Felin Lo was admitted to the hospital on Monday, October 4th, with a presumptive diagnosis of bacterial pneumonia. In the hospital, she was initially assessed by the lead nurse and an interpreter. Felin Lo's family was not present during the admission. The assessment revealed no significant health history. Medical records from her care at the health department in 1996 were not available and there was no hospital record of her prior positive PPD and TB prophylaxis. An IV was started for rehydration and antibiotic therapy.

Felin Lo's symptoms remained constant with no improvement. Felin Lo's family requested a second opinion on Wednesday, October 6th. Dr. Michael Bacterium, an infectious disease specialist, assessed Felin Lo, and did remember seeing her seven years earlier. He reviewed the hospital medical record, which revealed no significant history. He requested copies of her medical record from FQHC because of his suspect diagnosis of TB. He ordered sputum cultures for three consecutive days. The first culture was obtained immediately and Felin Lo was placed in a negative pressure isolation room. Isolation procedures were implemented with all hospital staff and visitors. The notes from the FQHC contain a copy of the "inconclusive" chest x-ray, his consultation notes, and a letter from the health department that Felin Lo was discharged from care and had completed a course of INH therapy seven years earlier.

The results of the first sputum cultures revealed the presence of acid-fast staining bacilli and the presumptive diagnosis of active *M. tuberculosis* infection was made. While awaiting the culture confirmation, which could take an additional two to four weeks, Dr. Bacterium began the standard 4-drug tuberculosis therapy of isoniazid, rifampin, pyrazinamide, and ethambutol[3].

Dr. Bacterium discharged Felin Lo on Friday, October 8th, to the care of her family with the following instructions:

1. Take all medication per bottle instructions,
2. Contact Dr. S. Putum on Monday for a follow-up visit, and
3. Call if any problems arise over the weekend.

Episode III: Revenge of the Bacillus

About mid-morning on Monday, October 11th, the health department's communicable disease public health nurse, Ress Purator, received a phone call from Dr. S. Putum's nurse regarding Felin Lo. Nurse Ress Purator was informed that Felin Lo had been released from the hospital on Friday, October 8th, with a presumptive diagnosis of active *M. tuberculosis* infection. Felin Lo had been given instructions on how to take her medications and was told to call Dr. S. Putum at the clinic today. Her family cared for her at home during the weekend, but she was not feeling well and returned to the hospital.

Nurse Ress Purator had worked with Felin Lo when she first entered the United States. The 1996 record revealed that Felin Lo had been treated for latent TB. Nurse Ress Purator had conducted monthly home visits at that time and was familiar with Felin Lo and her family. The chart notes indicated Felin Lo's family was given a great deal of information regarding signs and symptoms, control, and transmission of TB. Although Felin Lo lived periodically with each son, she currently lived with her eldest son, Alatu Chue, whom she lived with when she was initially treated with INH. Nurse Ress Purator

knew the family was somewhat familiar with the medication and the precautions that needed to be taken.

On Wednesday, October 13th, the health department received a communicable disease report from the hospital confirming the TB diagnosis.

Nurse Ress Purator made contact with the family through the health department's bilingual health aide. She informed the family that she would need to talk to the main caregivers of Felin Lo and would need to do a PPD on all family members and caregivers who have had recent contact with Felin Lo. The appointment was set up for mid-afternoon on Wednesday, October 13th, before the children returned home from school. Nurse Ress Purator wanted time to talk to the adult family members before administering the PPD. The signs and symptoms of TB, transmission, and control were again discussed with all family members. It was stressed that the children were at greatest risk and that it was important that the children are tested. This would include follow-up chest x-rays, if any of the PPDs came back positive. All adults and children in the home received a PPD, which was scheduled to be read on Friday, October 15th. There was concern about the pregnant daughter-in-law, Ah Chue, who was the main caregiver for Felin Lo.

The investigation into additional contacts began at this time as well. Since Felin Lo had been ill for a while, she had rarely been out of the home, but had been at the clinic and grocery store. Most of the visitors to her home were relatives, primarily the extended families of her two sons. When Felin Lo was well, she did provide some care for these children. None of the children were infants, so she did not carry the children, but was often in the same room with them for prolonged periods of time. All other visitors did not have close, prolonged contact (over 4 hours) with Felin Lo.

Dr. Bacterium's nurse notified Nurse Ress Purator that Felin Lo was being discharged from the hospital on Thursday afternoon, October 14th. Felin Lo would require directly observed therapy (DOT). Nurse Ress Purator planned to retire within the next month and spoke to the public health nurse, Ivanna Helpya, who was assigned the case and apprised of the household situation and the DOT order. She reviewed the chart and, with the assistance of the bilingual health aide, scheduled a home visit as soon as Felin Lo arrived home.

Episode IV and V: A New Nurse Hope and the Health Department Strikes Back

Initial visits by Nurse Ivanna Helpya and the bilingual health aide were unremarkable. Since DOT visits were daily and Felin Lo's immediate family was at least vaguely familiar with TB treatment, the family quickly developed a friendly relationship with Nurse Ivanna Helpya. The BHA services were only necessary for the first week of treatment because the younger family members were familiar with Western medicine practices and understood the importance of proper treatment and the risks associated with noncompliance.

Although Felin Lo was initially compliant with DOT, she became increasingly despondent after the first week of visits. Felin Lo began to refuse to eat or drink. Culturally, elders are to be left alone when this occurs, creating personal conflict between what the family knew about the benefits of Western medicine and respect for their culture and elders. Felin Lo, completely reliant on her family, agreed to eat when urged and hand fed by Ah Chue – at least for a while.

Soon, Felin Lo, with little, if any, acceptance and understanding of Western medicine, began to feel her family was turning against her. She complained that they were wearing masks in her presence because they don't want her anymore. She was feeling alone and afraid, and decided to stop eating all together. Although she was lucid, she nonetheless was weak and easily slipped and fell in the home and stated the medicines were making her ill and that her body was so "dry." Grounded in the spirit cause of illness and slowly weakening from inadequate nutrition, Felin Lo had ideations that her family was poisoning her so they could eat her when she died. Felin Lo told her family that if she died and they ate her, she would come back and make them die too.

Nurse Ivanna Helpya contacted Mr. Savin Thapeeple, the Health Officer, and Ms. Colleen Soapnwhater, the Communicable Disease Program Manager, for consultation. Nurse Helpya reported that Felin Lo was not doing well, refusing food and medications, and that she advised the family to take Felin Lo to Dr. S. Putum. Given Felin Lo's fragile condition, the risk to the family and the public, and the uncertainty that she would agree to go to Dr. S. Putum, Savin Thapeeple considered legal action. He consulted Mr. Idee O'Logical, the County Corporation Counsel, and a joint decision was made to mandate Felin Lo to the hospital. A court hearing was scheduled with Ms. Lotsa Wurds, a bilingual health professional representing Felin Lo. Unexpectedly, Ah Chue, the daughter-in-law, was able to convince Felin Lo to voluntarily enter the hospital.

Felin Lo was admitted to the hospital and received treatment for dehydration but continued to refuse to take medications as directed and couldn't tolerate food or the medications well. The family expressed concerns that if Felin Lo returned home and continued to refuse treatment, they and their children would be at risk for contracting the disease.

The court hearing to mandate Felin Lo's isolation was held on day three of her hospitalization. Savin Thapeeple and Idee O'Logical represented the needs of the community. Mr. Thapeeple described the nature of the disease and the risk to public health. Felin Lo was represented by Mr. Iben Cheetinum, an attorney, with assistance from Ms. Wurds, and was able to join the proceedings by phone. The Court upheld the recommendation of the Health Officer and ordered Felin Lo to remain hospitalized or maintain compliance with the treatment upon discharge. If noncompliant she would be returned to the hospital or some facility with suitable isolation capacity[4].

Felin Lo agreed to comply and, shortly thereafter, was discharged home. Nurse Ivana Helpya resumed DOT visits at the home and noted Felin Lo was not eating much. Within ten days, she was readmitted to the hospital with elevated liver enzymes and gastrointestinal pain. At this point, Dr. Michael Bacterium suggested a peripherally inserted catheter (PIC) be placed to assist with the administration of the medications. The family agreed; however, Felin Lo refused to sign the consent forms necessary to allow for the procedure and placement of the PIC.

The hospital ethics committee was asked to review the case and a psychological consult was ordered to determine Felin Lo's competence in relation to her ability to make health care decisions. The psychiatric review indicated she was not competent and, therefore, unable to make her own decision regarding her health. She apparently did not understand that treatment would prevent her own death. There were questions regarding her understanding of the disease and how her cultural beliefs impacted her willingness to accept death as an option. The ethics committee considered the many cultural

competency issues and her lack of understanding of the disease being germ-based rather than spirit-based. Also under consideration was the risk to others in the community, if she was not treated. A secondary concern was the precedent this case would set and the message it would send to the broader Hmong community regarding the public health response to TB. It was somewhat likely that another Hmong person with a history of exposure would convert to active TB infection later in life. The ethics committee decided, because of her risk to others, that there should be a limitation on her individual rights and that treatment should, in fact, be continued despite her wishes. On the same day of the ethics committee decision, Felin Lo agreed to voluntarily have the PIC placed for the continuation of treatment.

The discussions and decisions made as a part of this case were precedent setting for the community. The issues raised are important to the understanding of the need for access to affordable health care, social and economic factors, and the cultural disparities that exist in the realm of "assurance" of health care.

Closing -Episode VI: Return of the Ethical Mandate

Hmong refugees in the Thai camps had been shown magazine pictures of a turkey roasting and the belief was that this was a baby who had died. The rumors began that Americans eat people, resulting in Felin Lo's belief that "If I Die, You Will Eat Me." As cultures intertwine in our communities, we need to assure that the needs, values, and beliefs of all parties involved will be honored, without risking the health of the broader community.

The Principles of the Ethical Practice of Public Health document reflects "the rightful concern for the physical individuality of humans and one's right to make decisions for oneself must be balanced against the fact that each person's actions affect other people[5]."

The mandate to assure and protect the health of the public requires us to deliberate and make decisions involving a multitude of factors relevant to a particular issue. This case study demonstrates the steps that were taken and the importance of collaboration between community partners to protect the health of the public.

References

1. Information in the introduction comes from two sources: (a) personal communication with Savitri Tsering, Refugee Health Coordinator with the Wisconsin Division of Public Health, and (b) a paper, *The Hmong in the United States: a Demographic Profile*, written by Emily Heberlein for a Population and Policy Class in May 2003.
2. Fadiman, Anne. *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures.* (1998). North Point Press.
3. Centers for Disease Control and Prevention. Treatment of Tuberculosis, American Thoracic Society, CDC and Infectious Disease Society of America. *MMWR* 2003:52(No. RR-11): [inclusive page numbers].
4. Wisconsin Statute, Communicable Diseases (s.252.07) and Wisconsin Administrative Rules, Chapter HFS 145, Control of Communicable Diseases (s.145.08-145.13).
5. Public Health Leadership Society. (2002). *Principles of the Ethical Practice of Public Health*, Version 2.2. New Orleans, LA.

"If I Die You Will Eat Me"
Public Health Challenges Related to a Hmong Refugee TB Case

Teachers Guide

In Wisconsin, the core public health functions (assessment, policy development, and assurance) are mandated in state law and administrative rule. They are required authorities of the Wisconsin Department of Health and Family Services, local health departments, and local boards of health. Wisconsin has identified 12 Essential Public Health Services.

Assurance is the focal point of this case study. The 2010 Wisconsin State Health Plan defines assurance as: "addressing current/emerging community health needs/threats through governmental leadership and action with the public health system partners; taking necessary/reasonable action through direct services, regulation, and enforcement; and evaluating improvement plans and actions and providing feedback to the community."

The essential public health services that flow out of the core function of assurance in Wisconsin include:

- Enforce laws and regulations that protect health and insure safety.
- Link people to needed health services.
- Assure a diverse, adequate, and competent workforce to support the public health system.
- Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
- Assure access to primary health care for all.
- Foster understanding and promotion of social and economic conditions that support good health.

Questions to Consider:

1. What could the local health officer and local board of health do to assure that the health care workforce understands communicable disease laws and reporting suspect/actual communicable diseases to the local health department?

2. How might communications be strengthened between the local health department and the community's health care providers in order to assure a diverse, adequate, and competent workforce to support the public health system?

3. Do the major institutions in the community (health care, hospitals, human service) understand the public health ethics that come into play in this case? Specifically, do they recognize how the health department carries out the following ethical principle? "Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community[5]."

4. Should the health officer convene his/her staff and the medical care community to jointly evaluate what worked and what didn't in order to improve service delivery

processes in the future? How such actions might be related to the following public health ethical principle? "Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others[5]."

5. Should the health officer invite the family members to join in the process evaluation identified in question #4 above?

6. How is a cultural competency assured when administering a competency assessment?

7. When a patient is deemed incompetent, and then makes a decision that is supported by the medical providers, how does this affect the status of "incompetent?" Then, if the patient makes a subsequent decision to not receive treatment or utilize an unauthorized treatment, how does this effect competency status?

8. When is it appropriate to supersede the rights of an individual for the protection of the individual or of the community?

9. How do refugees become acquainted with the healthcare system upon entry into the United States?

10. When would you not use the standard 4-drug treatment for active tuberculosis?

11. When is it appropriate to collect sputa for analysis?

12. In this scenario, why are children at greatest risk of becoming infected with tuberculosis?

13. What contacts might you consider outside of the immediate family?

14. How would you try to convince this client that you were not "trying to poison her?"

15. What steps could be taken to develop, nurture, and sustain a strong partnership between the local health department and the federally qualified health center? What are the shared community interests between these two community entities when it comes to accessing and providing services to at-risk and/or low income population groups in the community?