



# The Value of Guidance

Fei Wang, BA; Ivy Leung, BFA; Melissa A. Simon, MD, MPH

(Fam Med. 2019;51(4):358-9.)

doi: 10.22454/FamMed.2019.256549

**T**he day after leaving my hometown of Boshan, China and moving across the world, my mother took me to a community clinic in Brooklyn for the required school vaccinations. I remember the fluorescent lights, the crowded waiting rooms, and the uncomfortable chairs. I remember watching my mother with the receptionist, not understanding their speech but sensing a growing panic. I remember how much I wished someone was there to help us when the receptionist turned us away because she couldn't understand our broken English.

Fifteen years later, I now work as a patient navigator in Chicago's Chinatown. As this personal story illustrates, patient navigators often provide underserved patients with essential services that complement the care provided by physicians.

It's a crisp winter day, and I am chatting in Mandarin with a woman as we sit in the waiting room of a hospital. When the receptionist calls her name, I accompany her and hand over a folder of materials we had prepared earlier in the week. When we finally see the doctor, I stand to the side and gently interpret the results of her screening mammogram from English to Chinese. When the doctor leaves, the woman and I linger behind, conversing in Mandarin once more and scheduling her next follow up. She thanks me and I can't

help but feel like it's fate that I've ended up in this work.

When I first started as a patient navigator, I was mentored by Ivy, our lead. We worked on learning culturally appropriate bedside manner for Chinese patients, how to address most commonly asked questions, and the best ways to link patients and community groups. Since then, I've interpreted for patients during their mammograms, before their surgeries, and during their chemotherapy treatments. Most of the time, the work is routine and simple—we see patients once a year for their exams and send them home with normal results.

However, the results sometimes come back abnormal. That was the case for Nina, a young mother with two sons who worked double shifts as a waitress every day.

Born in Liaoning, China, Nina moved to Chicago's Chinatown in 1998 and settled there with her husband and two sons. Her husband works full time as a masseur and she works at local restaurants while taking care of a family with two teenage boys. After enrolling in the navigation program, she had her first mammogram since moving to the United States almost 2 decades ago. When we received an abnormal result, Ivy, our lead navigator, immediately scheduled a diagnostic mammogram and biopsy at Mercy

Hospital. The tests showed that Nina had ductal carcinoma in situ, an early stage of breast cancer. Immediately after her diagnosis, Nina was devastated. She wanted to go the natural (自然) route, believing strongly in her cultural traditions and that "American doctors wouldn't understand me." She declined treatment and instead believed that traditional Chinese medicine—acupuncture and herbal remedies—would cure the cancer.

Deeply worried, Ivy reached out and implored Nina to consider Western medicine. After hours of phone calls, meetings, and consultations with Ivy, Nina eventually opted for a lumpectomy to remove the cancerous tissue.

However, convincing Nina to accept treatment was just the beginning. The lumpectomy revealed more extensive tumor growth than previously thought, and surgeons could not remove all of the diseased tissue. Exhausted by surgery and the bad news, Nina had a difficult recovery while Ivy hurried to schedule a mastectomy that would remove cancerous tissue left behind by the lumpectomy and subsequent

---

From the Department of Obstetrics and Gynecology, Feinberg School of Medicine, Northwestern University, Chicago, IL (Mr Wang and Dr Simon), and Chinese American Service League, Chicago, IL (Ms Leung).

reconstructive surgeries. However, before the surgeries could go ahead, Nina was told that her insurance no longer qualified. For many hospitals, the accepted insurance list changes on a regular basis. But, with her surgery already scheduled, Nina was stuck.

Ivy asked me to help Nina navigate through her insurance options. Initially, I thought resolving this would take nothing more than a simple phone call. But after the eighth “please hold,” I quickly realized that it was not going to be easy. It took several weeks of navigating automated answering menus, waiting for a human representative, and hours of talking to various insurance departments before the issue was resolved. The surgeries went as planned. Nina was declared cancer free in May of 2015 and everyone breathed a sigh of relief.

Today, Nina is nearing her 2-year anniversary without cancer. She still checks in for regular breast and cervical cancer screenings. We chat about her sons, the hot Chicago summers, and trade recommendations about local restaurants. She continues to reside in Chinatown and is pursuing a career in health care so she can help other women facing

similar challenges she herself had overcome.

It’s not difficult for me to imagine what might have happened had Nina not been a part of the navigation program. She might have become one of the many women who receive their cancer diagnosis at the emergency room, often at a stage where treatment becomes extremely difficult. She might not have been able to switch her insurance due to language and time barriers and been denied her mastectomy. Or, she might have opted to stick with Chinese traditional medicine as her sole treatment. Nina often tells us how thankful and lucky she is to have found the patient navigation program, and how we were able to make the confusing and scary process of cancer care a little less so.

For me, Nina shows the value of patient navigation and how it can be a lifeline for many in similar situations. Like Nina, many Chicago Chinatown residents work long and irregular hours, struggle to make ends meet, and have limited English proficiency. Growing up in a community of Chinese immigrants, I’ve witnessed providers relying on patients’ children to interpret or using Google Translate to communicate

with non-English-speaking patients. Although sometimes effective, this often leads to misunderstanding and confusion, especially around medical terminology.

Patient navigation is often seen as a Band-Aid approach to holding together a fractured system of care. Until those fractures are systematically addressed, you can find us patient navigators around Chinatown and its hospitals, navigating our patients, one step at a time.

**FINANCIAL SUPPORT:** This work was supported by the National Institutes of Health grant R01CA163830.

**DISCLAIMER:** Melissa Simon is a member of the United States Preventive Services Task Force (USPSTF). This article does not necessarily represent the views and policies of the USPSTF.

**CORRESPONDING AUTHOR:** Address correspondence to Dr Melissa A. Simon, Robert H. Lurie Comprehensive Cancer Center, Northwestern University Feinberg School of Medicine, 633 N. St Clair, Suite 1800, Chicago, IL 60611. 312-503-8780. m-simon2@northwestern.edu.