Navigating Care for the Uninsured

Authors: Alexandria Taylor, Brady Marburger, Thomas Hagerman, Mike Bowersox, Iman Hassan

Learning Objectives:

- To identify lack of insurance as a significant barrier to care
- To identify the impact of spirituality and social support on health outcomes
- To incorporate the concepts of cultural sensitivity into clinical care
- To develop multi-level solutions for helping uninsured patients overcome barriers to access, recognizing how inter-disciplinary teams can be utilized to help uninsured patients navigate the healthcare system

Case Synopsis:

Ms. P is a 70-year-old Pakistani woman with diabetes presents to a local free clinic with fatigue, persistent bloody nasal discharge, recurrent post-menopausal vaginal bleeding, vision problems and poor dentition.

Patient had a recent emergency room admission for facial bleeding and nasal obstruction and was found to have a nasopharyngeal and left cavitary mass with biopsy consistent with mucosal melanoma and requiring resection. She was also recently found to have endometrial thickening on pelvic ultrasound and endometrial biopsy showing complex atypical hyperplasia.

On this visit, her A1c is found to be uncontrolled at 9.2. She is taking Metformin 1000mg twice daily, Glipizide 10mg twice daily and NPH/Regular Insulin 70/30 at 14 units in the morning and 16 units at night.

Ms. P immigrated to the United States from Pakistan with her husband in the 1980's. Unfortunately, shortly after immigrating her husband died of a heart attack, leaving Ms. P alone. She is currently undocumented and does not have health insurance. For the last few years, she has been obtaining healthcare from an interprofessional free health clinic that provides medications free of charge. Ms. P has relied on a network of distant family members and friends. She currently lives about 45 minutes away from clinic with a young couple outside of the city limits, and has difficulty attending medical appointments. Ms. P completed a secondary level of education in Pakistan, attending beautician school, but never worked formally in the US. She has difficulty speaking and understanding English. She did not have children of her own, but helped raise multiple children in her extended family. Her Islamic faith is very important to her and she practices prayer (salat) multiple times a day at her home.

Questions:

1. **Construct a problem list for this patient**
2. **Conduct a root-cause analysis for each problem**
3. **Describe positive/protective social determinants of health for this patient**
4. **Describe negative social determinants of health**
5. **Propose patient-level solution with attention to facilitators and barriers**
6. **Imagine possible health system or institutional solutions**
7. **Discuss potential community/societal-level solutions**

Facilitator's Guide:

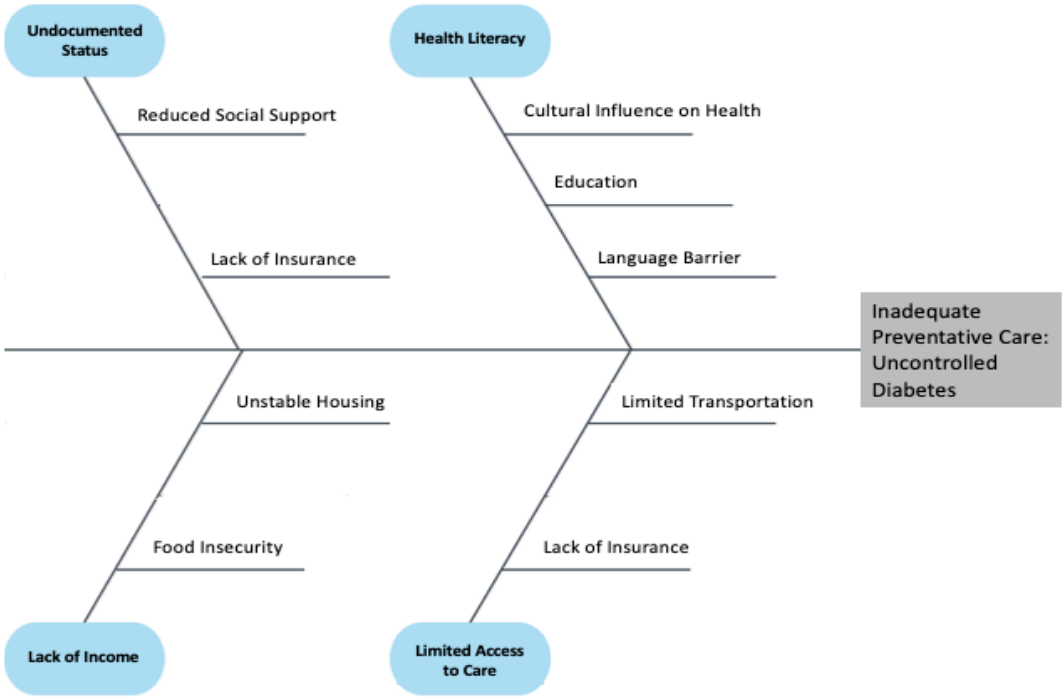
1. **Construct a problem list for this patient**

   A reasonable list would include the following:
   - Uncontrolled Diabetes
   - Mucosal Melanoma requiring treatment
   - Endometrial Hyperplasia requiring hysterectomy

   Encourage students to add lack of health insurance and undocumented status to the problem list.

2. **Conduct a root-cause analysis for at least one problem**

   Ms. P's undocumented immigration status, lack of insurance and, consequently, lack of access to preventative health care likely resulted in her late diagnosis and treatment of diabetes and inability to obtain treatment for her melanoma and endometrial hyperplasia. Her long commute makes it difficult to access services that might be available in the city for patients without insurance. Food insecurity has likely also contributed to a less than optimal diet.



3. **Describe positive/protective social determinants of health for this patient**

   Ms. P presented with several positive social determinants of health. Some of these include:

   - Social Support: Ms. P had a strong social support system that extended beyond just her family. Her support system included friends of friends and contacts within the Pakistani and Muslim community. This support system provided her with transportation, housing, and food, giving her a sense of security that she might not have had otherwise.

- Education: Ms. P had an unusually high level of education compared to most Pakistani women, having completed a secondary level of education. This education was clearly beneficial when having to understand medication changes and complex health problems. It also was apparent in her awareness of her blood pressure and lab values.

- Spirituality/Religion: Her strong spiritual health had a positive effect on her mental health and outlook on life. Her Muslim faith influenced her understanding of her nasal mucosal melanoma diagnosis. She believed that through prayer Allah would help her with her cancer.

4. Describe negative social determinants of health

Unfortunately, Ms. P also had to contend with a number of detrimental social determinants of health. Ms. P faced many challenges from an individual, health systems and societal perspective. At the individual level, she had barriers simply getting access to care because of her immigration status, lack of income, and location.

- Undocumented Immigration Status: Since the time of her husband's passing shortly after immigrating to the United states, Ms. P was unable to find work or gain access to Medicaid, Medicare, or any private insurance due to her undocumented status. Her lack of insurance and income left her with extremely limited options for healthcare, housing and food. This had a profound impact on her health over the years. Her immigration status and lack of income left her without access to consistent care and preventive screenings that may have allowed for earlier identification of her health problems.

- Housing Instability: With the government taking such a strong stance against immigration, particularly from Muslim-majority countries, many of Ms. P's friends now fear the potential repercussions of providing her aid. This has threatened Ms. P's housing and made her vulnerable to housing instability and homelessness.

- Lack of Health Insurance: As an undocumented immigrant, Ms. P is not eligible for Medicare or Medicaid. Her immigration status and older age eliminated her from the workforce and with no job and no source of income, she had no avenue for purchasing individual insurance on the private marketplace.

  The Henry J Kaiser Family Foundation released a report in 2019 concerning the health coverage of immigrants. They report that 45% of undocumented immigrants are uninsured compared to 8% of citizens.[1]

- Reduced Access to Food: She relied on the people she lived with and other friends to provide her with food and necessities. This dependency prevented her from choosing her own groceries. At times, her only options were carb-based meals which made it more difficult for her to control her diabetes.

- Language Barrier: English is Ms. P's second language, making communication with us difficult at times. The language barrier, along with deterioration of her eyesight due to old age, made it difficult for her to read her prescription bottles.

- Lack of Transportation: Because of her location and limited access to transportation, it would often take her two buses to come to her monthly appointments at the free clinic when she traveled alone. In addition, she had to find transportation to other appointments across Pittsburgh for cancer screenings and treatment, sometimes as often as five times a month. At times she was able to receive rides to her appointments from her friends, but the inconsistency and difficulty of transportation still made it an additional challenge for her.

5. Propose patient-level solution with attention to facilitators and barriers

Ms. P was able to obtain care through a local free health clinic, which included an interprofessional team of health care providers, including physicians, medical students serving as health care navigators, and on-site pharmacists and pharmacy trainees. Since 1978, the World Health Organization has advocated for interprofessional collaboration as a solution for providing accessible, affordable, and quality health care. Research demonstrates that an interprofessional approach to health care can reduce medical errors, hospital readmissions, decrease mortality rates, and improve health outcomes for those with chronic conditions.[2]

Overall, the language barrier and cultural differences played a big role in Ms. P's health. We had to be diligent in addressing any discrepancies in understanding or urgency of issues in order for Ms. P to feel like all her health needs were being addressed. Below are some solutions we implemented:

- Spiritual Assessment: While providing care for Ms. P, we learned how valuable spirituality and a faith community can be to one's overall health. When initially diagnosed with nasal mucosal melanoma, Ms. P turned to her faith and prayer. It brought her peace during this terrifying time in her life. A worker at the clinic was often able to provide Ms. P with a prayer space when the care team was running late. This important accommodation promoted a safe environment for Ms. P and was an acknowledgement of the importance of her faith in her medical care.

  Joint commission states "Spiritual assessment should, at a minimum, determine the patient's denomination, beliefs, and what spiritual practices are important to the patient. This information would assist in determining the impact of spirituality, if any, on the care/services being provided and will identify if any further assessment is needed. The standards require organizations to define the content and scope of spiritual and other assessments and the qualifications of the individual(s) performing the assessment [with many organizations requiring chaplains to be board certified]."[3]

- Culturally-competent Dietary Counseling: Overall, we lacked any genuine knowledge of Ms. P's foods that would allow us to connect with her and talk about changing her diet. To address this, we found a food chart on the Pakistani diabetes association website. Using this chart to help Ms. P discuss food choice options had a profound impact on her diabetes care. She could finally talk

to us about food in her terms, and we could understand and make suggestions that she was comfortable implementing. We made a plan to decrease from two spoons to one spoon of sugar for her tea in the morning. It may not have been a huge change, but it felt like a substantial win.

Research has shown that provider patient communication is linked to patient satisfaction, adherence to medical instructions, and health outcomes.[4] Thus, poorer health outcomes may result when sociocultural differences between patients and providers are not reconciled in the clinical encounter.[5]

- Pharmacist-led Counseling: Pharmacists assisted in pharmacotherapy decision making, medication counseling, and medication access. Before leaving clinic each month, Ms. P was counseled for 5-10 minutes on how to take each of her medications and any concerns were addressed by the pharmacy team. When counseling Ms. P on her medications, the pharmacy team, upon request of Ms. P, wrote the medication name and instructions on the bottle in extra-large font so she could read it easier and better adhere to her medications.

6. Imagine possible health system or institutional solutions

- Patient-Centered Healthcare: The free clinic consistently provided her with the utmost respect, showing her that they see health care as her human right. We often encouraged her to ask questions and worked hard to create a safe environment where she felt she could share about her past and current worries. She was able to contact the clinic care team at any time by phone, which helped alleviate the stress of knowing who to contact for what problem.

- Health Navigators: Health navigators accompanied Ms. P to as many appointments as possible. When connecting her with an immigration lawyer, the navigators helped provide information about her care and helped Ms. P ask important questions. When getting her dental care, a navigator used three-way calling to talk with the dentists and push for her to be seen. When she needed to be seen in the emergency room for an emergent eye issue, we accompanied her there to ensure she was seen specifically by an ophthalmologist.

- Transportation: Although friends most often brought Ms. P to her multiple health appointments, a taxi service account from the local free clinic provided a backup plan to get her to a dentist appointment in case her ride fell through.

- Safety-Net Healthcare System: The very existence of the free clinic was critical to providing Ms. P with the proper care she needed. Free clinics and other healthcare organizations which fall outside of the traditional insurance-backed system are vital to providing care to underserved populations. This “Safety Net System” includes other facilities such as public hospitals and Federally-Qualified Health Centers (FQHCs). To address Ms. P’s lack of insurance coverage for necessary resection of her nose cancer, we helped her get emergency medical assistance (EMA). The EMA process left her waiting for multiple months before she found out if she would have coverage for her procedures. It took more than one scheduled surgery date for Ms. P to obtain her needed hysterectomy. After this coverage expired, we then worked to get her into a

financial assistance program at a local health system for the ongoing surveillance of her mucosal melanoma. This coverage also helped her get a hysterectomy after a medical assistance application was submitted by her gynecological oncologist.

7. Discuss potential community/societal-level solutions

- Immigration Status: To address her immigration status, a significant underlying cause of her housing instability and lack of consistent medical insurance, the team worked with a local immigration-law nonprofit-organization that had a relationship with the free health clinic. After introducing her to the staff there, they were able to visit her home and get more detailed information. While we did everything in our power to try and help Ms. P, the immigration agency was unable to obtain legal status for Ms. P. A clearer path to citizenship would go a long way in addressing some of Ms. P's most foundational needs.

- Housing Support: An organization based at our free clinic with extensive community partnerships found information about a local Islamic community center that provided housing support for Ms. P. We also discussed with her the option of staying at local shelters, but she was understandably opposed to this. In the end, her friends were able to provide her housing, but she had to move with them to a new state in order for this to happen. This again highlights the need for immigration reform. In the meantime, local housing programs are needed to serve as a safety net for undocumented individuals at higher risk for homelessness.

- Healthcare Coverage: Ideally, the best solution to address her lack of insurance would be the implementation of a universal health care system. Such a system would have allowed Ms. P to get access to the necessary care without going through the hassles and delays of applying for EMA, waiting for her application to be processed, eventually losing that coverage, and then applying for financial assistance through the local health system. In addition, there needs to be immigration reform that would allow people like Ms. P to gain access to universal healthcare coverage. Without these changes, lack of insurance and access to care will continue to be a problem for Ms. P and other immigrants who seek opportunity in this country.

- Physicians have a unique platform to advocate for policy changes that would address the social determinants affecting Ms. P. Encourage learners to think of ways they can get involved in local, state and national advocacy initiatives.

What was the actual patient outcome in this case?

Fortunately, through advocacy on behalf of the multidisciplinary team at the free clinic, EMA through the State of Pennsylvania, and aid from a financial assistance program at a local health system, Ms. P was able to receive the proper care. Although Ms. P was provided free healthcare through the local free clinic, she still faced barriers gaining access even to that care.

Ms. P's underwent nasal melanoma resection and subsequently had a year of benign PET/CT scans; it appeared she was fully in remission. She recovered well from her hysterectomy and was not found to have any signs of endometrial cancer. Throughout this time, and especially after the radiation, the condition of

her teeth continued to decline and each month she seemed to lose another tooth. She eventually started eating softer foods and her A1C slowly went down. She began to have multiple hypoglycemic episodes each month. It was clear that the poor quality of her teeth was making it difficult for her to eat enough to keep up with her dose of anti-hyperglycemic medications. As such, her dosage was slowly dropped. She saw an oral surgeon for an initial consultation, but because of lack of dental insurance never was able to have a procedure. The month before she was to lose her housing, she came to clinic to inform us she would be moving south with another friend. We researched free clinics within the new area and prepared summary papers to take to her new provider. At the last clinic appointment Ms. P had been out to eat with friends for a goodbye meal. She talked at length about the delicious meal that she shared with them and showed us a cherished video of all of them around the lunch table smiling and making jokes. Her positive spirit was infectious.

Many of Ms. P's barriers to good health stemmed from her immigration status and lack of income. She was able to overcome many of those hurdles through the help and goodwill of her friends, who provided her housing and food for many years. With the current national stance against immigration, many of Ms. P's friends now fear the potential repercussions of providing her aid. As such, she has now been forced to find new housing and move with a different friend to a new state. With that move, her previous struggles with access to care will continue to reoccur. We have been making efforts to find a new free clinic that can provide her with care, however, getting her access to the cancer screenings she was able to get through the local health system's financial assistance program will be difficult. Thus, it will be a continuing battle for her to overcome the individual and societal barriers to good healthcare.

Final Update: Since we last had the privilege of caring for Ms. P, she has relocated back to Pakistan to live with family and friends. We are unsure of how she was able to acquire the documentation to do so but she made it without issue. She sent a video of her playing with children she helps care for at home, and even a welcome party when she first arrived at the airport. While she appears to have increased social support in Pakistan, we hope she will be able to access the medical care she needs as well.

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