

Dialysis nonadherence by Thuy Bui, Sharon Higginbothan, Dean Dranko and Iman Hassan

Learning objectives:

1. Explain how racial discrimination could result in treatment nonadherence
2. List strategies to help dismantle institutionalized racism when it comes to caring for minority communities with end-stage renal disease (ESRD)

Case synopsis:

Mr. B., a 36-year-old man, was repeatedly admitted for inpatient dialysis. He started dialysis about one year ago after his kidneys had failed from years of diabetes type 1 and hypertension. He was known for missing several dialysis sessions in a row and was ultimately discharged from one dialysis center. The hospital social worker was told that it would be difficult to get him accepted at another dialysis center due to “behavioral issues.” On this admission, Mr. B was advised to remain in the hospital for dialysis until the staff could get him accepted at another facility. However, he ended up leaving against medical advice (AMA) after 5 days because he could not wait any longer. His blood pressure reading was 165/99 on discharge; pulse was 110. Hemoglobin was 9.8 and A1C was 6.0.

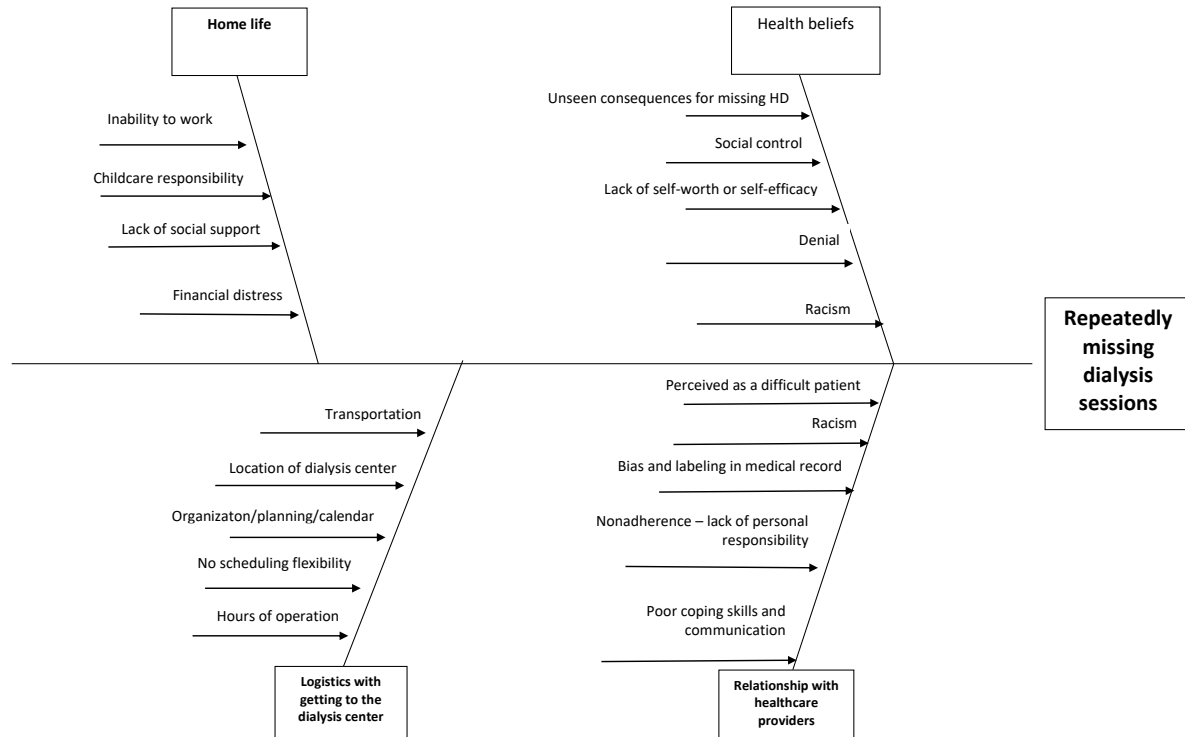
Following his admission, a physician from the Enhanced Care Program (ECP) tried to engage him in the hospital as well as during a subsequent home visit. ECP is a medical home for patients with complex medical problems who have frequent ED visits and admissions. Mr. B did not have a PCP prior to this. The ECP physician learned that Mr. B was a father of two young boys. The boys’ mother, Mr. B’s fiancé, worked late hours so he wanted to be home when the boys returned from school in the afternoons. She had never visited him in the hospital nor accompany him to clinic. Mr. B used to work part-time performing basic odd jobs but was no longer working. He did not understand why he was “fired” from the first dialysis center. Asked why he missed so many dialysis sessions, he said that it’s hard for him to make the effort to travel when he does not feel well. He relied on a public bus for transportation. In addition, he did not like to be tied to a machine for several hours. Mr. B expressed concern about dependence on the machine and loss of freedom. He did not understand why it was such a big deal to miss a few hemodialysis sessions. He felt that rules were imposed on him to make his life more difficult. He also felt disrespected by the staff because of his race and appearance. The ECP physician called the dialysis center to inquire about why he was discharged from the facility. She was told by the manager that Mr. B pounded his fists on a TV once because he was frustrated about something, but he did not threaten staff nor was he verbally abusive in anyway. There was random mentioning of “behavioral problems” in his medical record but interviews with nursing staff did not disclose any specific incident.

1. Construct a problem list for this patient
2. Conduct a root-cause analysis for at least one problem
3. Describe positive/protective social determinants of health for this patient
4. Describe negative social determinants of health factors
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.** Mr. B's problem list might be 1) End-stage renal disease (ESRD) on hemodialysis (HD) and no outpatient dialysis center, 2) Poorly controlled hypertension, 3) Diabetes Mellitus type 1, 4) repeated hospitalizations for inpatient dialysis
2. **Root-cause analysis.** For our purpose, ask students to focus on the root causes of missed dialysis sessions. Encourage students to think outside the box. Below is just one example:



According to the Aspen Institute Roundtable on Community Changes, the term **structural racism** refers to a system in which public policies, institutional practices, cultural representations, and other norms work in various, often reinforcing ways to perpetuate racial group inequity. It identifies dimensions of our history and culture that have allowed privileges associated with “whiteness” and disadvantages associated with “color” to endure and adapt over time. Structural racism is not something that a few people or institutions choose to practice. Instead it has been a feature of the social, economic and political systems in which we all exist. Encourage your students to think about how structural racism contributes to each of the root causes they identified. For example, how might structural racism contribute to Mr. B's financial distress, transportation access, risk for bias/labeling in the medical record, healthcare providers' perception of him, and his personal sense of social control?*

3. **Describe positive/protective social determinants of health for this patient.** Mr. B has 2 children and a significant other. Although he does not live with them, they provide purpose and a sense of belonging for him. He has insurance coverage.

4. **Describe negative social determinants of health factors.** Mr. B had limited social support and did not appear to have a good relationship with his healthcare providers. His fiancé was not very involved in his healthcare. He was relying on her income for daily living. He was not able to find work due to his dialysis schedule and not feeling well enough to work. Mr. B took the bus to and from dialysis and often felt too tired to travel by bus. Although we do not know how far his bus stop was, we wonder, are the bus stops conveniently located?
5. **Propose patient-level solution with attention to facilitators and barriers.** It would be helpful to apply two distinct yet related concepts which are central to services rendered by all healthcare providers--cultural competence and ethical decision making. We need to recognize that culture may influence the patient's communication style, beliefs about health, health seeking behavior and treatment compliance and to respect his values and preferences. Respecting Mr. B's preferences will facilitate decision making about his quality of life, which has not been raised. Working through the lens of compassion and respect for human vulnerability will allow his healthcare providers to garner trust and confidence from Mr. B. Sometimes it can start with asking about his priorities which could be anything from gainful employment to participation in his son's afterschool activities, seemingly unrelated to "healthcare" but it assists in building trust which may foster a meaningful relationship between the healthcare providers and the patient. The ECP physician began this process by eliciting Mr. B's views and attempting to understand his perspective. Mr. B might also benefit from connecting with a peer advocate. A peer advocate is someone who has similar conditions and background and who could provide support and mentorship. If he is agreeable, it might be helpful to have a family meeting to garner support for his care plan. Dialysis has profound effects on family roles and relationships, changing identify, and balance of power within relationships. Some healthcare providers thought that Mr. B had difficulty communicating with healthcare staff about his frustration and perhaps practiced avoidant coping mechanisms; therefore, assistance with these aspects from a social worker, therapist, and/or nurse would be helpful long-term. In recognizing the likely role that bias and racism played in the inter-personal interaction between Mr. B and his healthcare providers, accurate and unbiased medical record documentation and communication with fellow providers moving forward is important. Is home dialysis or peritoneal dialysis an option for Mr. B? Patients on home dialysis must be able to manage a lot of the dialyzing themselves or have the means to pay for a caregiver. A mutually acceptable goal for this patient might be not missing more than 2 dialysis sessions at a time.
6. **Imagine possible health system or institutional solutions.** In general, hospitals and practices create rules and regulations that are designed to ensure the best outcomes for patients and to provide a safe and collegial environment for staff. Sometimes, rules and guidelines are imposed to minimize financial risk. The American Medical Association has established guidelines regarding when a doctor may fire a patient, based on its Code of Ethics. Was the dialysis center's action in accordance with these guidelines? In addition, many states have laws about the circumstances under which a doctor may terminate a patient relationship. Should dialysis centers be able to discharge a patient for too many no-shows? Dialysis is a special case since it is a life-saving procedure and there are usually just a few companies that operate all the dialysis centers in a city or region. When does such institutional practice reflect structural racism? And what are potential remedies? In acknowledging the possible impact of racial bias in labeling Mr. B as a patient with "behavioral problems," implicit bias training and increasing diversity and

inclusion efforts might be helpful. When patients have no outpatient dialysis treatment center (for example, if they lack health insurance), they can only get dialysis through the emergency department or inpatient admission. The process of identifying and applying for a new dialysis center can be daunting for some patients. The complex medical and social contexts of patients like Mr. B do not fit into the disease-centered and process driven approach of management of ESRD and dialysis. Why did Mr. B have to remain inpatient in order to apply for outpatient dialysis? What is the rationale for this rule, if any? How could we achieve better patient-centered care for those with ESRD? Potential solutions include flexibility in treatment plan, employing system-wide peer advocate or navigators/promotores, and socioeconomic interventions (assistance with disability income application for example). Lastly, several health plans have ride hailing services for Medicaid patients and perhaps that would make it easier for him to get to the dialysis center and to get to appointments.

7. **Discuss potential community/societal-level solutions.** Students might want to talk about better funding for dialysis, transplant options and resources that would ultimately benefit patients like Mr. B. Facilitators could also steer students toward a discussion of non-adherence. How does our society perceive noncompliance or nonadherence? How do race and class affect our assessment of compliance? Is this labeling a form of medical social control? Nonadherence might be a patient struggling with powerlessness and a sense of dependency on machine and healthcare staff? Nonadherence is also reflective of medical mistrust among certain patient populations. There are several studies which suggest that racial discrimination was associated with lower medication adherence. Racism might also be associated with delaying or not getting healthcare. Do efforts to promote healthcare workforce diversity and inclusion address racism and lead to positive patient experiences and health outcomes? What could we do more as a society to prevent complications or development of diabetes and hypertension in the first place? (examples: food and nutrition policy, taxation on food products and insurance coverage for lifestyle modification)

**Facilitators are welcome to pose to students the questions inserted throughout this document to help guide discussion*

Outcomes:

With a supportive ECP staff and frequent check-in and reminders, Mr. B started going to dialysis at the new center on a more regular basis compared to before. An ECP nurse would call and meet Mr. B at the dialysis center to discuss any issues and facilitate communication with dialysis staff. ECP staff also worked with Mr. B on coping skills and regaining a sense of control over his health. Mr. B still insists on cutting dialysis short after 2 hours citing the need to be home for his children and not wanting to be tied to the machine for 4 hours at a time. Home HD was not an option due to housing limitations and he did not feel he could handle peritoneal dialysis. However, the ECP physician and Mr. B's nephrologist are still exploring other options. Mr. B is encouraged to engage in care to improve his chance for kidney transplant. He acknowledges that transplantation is his ultimate healthcare goal.

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