

HEALING HANDS

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Patient-Centered Care: Case Studies on End of Life

Introduction

People experiencing homelessness have diverse and complex health needs that can become increasingly difficult to manage when individuals are diagnosed with terminal or life-limiting conditions. As **Dr. Pia Valvassori** of Health Care Center for the Homeless in Orlando, Florida, explains, "We're seeing people experiencing homelessness in their 50s and 60s with a number of chronic health conditions that have gone untreated for extended periods of time (such as Chronic Obstructive Pulmonary Disease, diabetes, infectious diseases, severe mental illness, etc.). We have a shortage of affordable housing units so we try to house those who are most vulnerable in permanent supportive housing. Some of the challenges our patients face include severe mental illness, competing priorities, and barriers and stigma associated with accessing care. It is well documented in the literature that the life expectancy of people who experience chronic homelessness is 12 years less than that of the general population." Mortality rates amongst people experiencing homelessness are estimated to be three-to-four times greater than the general U.S. population¹, and the number of older adults without homes is expected to increase to 95,000 by 2050.²

In order to respond to these types of complex situations,

patient-centered care is a therapeutic approach that places the patient at the center of the treatment process. Patient-centered care involves focusing on the needs, values, and wishes of the patient when developing a health care plan. The process of providing patient-centered care can become even more complex when clients are facing the end of their lives. Patient-centered palliative care seeks to relieve suffering and improve the quality of life for individuals who are not likely to recover from their diseases, while also respecting their autonomy and their right to make their own decisions about their health care. The five case studies presented in this issue of *Healing Hands* will highlight issues and challenges that clinicians may confront while providing palliative care to patients experiencing homelessness.

Case #1: Mr. J

CASE STUDY

Mr. J was a man in his mid-50s who was admitted to a recuperative care program in Portland, Oregon, after living outside for 15 years, mostly in a forest. He was admitted to the hospital with severe lung problems and then referred for recuperative care to a residential medical respite care program that provided short-term housing for people with acute medical needs. When first referred for care, Mr. J was

difficult to engage and closed off. He had various beliefs not consistent with the care providers' medical knowledge regarding the impact of any inhaled powder. As a result, he would not take any inhaled powders or anything with steroids in it, believing that they would harm him. Despite his care providers' explanations that steroids are an essential part of effective management of lung problems, Mr. J did not want to take them. The care providers did what they could to arrange his treatment within those limitations, but his fixed beliefs about medications significantly limited therapeutic options.

After Mr. J was referred to the medical respite care program, his case managers learned that he had been receiving a regular disability check but was spending most of the money paying for two storage units filled with furniture from the house that he had left 15 years earlier. At first, Mr. J did not feel he could give up that furniture, but after a month in respite care, he was reunited with a family member and began to pass on some of the stored items to her. Soon after, Mr. J requested of his own volition to be discharged from respite care. He was depressed and had begun speaking about his partner who had died in his arms 10 years prior and was buried in the woods where he had lived; he was heartbroken to think about her being alone in the woods and felt he needed to return to live near her burial place. Despite offers, Mr. J was not remotely interested in treatment for mental health conditions or therapy for depression; instead, he insisted that all he wanted was to be discharged so he could return to the forest.

Dr. Eowyn Rieke, Associate Medical Director of Primary Care at the Old Town Clinic of Central City Concern, explains of this case: "I knew he was discharging himself to likely death... It forced me to question whether he had the capacity to make decisions, [given that he was making a decision] with the likely outcome of him dying... Prior to being discharged back to the woods, there was a moment when I wasn't sure whether I was engaging in traditional medical care where the goal is to get better, or whether it was palliative care with the goal of feeling better, or maximizing function recognizing that he had a life-limiting illness. He was experiencing so much depression and cognitive problems that it was hard to identify whether he could honestly make a decision to forego his medication and the oxygen he needed."

"Work within patients' frameworks. This is especially important with homeless care and people who are disaffected with the system..."

care providers accurately assess their capacity?

- Mental health: What if a person has a mental health issue interfering with his decision-making process? What if depression is playing a significant role and may affect whether the patient makes choices that may lead to likely death?
- Patient's beliefs: What should a care provider do when the patient's beliefs conflict with medical evidence or the care provider's experience?
- Patient's goals: How can a care provider respond when a patient's goals are not in his own best interest?

LESSONS LEARNED

1. Work within patients' frameworks. This is especially important with homeless care and people who are disaffected with the system. In this case, Dr. Rieke transferred all of Mr. J's medications to non-powder form and managed to convince him to take steroids when he realized that he would be giving up oxygen. From a harm reduction standpoint, Dr. Rieke prescribed more than she typically would, realizing that Mr. J would probably not use the medications optimally but that the risk of long-term side effects from misuse were less than the risks of not taking them. The care team then discharged him, as he wished, and encouraged him to come back to respite care by going to the hospital and telling them that he wanted to return for care. Mr. J never returned to the hospital, and Dr. Rieke believes that Mr. J did not survive his return to the forest.



CHALLENGES PRESENTED

- Capacity: At what point do people have the capacity to make their own decisions, and how can

2. Have direct and specific conversations about the patient's goals, particularly in cases that teeter on the edge of curative versus palliative care. As Dr. Rieke explains, "From a palliative care perspective, the questions would have been: How can I make you comfortable, recognizing that your time is limited? But I was still really focused on the getting better piece. In retrospect, I probably would have had a more direct conversation with him about exactly what his goals were, because then it would have been even more patient-directed. I could have said, 'I'm worried you'll die.'"
3. Engage with patients as a team. Dr. Rieke believes that an important component of responding to Mr. J's case was engaging a team of case managers and people to help him get to appointments and access care. "We didn't think he was going to be willing to engage at all," said Dr. Rieke, "so it was especially important in his case to facilitate him in making decisions about his own care. We tried to be explicit about the power he had in the situation and emphasize that he was in charge of his own care." Still, Dr. Rieke wishes that agencies had more capacity to interact with people on the far edges of engagement due to logistical and attitudinal barriers. "More outreach could help overcome these barriers," she says, "and create more opportunities to have these crucial conversations."

"I have been able to see how managing withdrawal and managing substance abuse in the context of a palliative care treatment plan does not always exist for patients experiencing homelessness."

- LAWANDA WILLIAMS, DIRECTOR OF HOUSING SERVICES, HEALTH CARE FOR THE HOMELESS, BALTIMORE, MD

Case #2: Ms. L

CASE STUDY

Ms. L is a 47-year-old African American woman who was diagnosed with vulvar cancer at the beginning of 2017. She is also HIV-positive. By the time Ms. L engaged in care, the cancer had proliferated quite quickly in the setting of a compromised immune system. Upon discovery of the Stage 4 cancer, doctors recommended a dose of radiation and chemotherapy. However, during the course of this episode Ms. L was struggling with substance use. During her hospitalization, she tested positive for a number of substances, including heroin and cocaine.

As a result, care providers had many discussions about pain management and which pain medications could be given to her. She was not on methadone treatment maintenance at first, so she was self-medicating to address

her pain. While Ms. L wanted to seek help for her addiction to substances, some of the traditional models were not appropriate given the magnitude of her physical issues. There were expectations that she would get into outpatient treatment but she did not follow through, primarily because it was difficult for her to tolerate being in groups for long periods. (Given the location of her cancer, she could not sit upright for long periods or on the bus for transportation.)

Ultimately, **Lawanda Williams**, Director of Housing Services at Health Care for the Homeless in Baltimore, Maryland, and her team were able to provide Ms. L with transportation and cab vouchers so she could access the full course of radiation that doctors had recommended. Her pain was never well controlled, because her physician refused to prescribe her any pain medications, due to the magnitude of her substance use. The radiation center gave her Percocet while she was there but would not give her anything that could not be directly supervised. After treatment, they sent her home with prescriptions for Tylenol and instructions to return and follow up with pain management teams, which she was unable to do because of her difficulties with transportation and sitting.

Ms. L completed radiation and is in a period of holding to assess effectiveness of the initial course of radiation, but she still does not have a prescription for her significant pain and, as a result, continues to use substances to manage her pain. Ms. Williams observes, "I have been able to see how managing withdrawal and managing substance abuse in the context of a palliative care treatment plan does not always exist for patients experiencing homelessness. She does not fit very neatly into any mainstream treatment model."

CHALLENGES PRESENTED

- Harm reduction: How can care providers best advocate for a harm reduction approach while seeking to deliver palliative care services, including hospice care?
- Withdrawal: What role should withdrawal management play in the development of a palliative care plan?
- Pain management: What are the best pain management approaches for cases in which extreme pain is combined with active addiction? What is the dynamic between balancing a physician's sense of risk

management and concern about overdose with the client's need for adequate pain control?

- Location: What treatment locations can be considered as options for people who need intensive care and palliative care? How do the options change when addiction is also involved?

LESSONS LEARNED

1. Recognize the impact that addiction has on health care. Harm management principles can provide useful perspective on how to best assess the relationship between addiction, addiction treatment, and pain management. According to Ms. Williams, "there's a need for really being able to balance treating addiction as a component of end-of-life care. How does one do that, and how can physicians achieve that as safely as possible?"
2. Consider the client's priorities and desired outcomes. In this case, doctors had at first proposed a radical surgery that would have involved taking off an entire side of her labia, but Ms. L had deep concerns regarding the aesthetic impact of such a surgery. The care plan changed to instead focus on a course of radiation, and Ms. L was relieved that the treatment would not involve disfigurement. Ms. Williams notes: "Initially I was pleasantly surprised to see how well her body responded to the treatment. There are still concerns about what might be going on inside, but aesthetically her result—which was really important to her actually, as it related to her relationship—she got the result there that she wanted."
3. Consider the client's location. As Ms. Williams explains, care providers should develop "an appreciation for the client's location—including where they are staying and whether they are homeless on the streets or in a housed environment that is not conducive to healing or recovery from substance abuse." She notes that actual and potential locations are key for integrating substance abuse treatment, as well: "Often when people have a myriad of different issues, you want to refer out. In some ways, I feel like when individuals are facing end of life, those services should be collapsed in. When we're doing palliative care, I can pull from these other areas. For example, having palliative care physicians and providers who are willing to do substance abuse treatment in tandem, or provide medications that will prevent withdrawal or manage withdrawal. How can the physician manage withdrawal symptoms in the context of end-of-life care?"



Case #3: Mr. D

CASE STUDY

Mr. D was a man in his early 60s. After being unsheltered and uninsured for 5-to-6 years, with an underlying diagnosis of alcohol and substance use disorders, he developed liver disease. **Dr. Pia Valvassori** and her team at Health Care Center for the Homeless managed to help him secure housing, but due to issues with identification, Mr. D was unable to get immediate access to specialty care services. Three weeks after being placed in permanent supportive housing, a caseworker found him unconscious in his unit and took him to the emergency room, where it was discovered that his end-stage liver disease had progressed to the point where the only option was palliative care. However, care providers had no advance directive for the patient, nor documentation of his wishes for end-of-life care.

After being placed in residential hospice care, Mr. D regained consciousness and was able to vocalize his wishes. He expressed that he wanted to be a "full code," meaning he wanted hospital staff to intervene if his heart stopped beating or if he stopped breathing. In the end, he was readmitted to the hospital and his status rapidly deteriorated. The hospital and hospice care provider contacted his daughter, who lived out of state, and he died within 10 days.

CHALLENGES PRESENTED

- Autonomy: Are conversations with patients about their wishes and goals being conducted as soon as possible?
- Beneficence: Are care providers assuming that they know the wishes and best interests of clients without consulting them directly?

LESSONS LEARNED

1. Train staff on the usage and development of advance directives, and introduce documentation early in the process. At Health Care Center for the Homeless, staff are trained by hospice care providers on developing plans for end-of-life care with patients. Staff members now have Five Wishes documents ready to review with clients and scan into electronic health records. "For us," explains Dr. Valvassori, Mr. D's experience "was a lesson that... we are going to uncover all kinds of things once we're able to engage patients, and we really need to put advance directives at the top of list of conversations to have. We can't make assumptions, since we want people to be engaged in making their decisions on their own."
2. Try to access insurance as soon as possible. Mr. D had no health insurance, "sick as he was," explains Dr. Valvassori, "and I feel like a lot of this could have gone differently. For example, if we could get him in to see a specialist, which we couldn't because of insurance, we could have had a diagnosis and could have discussed these things." It can take time to access services because of a wide variety of access challenges and technicalities, so if a patient is very sick, care providers cannot afford a delay in accessing any specialty care that is available.
3. Acknowledge patients' right to autonomy and self-determination. As Dr. Valvassori says, "I think probably one thing I learned is not to impose our own personal views on what we think a patient will want... We were surprised when in a lucid moment he verbalized 'full code'... So we learned about having respect for the patient's perspective, and not going in with your own preconceived notions."

"I think probably one thing I learned is not to impose our own personal views on what we think a patient will want..."

- DR. PIA VALVASSORI, NURSE PRACTITIONER AND CLINICAL PROFESSOR, HEALTH CARE CENTER FOR THE HOMELESS, ORLANDO, FLORIDA

Case #4: Mr. X

CASE STUDY

Mr. X is 61-year-old Army veteran. He was a healthy furniture repairperson until his 50s, avoiding doctors, and living with his wife and son until about five years earlier when, unfortunately, both his wife and son passed away. He became depressed, increased his drinking, and lost his job and his housing. He became connected to care through the homeless primary care clinic and housing resources at the US Department of Veterans Affairs (VA). He was fearful

and paranoid about all doctors, blaming them for the deaths of his wife and son.

Over the next three years, he slowly engaged with VA care and services. Currently, Mr. X receives a small disability stipend and chooses to live in a long-term motel. He was diagnosed with depression, alcohol use disorder, B12 deficiency, and progressive loss of function of his arms and legs. He was also diagnosed with cervical spondylotic myelopathy after C3-C6 laminectomies and fusion in 2015, which were unsuccessful in restoring function. At present, he has significant upper extremity bilateral weakness and spasticity in his lower legs, and has sustained countless falls in the community.

According to **Dr. David Rosenthal**, Assistant Professor of General Internal Medicine at Yale Medical School and

Medical Director of the Homeless Patient Aligned Care Team for VA Connecticut, throughout Mr. X's illness and multiple hospitalizations related to intoxication and falls/fractures, he has maintained a fiercely independent streak and regularly refuses care by home agencies. On multiple occasions, Dr.

Rosenthal's team has been informed by VA or Mr. X himself that he has fallen, but he refuses to seek medical care. He refuses most medical care and all mental health care and substance use treatment recommendations.

CHALLENGES PRESENTED

- Substance use: If a patient is able to clearly understand risks and benefits of treatment while sober, but not while intoxicated, how can a care provider account for the role of substance use in determining decision-making capacity?
- Refusal of care: How can care providers respond to patients who refuse care that would be in the best interest of their health?
- Outside agencies: What role could or should elderly protective care play in a case like this?

LESSONS LEARNED

1. Capacity is not static. A patient's capacity for decision-making is constantly changing and should be assessed regularly by clinicians. "Competence" refers to a patient's legal ability to make decisions, while

"capacity" refers to their clinical ability; as a result, a patient's capacity can wax and wane.

2. When a patient has capacity to make decisions for themselves, patient autonomy trumps medical beneficence. The core of patient-centered care is a principle of autonomy that allows patients to guide the clinical process. Patient-centered care requires respecting and responding to the patient's values, needs, preferences, goals, and hopes for the future.
3. Remember the emotional needs of the care team, too. As Dr. Rosenthal explains, "When witnessing significant human suffering, as in this case, it is vitally important for teams to openly discuss their concerns and, as a team, validate emotions to avoid caregiver distress and burnout."



Case #5: Ms. Q

CASE STUDY

Ms. Q was a 43-year-old Vietnamese woman who came to the US in 1990 and was diagnosed with HIV and Hepatitis C at that time. She came to the United States with her husband, who was also HIV-positive; her daughter was not infected. Her husband was abusive and their marriage eventually ended. Since her diagnosis, however, Ms. Q has struggled with adherence to antiretroviral therapy. She has been in and out of homelessness since the end of her marriage, often working as a nail technician. At one point, she moved to another state and came back with a CD4 count under 100 and a viral load of 700,000.

According to **Mary Tornabene**, Family Nurse Practitioner at Heartland Health Outreach in Chicago, Illinois, care providers were able to get Ms. Q's CD4 count up to 400, but around that time, Ms. Q complained of constipation. She received medication for the constipation, but it did not help, and care providers learned that the full scope of her symptomology had not been clear due to the language barrier. (Ms. Q persistently refused interpretive services, leading to miscommunications.) Three large tumors were discovered in Ms. Q's colon, and she was diagnosed with Stage 3 colon cancer. The first round of chemotherapy did not help, and the cancer progressed to Stage 4.

Since her cancer diagnosis, Ms. Q has had increasing difficulty securing housing due to her difficulties paying rent and keeping resources, even with financial help from her church and her 25-year-old daughter who lives out of state. Though she qualifies for some rental assistance programs due to her HIV-positive status, she does not want to reveal her status to potential landlords; this is also complicated by the fact that she holds a green card but is not a citizen of the United States. As a result, Ms. Q lived in a shelter and

"When witnessing significant human suffering... it is vitally important for teams to openly discuss their concerns and, as a team, validate emotions to avoid caregiver distress and burnout."

- DR. DAVID ROSENTHAL, ASSISTANT PROFESSOR OF GENERAL INTERNAL MEDICINE, YALE MEDICAL SCHOOL; MEDICAL DIRECTOR, HOMELESS PATIENTS ALIGNED CARE TEAM FOR VA CONNECTICUT

couch-surfed while undergoing chemotherapy. At this stage, she has been placed in a hospice program in a nursing home and is being provided with palliative care.

CHALLENGES PRESENTED

- Language barriers. How can care plans, particularly palliative care plans, be adequately explained to clients with language barriers?
- Cultural barriers. What role does cultural background play in the choices a client may make about their health care?
- Housing issues. What can be done if a client refuses housing assistance or chooses not to connect with resources that are disease-specific out of a preference not to disclose their health status?
- Citizenship or legal status. Consider what reasons immigrants who are undocumented or green card holders might be hesitant to access health care or housing resources that are available to them.

LESSONS LEARNED

1. Approach the conversation about interpreters up front. In Ms. Q's case, she carried a lot of stigma and shame around her HIV-positive status, and did not want anyone—even, for many years, her own daughter—to know that she had the disease. For this reason, she refused interpretive services even though her English skills were not strong enough to successfully navigate the health care system. Ms. Tornabene notes that other options—such as tele-interpreting services that use an anonymous process and do not know the patient's name—can be used whenever a clinician wants to ensure a client that their identity will be protected.
2. Be attentive to ways in which cultural context may affect interactions. Ms. Tornabene explains that she wishes she could have found a Vietnamese nurse to assist with explaining Ms. Q's options to her; for example, she had difficulty understanding the meaning and implications of being placed in hospice care. In some cases, and with the patient's consent, there may be community resources available to assist with cross-cultural communication in cases when clients need to be apprised of their options.
3. Establish ties with family members whenever possible. With the patient's consent and permission, end-of-life care plans can incorporate an element of family reunification or family involvement. In Ms. Q's case, her daughter lives in another state, but Ms. Tornabene has been able to develop a strong supportive rapport with the daughter. Clinicians have the opportunity to promote reunification between the family members while also developing a clinician-family relationship.

Conclusion

Care providers often face difficult and complicated situations when patients experiencing homelessness develop chronic, terminal, or life-limiting health conditions. Patient-centered care requires the development of a standard of care that is accessible, non-judgmental, consistent, multi-disciplinary, evidence-based, persistent, and creative. By focusing on the stated needs and desires of the patient, care providers can provide careful and sensitive care even when thorny and challenging issues arise.

Appendix

What follows is an example of a script (shared by **Annie Nicol**, Director of Homeless Services at Petaluma Health Center in Petaluma, California) that may be used to present the concept of advance directives to patients.

Script for Advance Health Care Directives

HAVE YOU HEARD OF AN ADVANCE HEALTH CARE DIRECTIVE?

- We are encouraging everyone 18 years and older to have one.
- It's a way for you to give instructions about your own health care if you became very sick.
- It also lets you appoint a person to make medical decisions for you if you could not speak for yourself.
- This can be difficult to talk about, but everyone has different things that are important to them in life, and no one is a mind reader. If something were to happen to you and you couldn't speak for yourself, having a written plan makes it a lot easier on family/friends and your health care team, because they won't have to guess what you would have wanted.

WE HAVE A VERY SIMPLE FORM THAT CAN BE COMPLETED. CAN WE GET STARTED ON THAT FOR YOU TODAY?

Part 1: Choose a Medical Decision Maker to make decisions for you if you could not speak for yourself. This should be someone who knows you well and would be able to make decisions for you as you would want.

Do you know whom you would choose?

- **If yes:** great, when you are done with your Advance Directive, it's important to talk to your Medical Decision Maker about your wishes.
- **If no:** here is some information on how to choose a Medical Decision Maker.
- **No one appropriate:** That's okay; you can still complete Part 2.

Part 2: Instructions for Health Care

- Your provider will talk to you about different choices you have for life-sustaining treatment such as CPR, breathing machines, and feeding tubes.
- This section helps guide your Medical Decision Maker and health care team in following your wishes.
- Here are some things to think about that might help in filling out this section.
- **Handouts:** Prepare Sheet / Reflecting on Values

I'm going to play a video for you that explains a little more about Advance Care Planning.

- If you are not sure today about your wishes or you are not ready to fill out the form, it's okay. Please review the handouts/videos and we can talk about it more at your next visit.
- The form needs to be signed by two witnesses. You can take the form home to have it signed, and return it to the health center.

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