



Experiences of care among individuals with opioid use disorder-associated endocarditis and their healthcare providers: Results from a qualitative study



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ABSTRACT

Purpose: Infectious complications of opioid use disorder (OUD), including endocarditis, are rising. Patients with OUD-associated endocarditis have poor clinical outcomes but their care is not well understood. We aimed to elucidate the prior experiences of care for patients with OUD-associated endocarditis and the healthcare providers who deliver that care.

Study design: This qualitative study was conducted through semi-structured interviews of patients and providers at a single academic hospital using a grounded theory approach. Patients meeting DSM-5 criteria for at least mild OUD who had previously completed an episode of care for OUD-associated endocarditis were recruited from inpatient and ambulatory settings. Multidisciplinary care providers who regularly care for patients with OUD-associated endocarditis were also recruited. Interviews were conducted until thematic saturation was achieved.

Principle results: Of 11 patient participants, six were recruited from outpatient settings. Of 12 provider participants, seven cared for patients with OUD “almost always.” Five major themes emerged across patient and provider interviews: stigma-related inequity and delays in care, the social and medical comorbidities of individuals with OUD-associated endocarditis, addiction as a chronic and relapsing disease, differing experiences of prolonged hospitalizations between patients and providers, and a lack of integration or discontinuity of care. Opportunities for care innovation and improvement were identified.

Conclusions: This qualitative analysis highlights multiple patient and health system factors that may explain poor clinical outcomes experienced by individuals with OUD-associated endocarditis. A sick, complex, stigmatized patient population was noted, with new physical and mental comorbidities often developing on top of pre-existing ones. Perceived barriers to effective treatment of OUD-associated endocarditis included the complexity of managing two life threatening illness simultaneously, external stigma towards individuals with OUD, and discontinuity in longitudinal care.

1. Introduction

Opioid use disorder (OUD) and opioid overdose deaths have reached epidemic levels in the United States (Rudd, 2016), driven increasingly by injection use of heroin and synthetic opioids (Martins et al., 2017; Unick, Rosenblum, Mars, & Ciccarone, 2013). While overdoses contribute significantly to opioid-associated mortality, injection drug use-associated infections represent a growing cause of morbidity (Wurcel, Anderson, Chui, et al., 2016). In addition to viral infections such as hepatitis C and HIV, people who inject drugs are at increased risk for invasive bacterial infections, including endocarditis

(Ronan & Herzig, 2016; Fatima, Dao, Jameel, et al., 2017).

The number of hospitalizations for injection drug use-associated endocarditis has risen sharply in the US, particularly among people who use drugs who are younger, white non-Hispanic, and from rural areas (Wurcel et al., 2016; Fleischauer, Ruhl, Rhea, & Barnes, 2017). In a recent retrospective cohort of hospitalized patients with injection drug use-associated endocarditis in Boston, patients received sub-optimal addiction care (Rosenthal, Karchmer, Theisen-Toupal, Castillo, & Rowley, 2016). Among 102 patients, 24% received addiction consultation, fewer than 8% initiated medications for addiction treatment (MAT), which can reduce all-cause mortality for individuals with OUD

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by 50% or more (Clark et al., 2015), and none were prescribed the overdose reversal medication, naloxone. As a result, clinical outcomes were dismal, with 26% of study participants having died at a median age of 41 years.

Care for individuals with OUD-associated endocarditis is complex and expensive, involving long hospitalizations, prolonged post-acute hospitalization care at skilled nursing facilities, lengthy courses of IV antibiotics, continued addiction and heart failure treatment, and mental health care (Fleischauer et al., 2017; Libertin, Camsari, Hellinger, Schneekloth, & Rummans, 2017; Englander et al., 2017). Stigma towards individuals with OUD and internalized shame also negatively impact care for patients with OUD and endocarditis (Wakeman, Metlay, Chang, Herman, & Rigotti, 2017; Van Boekel, Brouwers, Van Weeghel, & Garretsen, 2013; Englander et al., 2018; Velez, Nicolaidis, Korthuis, & Englander, 2017). Optimal care for individuals with both of these comorbid conditions is not well understood.

The objective of this study was to elucidate the experiences of care for people with OUD-associated endocarditis by conducting semi-structured, qualitative interviews with individuals who had completed a full episode of care from pre-hospitalization to eventual return to the community. In order to better understand the implications for the health system of caring for these patients, we also interviewed healthcare providers who care for individuals with OUD-associated endocarditis.

2. Methods

2.1. Setting and context

This qualitative study was conducted at Massachusetts General Hospital (MGH), a 1000 bed academic hospital in Boston, Massachusetts. Since 2012, MGH has developed a comprehensive substance use disorders initiative, going from minimal programming to having an inpatient addiction medicine consult service, a recovery coach program, office based addiction treatment programs in primary care, and a low threshold bridge clinic for on-demand access to MAT (Wakeman & Rich, 2017; Jack, Oller, Kelly, Magidson, & Wakeman, 2017; Wakeman & Kane, 2018). MGH's outpatient practices include 20 primary care practices and 6 community health centers, serving a diverse population including communities impacted by the opioid epidemic (Center for Community Health Improvement, 2018).

The study was approved by the Partners Healthcare Institutional Review Board.

2.2. Participant recruitment

Patients were recruited from both outpatient and inpatient settings. Outpatient participants were recruited through their primary care physician (PCP) who identified potential participants. Once consent to be contacted by the study coordinators was obtained, inclusion criteria were confirmed by the coordinator using the electronic medical record. For inpatient recruitment, a research coordinator identified patient participants who met inclusion criteria and were being cared for by the addiction medicine consult service. A purposeful effort was made to recruit a diverse cohort of participants, including participants who experienced a range of post-acute care settings and outpatient follow-up.

To identify healthcare providers for recruitment, clinical teams and hospital units that regularly care for these patients were identified. Providers who identified potential patient participants, as described above, were not recruited for interviews.

2.3. Inclusion criteria

Patient inclusion criteria were having completed a prior episode of care for a culture-positive diagnosis of infective endocarditis at MGH,

and a diagnosis of at least mild OUD per DSM-5 criteria (American Psychiatric Association, 2013). Interviews were conducted between 2017 and 2018, with patients asked to retrospectively recall and comment on their initial episode of care at MGH for infective endocarditis. After hospitalization at MGH, many patients continued their care in one of three post-acute care settings: a homeless healthcare respite program or two public rehabilitation hospitals. Most patients who continued care at an MGH clinic or community health center were cared for by a primary care physician waived to prescribe buprenorphine.

Provider inclusion criteria were current employment at MGH as a physician, nurse, social worker, health coach or case manager, and working on a clinical service that cares for patients with OUD-associated endocarditis.

2.4. Sample-size determination

Participant recruitment and interviews were continued until thematic saturation was achieved per grounded theory methodology (Ando, Cousins, & Young, 2014).

2.5. Interview guide development

We developed separate interview guides for patients and providers. Semi-structured interview guides followed an episode of care from hospitalization to post-acute care and then transition back to the community. Interview guides were informed by expert opinion, clinical practice, and prior conceptual work on caring for patients with OUD and injection-related infections (Velez et al., 2017; Hooten, Brummett, Sullivan, et al., 2017; Fanucchi, Lofwall, Nuzzo, & Walch, 2018). The guides were further refined to clarify semi-structured interview questions and improve sequencing of follow-up probes after four pilot interviews (two patient and two provider interviews).

Patient interviews focused on the experiences of care as patients transitioned from the acute care hospital, to post-acute care setting and eventually home, highlighting these encounters as opportunities for patients to engage with the healthcare system, perhaps for the first time. Provider interviews focused on the experience of caring, independently and within multidisciplinary teams, for patients with OUD-associated endocarditis.

2.6. Data collection

All interviews were conducted by study investigators (BB, JM). Interviews lasted 30–45 min and were conducted in-person from May 1, 2017 to February 1, 2018. Participant demographic information was collected by a survey administered along with the interview.

Participants were asked whether they would be willing to participate in a recorded in-person interview and have their electronic medical record accessed as part of the study. After all questions were answered, recorded verbal informed consent was obtained, as recommended by the IRB. Patient participants were offered a \$25 gift card. Interviews were recorded, deidentified, and transcribed verbatim, to facilitate import into the qualitative analysis software (QSR International NVivo, Version 11).

2.7. Data analysis

Research staff (BB, JM, MH) communicated on a weekly basis to review recruitment and discuss emerging themes. We conducted an interim analysis after completing a quarter of anticipated interviews, and developed a preliminary codebook. Emerging themes were discussed in detail and significant thematic agreement was appreciated between the research staffs' analyses. A separate codebook for patient and provider data analysis was maintained through the interim process. After thematic saturation was achieved, three coders (BB, JM, MH) independently reviewed all interviews a second time using the

Table 1
Demographics of patient and healthcare provider participants.

Patient characteristics	N = 11
Demographics	
Age, median [IQR]	38 [29–44]
Female	6
White	9
Unemployed/disability	8
Unstable housing	6
Substance use and treatment history	
Hx of fentanyl use	6
Hx of tobacco use	10
Hx of cocaine use	10
Hx of amphetamine use	4
Hx of buprenorphine use	7
Hx of methadone use	1
Provider characteristics	N = 12
Demographics	
Female	9
White	7
MD/NPs	5
“Almost always” work with patients with OUD	7

qualitative analysis software. Coded interviews were then compared for agreement and refined during an iterative process. We finalized separate codebooks of themes and subthemes for patients and providers by consensus of all investigators, and illustrative quotes were collected. The separate patient and provider codebooks were then merged into a cross-sectional codebook in the final analysis process given significant agreement between patient and provider themes, with a few key differences highlighted and maintained in the results.

3. Results

We enrolled 23 participants, 11 patients and 12 healthcare providers. Demographic characteristics are presented in Table 1. Of the providers, all four of the social workers cared for patients on the inpatient addiction consult service. One nurse worked in a cardiac surgery unit and the other on an inpatient general medicine floor. The five physicians/NPs included one addiction specialist, a cardiologist, an infectious disease specialist and two primary care providers.

3.1. Theme 1. Individuals with OUD-associated endocarditis experienced stigma-related inequity and delays in care relative to those without addiction

Both patients and providers described stigma towards individuals with OUD-associated endocarditis and discrimination in care delivered. This was reflected in delays in care, barriers to cardiac surgery, and restricted and sub-standard post-acute and home care options. Because of this culture, patients interacted with the health system in dysfunctional ways, further reinforcing delays. A 58 year-old patient said she was made to feel “second-class.” She elaborated, saying, “the nurse was like, ‘well this is your fault.’ The minute you say you are an addict, it’s just like you have a bull’s eye on your back.”

This same patient, along with several others, described what they perceived to be stigma-related delays in their care: “I’d be dead because they didn’t even treat me for the [infection] because they just let me sit there and be sick. Wouldn’t even give me a freaking bed. [They] told me I had a virus, to go home or something like that. They waited a week to tell me I had [endocarditis], and I was still really, really sick.”

Patients described experiences of their cardiac surgical care being affected by their OUD, with providers acknowledging that proceeding with heart surgery is a complicated decision requiring multidisciplinary input, but that many of these patients are held to a different standard. A 34 year-old physician said: “I think every doctor would tell you that we advocate for patients who potentially would not get a surgery consult because of prior documentation in the charts, because of some sort of

inherent bias.” A 27 year-old patient shared his experience interacting with surgical providers: “The [surgery] team was like, ‘if you use intravenous drugs again after you have the [valve] replacement you’ll die. And if you don’t die, it’s going to ruin the valve, and we’re not going to do it twice.”

Choices for post-acute care are limited when patients had a diagnosis of OUD. Providers discussed difficulties in placing patients in rehab facilities when they were on buprenorphine or methadone: “I don’t know that we have an appropriate post-acute care setting. I don’t know that any of the settings we’re offering patients are appropriate. They’re absolutely horrible from the feedback I’m getting from patients” (51 year-old social worker). Patients were similarly frustrated with the inability to choose where they go for post-acute care, often ending up in institutions far from their supports and exposed to active drug use at a time of early sobriety. One patient, a 58 year-old, shared her frustration: “I was upset because I couldn’t go where I wanted to go [after the hospital]. It’s like they didn’t give a [expletive] and ignored my preferences.”

Severe infections like endocarditis usually require long-term parenteral antibiotics. Patients without OUD are often offered continued IV therapy at home via a peripherally inserted central catheter (PICC) while patients with OUD are rarely, if ever, presented with this option. A 32 year-old social worker spoke of this disparity: “Even if you have housing, you can’t go back to your house because [Visiting Nurse Associations] will not allow patients to be discharged with a PICC line in, which is unfortunate. You can [be in] long-term recovery and never relapse again, but you can’t go home with a PICC line, even if you’ve been sober for 12 years.” A 27 year-old male patient shared his experience of having a PICC, highlighting his motivation to not misuse the parenteral access: “Did I have any fleeting thoughts or considerations of misusing the PICC line? No. I mean, because honestly – if anything, it scared me [...] Because it’s like that goes straight to my heart.”

3.2. Theme 2. Critical social and medical comorbidities preceded hospitalization for OUD-associated endocarditis and were compounded by new physical and cognitive impairments

Our interviews with patients and providers highlighted a bidirectional relationship between social and medical comorbidities and substance use. Prior to hospitalization for endocarditis, social determinants of health and psychiatric illness impacted high-risk drug use patterns. Experiences of poverty, housing instability, incarceration, and social isolation before hospitalization were described as drivers for drug use and barriers to seeking care by patients. One provider shared their thoughts: “I mean, if you’re homeless [...] you’re already well behind the eight ball. If patients do not have stable housing, safe housing, [they] always have to kind of wait in line or jump from shelter to shelter or find a place to stay” (30 year-old physician). Many of the patients interviewed described their experiences with unstable housing: “Technically, I’m homeless. But, I mean, I stay at my girlfriend’s house, my mom’s, my grandmother’s. Those three addresses” (27 year-old male). Critical illness from endocarditis often led to the development of new cognitive and physical impairments which exacerbate existing comorbidities, and these conditions were not sufficiently addressed by the healthcare system.

Many patients suffered from comorbid depression and anxiety, with patients describing an isolating experience as an “addict”: “I didn’t want to be clean [...] I didn’t want to be anywhere really. I was just in a cloud. I was depressed. Really depressed. Scared, I just felt alone” (44 year-old female). Providers emphasized how undertreated depression and anxiety can contribute to substance use and a return to drug-use. A 44 year-old nurse shared her thoughts: “I think about being sick [and] young. You probably have a substance use disorder because you have some underlying anxiety or depression or something [...] You haven’t been treated for it, so you’re treating it for yourself. So now it’s like ‘This poor kid. The only tool in his toolbox to deal with his anxiety was to

take the Klonopin that we were trying to get him off.” Patients, including a 44 year-old female, described experiences consistent with trauma and post-traumatic stress disorder after long and complicated critical illness: “I have never been so scared in my life ever, ever, like, really, never. The things that I’ve endured in the last three weeks: the pain, the coming out of that cloud I was in for three months. Not using, being just on methadone, and not numbing myself. Operations like every three days. Every time I felt better I’d go back in, learning how to go to the bathroom. It was hard. Lot of tears - I’ll tell you right now, a lot of tears.”

Months after hospitalization, patients described still being profoundly affected by their experiences of critical illness. This trauma was often compounded by neurologic sequelae of endocarditis and heart failure, resulting in physical disabilities that required significant physical rehabilitation in post-acute care, and cognitive disabilities that presented new barriers to patients’ engagement in important and complex care decisions. Patients spoke about their inability to communicate and make their own medical decisions during the transition from the hospital to post-acute care: “The infection broke off into my brain, my spleen, my kidney and my liver [...] I had to learn to walk again, I lost all peripheral vision in my right eye. My brain was hemorrhaging. I was really really bad” (29 year-old female patient). One provider, a 31 year-old nurse practitioner, stated: “I think some [patients] who have severe substance use disorders can be cognitively impaired. They also have a lot of concurrent health issues which I think impair their ability to really process their disease pattern [...] and how it’s impacting their healthcare.”

Finally, providers were aware of the high health literacy needs of these patients, suggesting that patients confront complicated medical decisions but may be less inclined to ask clarifying questions about their health care because of shame or internalized stigma. One provider shared: “There’s a piece of shame and guilt that people feel, that when they don’t have that knowledge, when they don’t have that education, they’re afraid to ask because they may feel like the doctor is looking at them as if they’re stupid [...] And it’s just like, ‘No. Not everybody knows about everything’” (51 year-old recovery coach).

3.3. Theme 3. Return to substance use as an anticipated outcome following discharge

Our interviews with patients and providers demonstrated that a return to substance use is an expected part of the clinical course of OUD-associated endocarditis, despite patients’ self-assessment of risk and intention not to use. Return to substance use often occurred multiple times before an individual entered durable recovery and may not have represented a failure but an opportunity for patients to be re-engaged in care and to mitigate risk through harm reduction strategies. Patients were re-hospitalized not only for reasons related to their addiction, but also due to infectious complications and heart failure.

Several patients described returning to drug use on discharge, despite their strongest intention to not use drugs again. As one patient poignantly shared: “I was in that hospital for four months and honestly could’ve passed a lie detector test stating that I would never use again. The day I got out, I had a needle in my arm and I was getting high again, wondering how the hell I got there and what happened” (29 year-old female). Patients reported not always being ready to stop using drugs when providers or others wanted them to, and that it often took multiple attempts before successfully being in recovery. Patients described the “people, places and things” that often triggered their drug use: “It’s just a lot of stuff. Getting raped when I was younger, being around the wrong people, the wrong friends. It was just a whole bunch of stuff. [The] environment I lived in, the people. A lot of people used around me. That’s what I grew up around in the neighborhood” (44 year-old female). Providers, including a 51 year-old social worker, shared similar observations: “A lot of times people don’t come from great living situations. They come from homes where [drug use is]

multi-generational, where the parents were using IV drugs. So, it could have been something that they grew up [with] and saw everywhere in their environment.” These settings were often the same risky settings that patients returned to following hospitalization. In observing this trend, many providers understood return to substance use as an expected part of the clinical course of OUD, emphasizing a non-judgmental, harm reduction approach to return to use.

Both patients and providers reported that many patients returned to the hospital to seek further help when their care plans, including therapy for OUD and heart disease, broke down after discharge: “So I had methadone maintenance while I was in the hospital and I did not really have anything lined up when I left [post-acute care], which, ultimately, could be one of the many reasons why I ended up re-infecting my valve and back in the hospital” (28 year-old male patient). Patients frequently re-presented to the hospital with symptoms of heart failure. Several providers, including a 34 year-old physician, stated that they expected patients to return to the hospital: “Even though we may only actually see them for six weeks, we know there’s a chance that they could come back, and we are happy and willing to assist.”

Most patients described impulsive and risky injection practices that put them at risk of infection, despite knowledge of safe practices that mitigate harm: “I kept getting high and I used to lick the tip of the needle, and one of my friends was like, ‘You need to stop doing that, you’re going to end up getting sick.’ I don’t know why I did it, I don’t know what it was, it was just part of the process in me getting high” (29 year-old female patient). Access to sterile syringes and injection-related paraphernalia were variable and have changed over time. Several patients described infectious complication of OUD as a motivation to change their injection practices. Providers highlighted the importance of harm reduction education but recognized that there were barriers to providing patients with the equipment needed for safer drug use: “We do talk about their needle practices and [the] likelihood of reinfection. It hasn’t really been our practice to hand out safe injection kits, [it’s] kind of a controversial subject around the hospital. I don’t think that we do a good job in terms of educating patients on how not to re-infect and what the chances are of fatality with a second [or] third infection” (31 year-old nurse practitioner).

3.4. Theme 4. Prolonged hospitalizations are perceived as excessively long and potentially injurious by patients, but as positive opportunities by care providers

Long courses of IV antibiotics were required, keeping patients in institutionalized settings for extended periods of time. Patients and providers brought different perspectives to this period of inpatient care. Patients described inadequate pain treatment and fear of withdrawal during long hospitalizations. Providers described hospitalizations as an opportunity to motivate and engage patients in care. There was agreement by both patients and providers that additional addiction care, in particular peer-support groups, would improve the experience of hospitalizations.

Patients spoke of how long they had to stay in the hospital to treat their infected heart valves. They often expressed surprise at how critically ill they were at presentation and how long it took to heal: “I’m lucky I’m not dead. Because they told me one in three people die in five years with what I have, and I’m still here [...] I want to feel better again. I’m sick of feeling like [expletive]. God, I used to be able to run six miles a day. I can’t even run anymore” (58 year-old female patient). Being in the hospital for a prolonged period of time could be a challenge, especially for young and otherwise healthy individuals. A 31 year-old physician stated: “I’d say that the patients we end up intersecting with a lot are the ones who are very young, who are dealing with something like very early valvular disease and it may be the most stressful thing that any of them will ever have to deal with. That valve is going to require a lot of work over the course of the next decade.”

Patients with OUD have often developed physiologic tolerance and

dependence to opioids and described a fear of withdrawal and severe pain when medications were withheld or inadequately dosed by providers. One patient, a 59 year-old female, shared her experience: “I was just asking for something to ease the pain so I could lay down and take the test. And they wouldn't give me [expletive]. The next thing is – I mean, I was so [expletive] mad - I couldn't take the test.” The patient continued: “So when you're dope sick, when you're really sick, you just want to get it in you because you're just that physically sick. [...] Opiates, I feel once you start, once you're an opiate user, forget it. It's the hardest thing to stay away from.” Providers emphasized the importance of treating withdrawal to keep patients engaged in care and decrease the likelihood that they leave against medical advice (AMA): “[Patients] leave AMA and don't get the tests [they need] because they're going into withdrawal” (32 year-old social worker).

Providers spoke of long hospitalizations during treatment for endocarditis as an opportunity to use counseling, motivational interviewing, and harm reduction approaches to address patients' underlying OUD: “People with endocarditis are in the hospital for a long time, and it's a big window of opportunity for us to be able to elicit some type of change talk and some type of motivation with these patients. [...] So even if we can provide just that psycho-education piece, and harm reduction, risk reduction [...] maybe we can talk about cleaner needle practices, injection practices, maybe get them connected to a shelter that will be more supportive” (32 year-old social worker). One patient shared their experience of asking for help while hospitalized: “The addiction team taking me out of [my hospital] room and to some groups, addiction groups, [was so helpful] because of the isolation of being alone in the room all the time. It's nice to be able to talk with some people [...] I was actually calling out for help a lot. I was depressed. ‘I need to go to a meeting. I need something’” (41 year-old female patient). This momentum for change was often lost when patients transition from the hospital to post-acute care settings.

3.5. Theme 5. Lack of care integration within institutions and the discontinuity of longitudinal care contribute to poor health outcomes

Patients and providers described fragmented care, identifying a lack of integration within an institution and discontinuity between care settings, as patients transitioned from the hospital to post-acute care and eventually home. This included difficulty accessing and continuing MAT and naloxone. Patients benefited from low-threshold addiction care and PCPs who were engaged in the hospitalization and could continue integrated addiction treatment after discharge.

Providers emphasized the importance of integration and effective communication between multiple specialties and health professions within an institution: “It's a team effort, doctors and nurses and therapists should [communicate], and recovery coaches [should] be a part of this team [too]. We should all be at the beginning, middle, and end, all the way through” (51 year-old recovery coach). Patients with endocarditis and OUD were cared for by multidisciplinary teams that frequently included cardiologists, cardiac surgeons, infectious disease consultants, and addiction medicine specialists. Patients described their frustrations when care coordination and communication between providers broke down, with one patient, a 47 year-old female, highlighting the extra steps she had to take to address the systemic failures: “You're always jumping through hoops, and something's always going on. It's never [straight forward], get your prescription, go to the pharmacy, pick it up, and have it in time. It just really doesn't work that way.”

Both patients and providers addressed many areas where the continuity of care between institutions could break down, as patients transitioned from hospital to post-acute care settings to outpatient clinics on their return home. Patients talked about how challenging it can be for them to navigate a complex health care system and to coordinate care between institutions. A 28 year-old male patient described how he prepared for expected systemic failures when transitioning from one care setting to another: “I'd made sure to get that all

squared away before I left [the hospital] to make sure that I wasn't kind of in the dark over [in post-acute care] after discharge.” Providers acknowledged these failures and pointed to the value of clinicians following patients longitudinally through their episode of care from one institution to another: “Sometimes, we do all this great work for two, three weeks with a patient [in the hospital], then they go to a [post-acute care] facility for six weeks of antibiotics and there is no one to continue the plan. So all that hard clinical work they did kind of falls away, and they're left with, ‘Oh, seven weeks ago I talked to someone about this but now there's nothing’” (25 year-old social worker). Providers also highlighted the value of peer support or recovery coaches who support patients through these complicated transitions.

Providers highlighted that facilitating continuity includes assuring reliable and uninterrupted treatment for OUD. Providers and patients both brought up multiple barriers to the initiation and continuation of MAT, including buprenorphine, methadone, and naltrexone. Some of these barriers emerged when patients were transitioning from the hospital to post-acute care, with providers pointing to limited post-acute care choices determined by which type of MAT a patient is prescribed. A 44 year-old female patient shared her difficulty in accessing MAT: “I knew I wanted to get on [buprenorphine] for like the last three, four years [...but] there's waiting lists. There's lists that you have to wait and wait and wait. And you just get tired of waiting and then you just, whatever. You're just like, screw it.” This was in contrast to the experiences of patients who reported that their primary care doctor was integral to their hospital care, especially when that provider also provided them with addiction care.

Patients spoke of how difficult it is finding an outpatient buprenorphine provider, often resulting in treatment lapses: “My primary care is [at another hospital] and I switched primary care [providers] like four times since I got out of the hospital because I went to one and he wouldn't prescribe me anything. [...] I'm just going to switch them over to here. So I can do the [buprenorphine] here and have all of my doctors literally under one roof” (27 year-old male patient). Unnecessary barriers to both evidence-based treatment and life-saving overdose reversal medication, naloxone, exist: “It's very hard to get patients discharged with [intranasal naloxone], even if they're leaving AMA. People just aren't familiar with how to get it, and our outpatient pharmacy sometimes takes two hours [to dispense it]” (32 year-old social worker).

3.6. Care innovation

In conducting our thematic analysis, we noticed that multiple healthcare providers offered innovative solutions to some of the barriers discussed above. These largely addressed the call for more integrated patient-centered care that follows patients from hospital to post-acute care and home, to help them navigate a complex healthcare system: “We have to have a better way to automatically connect them to a person who could follow them through their process [as an] outpatient, whether it's a recovery coach or a case manager or someone who isn't tied to inpatient or a facility, a [provider] who goes with them and follows them and can reach out to any facility and say, ‘Hey. This is the next step’, or, ‘Hey. This is what you need’” (51 year-old social worker). Another provider, a 44 year-old nurse, highlighted the need for better interdisciplinary care team management and communication: “I feel like it is an opportunity with our cardiac surgical colleagues to get them more involved as part of the substance use disorder team. Let's have this sort of united front where we go in [to talk with the patient] and say, ‘Yep, your valve is really bad. Yep, we think you need to have it replaced, but to really, really make you successful because this is a huge surgery [...] we want to optimize you, and these are the things we really need you to help us with.’ I think it needs to be the whole group. It needs to be whoever the addiction consult team physician is, the social worker, someone from the medical team, nursing, everybody in there together having one meeting.”

Both patients and providers identified a need for more appropriate and supportive post-acute care settings, including home services and flexibility in outpatient clinic services that encourage continued engagement in care after discharge: “I think one of the great things about the medical walk-in clinic [is it] allows patients to go [to clinic] when they can. And I wish that more PCP offices had walk-in times to provide a little more flexibility [for the patient]” (32 year-old social worker).

4. Discussion

Amidst a growing crisis of OUD morbidity and mortality, we believe this to be the first qualitative study to specifically investigate the experiences of care for patients with OUD-associated endocarditis. Our analysis revealed a sick, complex, and stigmatized patient population with severe physical and cognitive disabilities on top of pre-existing comorbidities. The five major themes demonstrated a splintered health care system and a complicated experience of care for patients with OUD-associated endocarditis as they endure long hospitalizations, move between multiple care institutions, and face lapses in care at critical transition points. These shortcomings may begin to explain high rates of return to drug use, rehospitalization, and death in this population (Rosenthal et al., 2016; Kim, Ejiofor, Yammine, et al., 2016; Rabkin et al., 2012).

Striking findings include recognition of the increased complexity of caring for these patients, requiring long-term treatment for OUD and complications of endocarditis simultaneously. Some of this complexity is reflected in the observation that patients do not follow a linear episode of care trajectory from hospitalization to post-acute care and eventually home. Patients frequently left care before treatment was completed, and often returned for care with recurrent infections, heart failure, and addiction needs. Patients and providers agreed that our current health system is not well suited to meet the complex needs of this patient population.

While stigma towards individuals with substance use disorders and the medications used to treat addiction have been previously described (Wakeman & Rich, 2017; Van Boekel et al., 2013; Englander et al., 2018; Velez et al., 2017), our study identifies additional areas of inequity and discrimination. This prejudice may begin to explain disparities in care outcomes between patients with OUD-associated endocarditis and those without a history of addiction. Stigma can alienate patients from coordinated and comprehensive care, designed to support them through setbacks and care transitions. Additionally, perceived discrimination compounds the already challenging experiences of patients with severe cognitive, physical, and neurologic barriers to care.

There are several limitations to this hypothesis-generating, qualitative study: we are unable to examine the association between experiences of care and clinical outcomes for patients with OUD-associated endocarditis; we expect recall bias when asking participants to comment on past experiences; interviews were conducted within a single hospital system now with a comprehensive substance use disorders initiative. However, while patients were less diverse than the general population, they closely match the demographic trends in people who use opioids in the US and participants were purposefully drawn from both inpatient and outpatient settings, representing a heterogeneity of care experiences.

Our results are generally consistent with several other descriptive analyses of hospitalized patients with substance use disorders and their multidisciplinary healthcare providers (Velez et al., 2017; Englander et al., 2018; Jicha, Saxon, Lofwall, & Fanucchi, 2019), further highlighting the importance of directly addressing addiction among hospitalized patients and linking them to longitudinal substance use disorder care. Complicating the findings of Velez and colleagues who found that hospitalizations may represent a “reachable moment” for initiating and coordinating addiction care, the patient participants in our study reported that the prolonged episodes of care required for treatment of OUD-associated endocarditis felt excessively long and potentially

harmful, particularly when pain and withdrawal symptoms were under treated.

Our analysis also identified several important opportunities to improve care for patients with OUD-associated endocarditis. These included embedding low-threshold addiction care within primary and specialty care, addressing a dearth of appropriate post-acute care options, longitudinal social work and case management involvement, and standardized, non-stigmatizing communication among multidisciplinary treatment teams. We can learn from successful models of care for other complex and chronic diseases, such as heart failure, diabetes, and HIV, to design long-term care systems to match the needs of the patient populations they serve.

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