## **REFLECTION**

# Sam's Story: The Financial and Human Costs of Disjointed Logics of Care

Jennifer Karlin, MD, PbD
University of California, Davis, California

#### **ABSTRACT**

I am an anthropologist and family doctor who has the good fortune of working in northern California with colleagues who prioritize the social needs of our patients alongside medical ones. In the essay that follows, I share details from my patient Sam's (pseudonym) last 2 years of life to underscore how attending to social precarity cannot be fully achieved within our safety net institutions as they are currently structured. While we have strong evidence that addressing social needs as part of clinical care offers good return on investment, Sam's story makes visible the problems we face when attempting to address social determinants of health. After introducing a concept from the social sciences about rationales that underlie health care delivery, I call on primary care doctors to redefine the medical paradigm to remedy the disjointed logics of care that result in unnecessarily high financial and human costs.

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first met Sam as we jammed ourselves into my clinic room alongside his bike and most of his belongings. Perspiration dripped down his face after cycling across this northern California city to our appointment. Sam had gentle, piercing eyes and a smile that materialized easily across his black skin as he told me his personal history. His bike was his prized possession, and he rode it everywhere. From his youth spent in Louisiana, he loved southern cooking and wanted to find employment again as a chef. I shared with Sam that I, too, grew up in Louisiana and loved spicy food. Sam told me he currently lived alone in a tent. Recalling the trauma from a night when his tent was set on fire right after his divorce, Sam showed me the scars from his burns and described the hallucinations for which he tried to self-medicate with intravenous (IV) heroin to little avail.

Sam had not sought care from a physician over the last few years but was inspired to see me to obtain hepatitis C treatment which was now covered through Medicaid. Sam desperately wanted to quit using heroin and to start treatment for his hepatitis. After we made a pact that he would come to all his appointments, I started treatment with methadone, psychotherapy, and antidepressants. I submitted the prior approval paperwork along with a laboratory and imaging work-up for hepatitis C treatment. For his part, Sam faithfully made each of his appointments and took his medications.

# SAM RECEIVES CARDIAC SURGERY

A year later, Sam was admitted to the county hospital with shortness of breath caused by heart failure from endocarditis. Securing a replacement aortic valve requires transfer from the general medicine service to cardiology, and then a surgeon's approval—one who works at both the county hospital and academic medical center and who effectively serves as the gatekeeper determining who can obtain life-saving cardiothoracic surgeries. The cardiac surgeon was hesitant to replace Sam's valve; she argued that the valve might get reinfected and worried that her own performance measures might be affected by an unsuccessful surgery. From his impeccable outpatient attendance record, I knew that Sam was determined to stay sober, and I advocated strongly on his behalf. The surgeon agreed to replace his aortic valve on the condition that he was discharged to a drug treatment program.

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#### CORRESPONDING AUTHOR

Jennifer Karlin 4860 Y Street, Suite 2320 Sacramento, CA 95817 jkarlin@ucdavis.edu

### SAM IS DENIED PERMANENT HOUSING

Sam remained sober at the rehabilitation center and was hopeful about his transition back to community living. After 90 days, his planned discharge was foiled when transitional housing denied his entrance, claiming that methadone maintenance therapy precluded his acceptance. I switched his methadone to buprenorphine, hoping that the latter medication would not carry as much stigma, and contacted legal counsel on Sam's behalf. Pro-bono lawyers took on the case enthusiastically, arguing that disability discrimination laws protected Sam from being barred from housing while the treatment facility extended his stay for another 30 days.

Despite the treatment modification and the legal team's attempt to remedy his housing denial, when Sam's 30-day extension at the rehabilitation facility expired, he was discharged to a homeless shelter in his old neighborhood. Knowing that homeless individuals have a significantly higher risk of opioid overdose (in fact, some studies estimate an 8.9% adjusted increased risk of opioid-related emergency department visits for those who are not housed), I spoke to Sam daily trying to keep his spirits up and drug use down while the lawyers continued to work on his case.

# SAM BECOMES AN ETHICAL DILEMMA

Forty-five days after discharge from the rehabilitation center, Sam obtained his long sought-after hepatitis C treatment. As I was providing the first dose, I noticed his cough. An initial work up revealed an abscess, or a collection of pus from an infection, on his newly replaced valve extending through his left ventricle. I admitted Sam to the hospital and requested that the surgical team assess him for surgery. Removal of the abscess would require extensive cardiac surgery due to its location and because treatment with antibiotics alone was unlikely to kill the infection. A hospital ethics committee meeting convened to discuss the merits of his surgery. Members of the committee disagreed about the cause of the infection: Sam had relapsed once but also had undergone a dental procedure, either of which could have introduced the bacteria into his heart. They questioned whether the etiology of the infection should even have any bearing on the decision to allocate more resources to Sam. As the debate churned, the committee received an imaging report that showed bacteria had also seeded Sam's brain. The blood thinner needed to prepare Sam for surgery now posed too great a risk for hemorrhagic stroke, according to his surgical team. This last piece of clinical information preempted the ethical debate, tipping the scales away from surgical management.

The night after the ethics committee meeting, I was in the ICU holding Sam's hands—scarred from the fires that no longer gave him nightmares—and told him that he wouldn't be transferred this time for surgery. Sam looked distressed, shaking his head in dismay that injecting once could have such devastating consequences after his 150 days

of sobriety. He lamented his one relapse. I told him that the cause of infection was unclear; it could have been caused by his dental surgery. His guilt eased as he showed me pictures of his grandchildren with whom he had reunited, and we laughed as we recalled the hullabaloo of crawfish boils on the bayou. He hoped to enjoy another festival after his hospitalization.

That is how I last remember Sam. I received a page 3 days later telling me that Sam had died from cardiac arrest overnight. Now it was my turn to shake my head in dismay. I knew the cause of death was a defect in the social safety net, not in his heart.

# **DISJOINTED LOGICS OF CARE**

In an analysis of medical practice in the Netherlands, philosopher and anthropologist Annemarie Mol describes the diverging logics, or rationales, that inform the management of disease in patients.<sup>2</sup> Mol argues that a logic of choice, embedded in market capitalism, dominates administrative and public discourse about health as well as medical practice. In this logic of choice, individuals are managed through compartmentalized programs with carefully curated notions of what is worthy of investment. In contrast to this, Mol describes the logic of care as "a process: it does not have clear boundaries. It is open-ended... care is not a (small or large) product that changes hands, but a matter of various hands working together (over time) toward a result." While a logic of choice is transactional, outcome-driven, and casts patients as customers; a logic of care is relational, requires interaction, and is embedded in evolving practices that require continual adjustment and not singular outcomes. Mol insists that "gathering knowledge is not a matter of providing better maps of reality, but of crafting more bearable ways of living with or in reality." Care, then, is possible where cure eludes us.

Sam's case demonstrates how a narrow focus on a logic of choice in medicine without a complementary logic that commits resources and understands outcomes as processes that require continual fine-tuning, all but guarantees further fragmented care. Strong economic, political, and cultural factors favor technological interventions over providing social benefits to people considered undeserving. Positionality refers to how differences in social position and power shape access in society. If Sam had different demographics—if he was insured, or white, or lived in a wealthier part of town he would have been more likley to present at the hospital that performs these surgeries in house. That might have made him more likely to recieve a timely surgery the first time without having to covince anyone of his worthiness, and it may have made him eligible for the second surgery. But, the structural and social factors that constricted Sam's possibilities for medical care dictated his outcome. This insistent separation of the medical and social ultimately supports a structure in which institutional boundaries and bureaucratic

practices together reinforce an artificial separation between "social work" and "medical practice," despite good evidence that 60% of health care costs result from social, environmental, and behavioral factors.<sup>3</sup> Physicians are advised to take social needs into account when providing care, but they are provided neither the tools nor the power to control factors that are customarily considered outside their purview.<sup>4-6</sup>

#### THE COSTS OF FRAGMENTATION

These disjointed logics not only further injure and marginalize vulnerable populations, but also burden the system with high costs. As his primary care doctor, I understood Sam's vulnerability and attempted to bridge artificial boundaries of care. I devised ways around otherwise disabling glitches—I found him a pro-bono lawyer, vouched for his "worthiness" with the surgical team, and tried to call Sam every day to bolster his determination not to use heroin again. Although there are many examples of health care workers defying business-as-usual to provide care for the most vulnerable, odds of success are not high. And even when they work, contriving workarounds is exhausting, dependent on luck, and has the disadvantage of enabling the structural faults to persist.<sup>7,8</sup>

Medical providers are given the authority to intervene in cases of life-or-death by providing direct medical services but can do little about most preventable deaths attributable to social determinants of health. This remains the case despite ever-mounting evidence that addressing social needs as part of clinical care offers good return on investment.<sup>9,10</sup>

Although I successfully advocated for Sam to get a life-saving surgery, I was unable to procure him housing. Because the housing system is thought of a "social" resource, separate from "medical" treatment, the hospital bore an inordinate financial risk by devoting clinical resources to Sam without a commitment from the housing system. Rationally, to protect its own investment of time and resources, the hospital needed preferential consideration for Sam's housing. The utility of providing Sam's medical care (over \$500,000 for the surgery and hospitalization) was contingent on the later, much smaller provision of housing (approximately \$600/month for a single-room occupancy [SRO]), which never eventuated.

Bounded domains of responsibility lead to unsecured risks and tragic outcomes; formidable clinical efforts fail to translate into recovery, reaping waste and gratuitous mortality in the bargain. This kind of incoherence has high social costs; and yet, social cost is not on any organization's budget line. Compartmentalized siloes, calculations of responsibility, liability, and accountability: effective care requires that they be meshed. As Mol urges, an alternative vision of care across institutional settings would ensure a collaborative approach grounded in shared moral understandings and collective commitment, would protect domain-specific investments (like medical care), and would attend to convergent outcomes (like socially supported recovery).

# CONCLUSION: ENACTING A LOGIC OF CARE ACROSS ARTIFICIAL DIVIDES

Most physicians are aware that pre-surgical risk estimations should include social as well as clinical factors. However, in a logic of care that prioritizes consumerist thinking alongside an artificial separation of the social and the medical, socially vulnerable patients will always be undervalued. Radically different options for Sam were possible in different institutional fields. Partially socialized medicine, even in a weak welfare state, made expensive clinical treatment available to Sam; however, an almost completely commodified housing market foreclosed any but "emergency" shelter once "treatment" concluded. Sam's cardiac surgeon faced pressure to achieve positive surgical outcomes driven by institutional quality scores that decrease when a patient dies within 30 days after surgery. Such short-term incentives often lead to treatment exclusions and cherry picking, leaving out our most socially vulnerable. But, in this case, the economic pressures actually inspired the surgeon to consider Sam's social world in creating a successful discharge plan that would decrease his risk of continued heroin use and increase her success outcomes. Attempting to safeguard against the risk of re-use inspired her to think beyond the confines of the surgery itself and towards Sam's successful discharge to a drug treatment program. Unfortunately, the hand-off went afoul of a 30-day limit that counteracted the longer-term benefits that the inpatient teams hoped would follow. Even the ethics committee evaded deliberation on the moral questions embedded in the social and structural domains and instead predicated their decision almost entirely on the clinical data.

As an anthropologist, I know that the boundaries that define clinical care are not innate or fixed. We decide as a society the categories and time intervals that constitute medical interventions. Few would argue now against including rehabilitation in post-surgical care, even though it took the Patient Protection and Affordable Care Act (ACA) to incentivize bundled payment packages.<sup>11</sup> Analogously, we could redefine medical interventions to include housing for patients as part of the standard therapeutic practice and use money allocated to "medical needs" to procure (and partially pay for) supportive housing. 12 Not only have economic models shown cost-savings when Medicaid pays for housing for individuals without homes, 13 but several hospitals in Chicago have already invested in permanent housing and seen a concomitant reduction in expensive emergency department visits and improved health outcomes.<sup>14</sup> Further, an expert consensus report concluded that providing supportive housing as part of competent treatment for some clinical conditions conferred clear benefit.<sup>15</sup> These initiatives in supportive housing are just some successful examples of how considering a social variable as included, and not simply ancillary to, the category of medical care confers benefit to both the individuals directly involved and the collective.

Primary care physicians are ideally situated to advocate for this broader and longer-term thinking because we are

trained to think throughout the life course and across care settings. Redefining the boundaries of medical intervention from an individualistic, compartmentalized logic of care that values choice to one concerned with structures that support patients' needs comprehensively across care settings, would not only prevent these ever-accumulating human and financial losses. It would also honor the legacy of Sam.

#### Read or post commentaries in response to this article.

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