

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Ally With Patients Whose Health Is Unlikely to Be Improved by Even Numerous Clinical Encounters?

Adam T. Perzynski, PhD and Kurt C. Stange, MD, PhD

Abstract

Patients experiencing homelessness and mental illness face conditions and circumstances that deserve focused ethical and clinical attention. The first commentary on the case applies insights from qualitative research about social determinants of health to these patients' care and dignity. The second commentary describes 3 kinds of power wielded by physicians—charismatic, social, and Aesculapian—each of which is considered in terms of whether and to what extent physicians' power should be owned, aimed, or shared.

Case

JJ is a 27-year-old man with schizophrenia, who is brought to the clinic by staff members from a local shelter. JJ does not adhere well to his antipsychotic medication, has experienced several inpatient psychiatric civil commitments and other encounters with numerous clinicians in the region's health care system, and does not have reliable access to shelter, food, water, or hygiene. You, JJ's caregiver in the clinic right now, empathize with him, staff from the shelter, and others trying to help JJ avoid poor health outcomes for which he is at such high risk.

You refilled JJ's medication and reviewed his laboratory values, but you know there is little you can do for JJ that can counter the myriad and well-known social determinants undermining the effectiveness of even the most skilled intervention any clinician could offer JJ during a clinical encounter. You wonder how to make the most of this moment you have with JJ on his life journey.

Commentary 1

by Adam T. Perzynski, PhD

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Recent years have seen dramatically increasing levels of health care system interest and investment in addressing social factors in primary care.^{1,2} Some of this interest is driven by growing recognition of the immense financial expense and squandered human

potential associated with social inequity in examination rooms.^{3,4} Social needs screening, referral, and coordination among social service organizations have demonstrated potential to fill some social care gaps in primary care settings.^{5,6,7,8,9,10,11} However, the number of patients helped by these interventions is still somewhat limited. For example, one study found that, of 848 patients screened who had food insecurity and wished to be contacted, 98 (12%) had their referrals ultimately resolved by a local food bank.¹¹ Other work has further exposed the need for improved communications with patients¹² and the severe limitations of high throughput workflows.^{8,13} An entire industry of startup companies and entrepreneurs is developing technologies around the promise of **integrated care** for patients with unmet social needs,¹⁴ but health technology for this purpose needs to further reinforce solidarity and shared well-being.

JJ seems very familiar to health workers; the social, psychological, and disease challenges faced by the most vulnerable patients cared for in clinics, hospitals, and emergency rooms are daunting. Beneath the snapshot of his clinical encounters is a rich personal history involving relationships, events, places, passions, and the vicissitudes of life's fortunes and misfortunes. Present, but possibly not accounted for, are JJ's personal triumphs and tragedies. JJ's case helped me to reflect on my 2 decades of work with colleagues conducting qualitative interviews and listening closely to the concerns of persons who have various combinations of serious mental and physical health challenges.^{14,15,16,17,18,19,20,21,22} I've talked with baseball fans about their diabetes control and the staggering weight gain they had from their antipsychotic medications.^{20,21} Men who love yoga and meditation shared with us their fears and personal struggles after having a stroke.^{15,16} Medications that caused weight gain or fatigue meant they could not lift what they needed to or stay awake and alert enough to make it through an 8-hour night security shift in the warehouse.¹⁶ My own and others' research has found that patients' not taking medicine was occasionally due to clinical care teams' affronts to their personhood or patients' suspicion that prescribers' motives were financial rather than beneficent.^{15,22,23,24,25}

How Stillness Moves Us Toward Solidarity

The stillness of a medical encounter in some ways is not still at all; time is short in busy clinics. Private talk about deeply personal needs, however briefly, can move our encounters with patients—especially those experiencing homelessness—beyond the often morally hazardous conditions on the outside of the examination room toward solidarity. Stillness can move us toward trust and the health benefits of **trusted relationships**. Even steep barriers to trust in clinical encounters can be surmounted with the simplest of “common ground” approaches—simply finding out what we share with one another.²⁶ When our experiences and those of the people we serve do not align, we can maintain solidarity with their suffering and offer our love.²⁷

I remember an interview with a woman experiencing homelessness who told me about how she was raped the first night she had to sleep in a bus shelter. This woman's story came as a shock to me; I had simply asked her a question about why it was sometimes difficult to take her medicine for her bipolar disorder. Sometimes it just wasn't a high priority, she explained. Days before our conversation, she had received 3 new sets of clothes from a church group, but the clothes, the bag they were in, and her medicine were stolen at the shelter. She explained that she wanted to take her medicine, but she didn't always have it with her.

We felt solidarity in that particular moment because both of us felt ashamed, powerless, and a bit broken. Both of us were glad to have someone to talk to within the gray, air-conditioned walls of the clinical research unit, but nonetheless we experienced the fear and the trauma of those events—I, vicariously—when just talking about them. It's through this lens that I write with concern for JJ and what will happen to him and others in our tightly choreographed systems of social care. The **social needs screening** questions used at MetroHealth ask:

1. Have you worried your food would run out before you had money to buy more?
2. Were you unable to pay the rent on time?
3. Have you been humiliated or emotionally abused by your partner?

Qualitative inquiry has found that patients are generally appreciative of the opportunity to fill in the care team and possibly receive assistance with some of their needs.²⁸ Nonetheless, some vulnerabilities are so overwhelming that our patients struggle to contain their tears before they finish answering even one of the questions. The tables and figures on the social determinants of health can seem like a disservice to the truth of the challenges faced by our patients. How can we confront these challenges while preserving the dignity of patients like JJ? At times I'm frustrated with the safe, climate-controlled halls of the health care system, having commuted from the suburbs and a house with an overflowing pantry. As others have pointedly asked^{29,30}: Who is this safe setting really for? I hope JJ feels safe in the clinic. I want him to. If he were my patient, I would consider whether I'd asked him lately how he feels about this place and his experiences here. JJ's case and every encounter with a vulnerable patient can be viewed as an opportune reminder for all members of clinical teams to anchor their efforts to meet instrumental health and social needs in a foundation of interpersonal, narrative humility and an unwavering respect for dignity.

Commentary 2

by Kurt C. Stange, MD, PhD

One of the most gratifying clinical teaching encounters is when a resident raises the exasperated question, "Why does this patient keep coming back to see me? I'm not doing anything for him!" So many clinical teaching episodes, like the clinical encounters they mirror, are transactional—linking symptoms and signs to diagnoses and using those diagnoses to launch **evidence-based treatments**. Those evidence-based treatments are based on the average effects of treatments in clinical trials in which selection and randomization make individual differences and social context inapparent to allow us to focus on a single factor.^{31,32}

But, like JJ's schizophrenia, which is exacerbated by medication nonadherence for a complex mix of reasons, most health problems aren't caused by a single factor. The causes of suffering, disease, and illness—and even explanations of opportunities for healing—are multifactorial and multilevel, from the molecular to the societal.^{33,34} Our efforts to put people's problems in neat little boxes give us a sense of control that often is out of touch with the complex contexts of people's lives and the possibilities for care that extend beyond delivering "commodities" of narrow diagnoses and treatments to the possibility of holistic healing.³⁵

We should be aware of what our patients do and don't want from us. Patients do not come to serve as data for quality and performance metrics that sometimes provide

useful guidance but often serve to financially incentivize us and to wrest control of our motivations to be personal physicians and healers.^{36,37} Moreover, patients do not come to gratify our egos as healers. For many patient conditions, we do not provide a cure; many patients coming to hospitals and to primary care, especially those age 45 and older, have multiple chronic illnesses of which we are witnesses and that we help palliate.^{34,38} In talking about healing, patients say that they would like a cure, if possible, but when that is not possible, they want someone to stick with them **on the journey**.³⁹ They want someone to help them to transcend their suffering.⁴⁰

Fostering Healing

In analyses of in-depth interviews of physicians identified as excellent healers on the basis of their scholarship, reputation, and awards and of their patients thought to have experienced healing,⁴¹ my colleagues and I discovered that healing relationships require certain competencies in the physician: self-confidence, emotional self-management, mindfulness, and knowledge. Healing relationships also embody practices of valuing, being present, sharing power, and abiding. *Valuing* means actively appreciating patients in a nonjudgmental manner, regardless of their level of functioning, social situation, ethnicity, or life circumstances; such appreciation adds value to care over time, even when the care is ostensibly “futile.” *Being present* means paying **caring attention**, witnessing, and empathizing with patients’ suffering and joy. *Sharing power* means respecting patients as experts about themselves and leveraging trust and respect to encourage changes that support patients’ health. *Abiding* means sticking with patients, providing continuity of caring over time, accompanying patients during crises, and ensuring that patients know we will not give up on them even if we are not able to provide a cure.

Enacting these competencies and healing practices leads to relational outcomes of hope, trust, and a sense of being known.⁴¹ Healing practices impart a sense of stillness and solidarity within and between practitioners and patients.^{42,43} Martin Buber described these kinds of connections as “I-Thou” relationships,⁴⁴ which are characterized by dialogue and mutuality and fundamental to healing; such relationships contrast to “I-It” relationships, which aptly apply to commercialized, commoditized, impersonal features of US health care.⁴⁵

With my colleagues, I have conducted further analyses of the interviews used to identify the competencies and healing practices, which show that patients’ healing journey is full of stops and starts.⁴⁶ In the middle, it often looks like a failure. But through personal and relational persistence, patients who have a sense of safety and trust can move from being wounded and suffering to developing diverse healing relationships based on kindness and unconditional love. This experience leads to reframing of suffering, taking appropriate responsibility for healing, and positivity that sometimes help the person to transcend their suffering and circumstances and find meaning, purpose, and often generativity, or the emergence of interconnections between relationships and resources that foster hope and “a sense of wholeness and integrity that constitutes healing.”⁴⁶

Higher levels of care that involve integrating and prioritizing care, abiding, and assisting in transcendence of suffering⁴⁷ are neither recognized nor supported by the current organization of health care, which measures and supports basic care of acute and chronic disease, preventive service delivery, and mental health care. Our fragmented, depersonalized, greed-driven system actively works against providing these higher levels of care.^{35,48} The mismatch between what clinicians know we can do to help people in a

relationship over time and how we are organized, rewarded, and punished in the current reductionist, commodified health care system is a major source of moral distress and burnout for clinicians and of loneliness, fear, and despair for vulnerable patients.^{49,50,51,52,53} My colleagues and I have recently developed a patient-report measure based on careful analysis of what patients and clinicians say is important in health care.⁵⁴ Such a measure can be used to refocus the attention of clinicians, patients, and the health care system on what matters.

Understanding and Using Physicians' Power

Howard Brody identifies 3 kinds of physician power: charismatic (based on personal characteristics, such as character and charisma), social (based on our societal and community status), and Aesculapian (based on our knowledge of medicine). He asks us to consider whether our power is owned, aimed, or shared.⁵⁵ As physicians, we can engage in personal reflective practices^{42,43} and share our power with patients by abiding as witnesses^{45,46,56,57} and being available for teachable moments when healing is possible.^{58,59,60} We can own our larger professional responsibility to address societal inequities that cause illness and suffering.⁶¹ We can band together in professionalism^{62,63,64} rather than in narrow self-interest to work toward a system that invests in relationships, measures what matters,^{37,54} and supports healing and health.^{65,66}

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