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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Should Clinicians Be Activists?

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Abstract

Physicians are ethically bound to respond to undocumented, underinsured, and uninsured patients' health needs, even those demanding complex, expensive interventions, such as organ transplantation. A social medicine skill set of structural competency, allyship, accompaniment, and activism is required to best serve patients and communities and should be widely regarded as core competencies for all health professionals. This commentary on a case considers the nature and scope of the skill of activism, specifically.

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Case

JM (an actual patient) was 1 year old when he was brought to the United States from Mexico.[1] At 16, he developed end-stage renal disease, and JM's mother was an exact tissue match for a kidney transplant. Although undocumented, JM was insured through Medicaid under the Children's Health Insurance Program (CHIP). However, the Chicago children's hospital transplant program refused transplantation because it could not guarantee the lifelong antirejection medication regimen, as JM's CHIP coverage would expire in 2 years.

JM required dialysis 3 times weekly, a less effective treatment than, but a bridge to, kidney transplantation.[2] JM's mother sought assistance from an activist priest whose congregation comprised undocumented and uninsured residents, many of whom had organ failure. Like JM, they were denied access to transplant evaluations at Chicago transplant centers because they were uninsured.

While transplant ethics and law demand equity in access to transplantation based on medical need, the system generally excludes uninsurable patients like JM.[3] Relative to other transplant-eligible kidney patients, undocumented patients like JM tend to be healthier, younger, and more likely to have access to living donors.[4] But because organ transplantation is costly and includes lifelong antirejection medications, financial concerns dictate transplant center policies that prevent eligible patients like JM from receiving transplants. In effect, the cost to save a life is valued over human life itself.

While a systemic solution was not apparent in JM's case, we (a group of physicians and students from transplant centers) agreed to ally ourselves with the community as advocates. The community held demonstrations, hunger strikes, and hospital sit-ins. We supported this activism by coordinating with the community, including by providing medical support for the hunger strikers and speaking publicly on their behalf. Ultimately, because of this activism, 8 years after his diagnosis, JM was transplanted with his mother's donated kidney.

Simultaneously, we convened a taskforce with the community and transplant center leaders. We engaged the Latino caucus of the state's legislature, and a law—the first in the nation—was passed to provide uninsured residents of the state access to organ transplantation.[3] The regional organ procurement organization also established a fund to purchase insurance to help cover costs of patients' posttransplant care. In the first 6 years, this fund has allowed over 200 undocumented, uninsured patients to undergo organ transplantation across the state of Illinois, with 150 more on the waiting list (personal communication, J. K. Cmunt, Illinois Transplant Fund, November 23, 2021).[5] JM has gone on to attend college.

Commentary

While social justice is a pillar of health care,[6] clinical decision making for uninsured noncitizen patients—particularly for complex and expensive care like organ transplantation—tends to pivot around cost and margin rather than the value of human life, with the exception of the aforementioned law.[3] Physicians face 3 choices in deciding on treatment: (1) accept the status quo, which entails that some patients like JM won't receive treatment; (2) advocate for patients on a case-by-case basis; or (3) imagine and advocate for structural interventions to affect political and social change. The overlapping skill sets of structural competency, allyship, accompaniment, and activism—which together might be viewed as the practice of social medicine—are necessary core competencies of medical practice in the face of an unjust health care system. In analyzing this case of an undocumented patient denied a lifesaving kidney transplant for financial reasons, we highlight the moral obligation of physicians to bring advocacy for needed medical treatments into the public and political space through application of the social medicine skills of structural competency, allyship, accompaniment, and activism.

Social Health Skills

Structural competency. In redressing a health inequity—access to kidney transplantation for uninsured noncitizens in the state of Illinois[6]—advocates applied a structural competency approach, with the understanding that access to care was a systemic problem. Structural competency teaches physicians how social, political, and economic determinants of health cause illness.[7] This approach, which focuses on the forces that influence health outcomes beyond the individual encounter, consists of 5 core competencies: (1) recognizing how structures like racism and other forms of marginalization shape clinical interactions; (2) "developing an extra-clinical language of structure"; (3) "rearticulating 'cultural' formulations in structural terms"; (4) "observing and imagining structural interventions"; and (5) "developing structural humility"––the awareness that professionals must be led by the community to solve problems.[7] However, the structural competency approach is inadequate without applying the skills of allyship, accompaniment, and activism.

Allyship and accompaniment. Allyship is an intentional practice in which persons in positions of privilege and power build authentic relationships with marginalized groups based on trust, consistency, and accountability in order to address unjust power structures in a manner that the community can recognize, acknowledge, and name. We were able to build trust by showing up consistently in the community at meetings and gatherings while amplifying the community's demands in public and political spaces, as well as within the transplant health centers by convening a task force.[5] Related to allyship, Paul Farmer speaks of physicians' obligations to practice accompaniment, an ethical value expressed in actions of pragmatic solidarity with the community.[8] In practicing accompaniment, health care practitioners are present with a patient or community during a journey toward equity. Similar to allyship, accompaniment is a deeper form of commitment to change.[8] It does not prioritize a physician's technical expertise above solidarity, compassion, or willingness to acknowledge and respond to inequity in a community, and the physician is not released from this obligation until the community makes that decision. For us, the Chicago physicians advocating for undocumented immigrants' access to transplantation, accompaniment meant committing to years of struggle in solidarity with the community with no obvious solution in sight. It also created urgency for physician advocates to partner with community leaders, transplant centers, and politicians to resolve a seemingly intractable problem.

Activism. In effect, activism is a natural consequence of the decision to be allies and *accompagnateurs* after applying a structural competency analysis to the problem. Activism requires health professionals to publicly leverage their privilege for social change. In this case, activism meant showing up at demonstrations at the transplant centers, convening meetings with the demonstrators and transplant leaders, and being vocal supporters for the petitioners in the media and in dialogue with political leaders.[3]

If the social medicine skills of allyship, accompaniment, and activism are necessary to achieve morally appropriate health outcomes for our patients, why are they not more widely practiced? There are 2 major reasons: (1) practitioners' concern that their activities on behalf of the community could cause risk to themselves and their institutions; and (2) practitioners' resistance to activism—arising from ideological opposition, lack of experience, or the belief that activism is beyond the scope of medical practice.

Individual and Organizational Risk

While the World Health Organization has defined health care as a human right,[9] in the United States, access to health care is, in practice, not a human right. Most hospitals operate within the parameters of a racialized capitalist system,[10] wherein the financial bottom line can drive clinical decision making. As Black and Latinx communities are disproportionately more likely than White communities to be uninsured or on government insurance that reimburses more poorly than private insurance, decisions about access to care have become racialized. Most physicians have been trained to comply with the economically determined rules of their organizations, and this passivity can perpetuate structural racism and other inequities.

In this case, the group seeking redress in Chicago comprised uninsured Latinx patients who were denied appointments for transplant evaluation. Clinicians and administrators were reluctant to take a stance on behalf of the transplant petitioners, as doing so could have jeopardized their hospital financial position.[2,3] The average kidney transplant direct surgical costs and charges for extensive follow-up care and monitoring are estimated to

be over $400 000.[11] Furthermore, if patients cannot adhere to the necessary clinic follow-up and medications due to a lack of insurance, the transplanted kidney could fail, thereby jeopardizing the reputation of the transplant program.

Resistance

The practice of social medicine requires physicians to move from being passive participants and de facto defenders of unjust systems to practitioners of the social medicine skills of structural competency, allyship, accompaniment, and activism. There are a number of reasons why doctors might resist embracing this skill set. First, physicians may view themselves as apolitical and intervening on social and political determinants of health care access as outside their domain of influence. They might take refuge in moral relativism, believing that any treatment is better than no treatment and that those with lesser means should get lesser care.

Second, some might disagree fundamentally with the notion that health care—in this case, access to transplantation—is a human right. As the economic class and social background of many physicians are vastly different from those of historically marginalized communities, they are economically and socially more aligned to maintain rather than challenge the status quo.

Third, because most health systems are hierarchically organized, health practitioners who are also employees might view activism as being a potential risk to their employment. Sometimes concerns about employment are explicit, but more often they are implicitly held within the organization and thus deter individuals from pursuing any action deemed risky. These are not trivial concerns, as speaking up and activism might have negative consequences, particularly for those whose race, gender, or position render them more vulnerable to retaliation. At the same time, however, physicians hold some of the most privileged positions within health systems and have disproportionate power to influence change.

Finally, health professionals might feel deterred from practicing allyship, accompaniment, and activism because they do not think that they have the time or the expertise to do so. Time devoted to health activism is often outside the scheduled clinical or administrative hours of most clinicians. Moreover, practitioners might not have expertise in structural competency or have participated in civic activism of any sort. Training in allyship, accompaniment, and activism is not yet central to most medical school and residency curricula. And, in consequence of their lack of training or experience, health professionals may view structural competency, allyship, accompaniment, and activism as beyond the scope of their expertise rather than as a core responsibility. Like all competencies, social medicine skills require practice and repetition, although they are not difficult to grasp and apply. Physicians' lack of training or experience can be rectified by more rigorous training in social medicine concepts during medical education.[12,13]

Social Medicine Practice

For those hesitant about or unfamiliar with social medicine, we suggest the following steps.

Practice structural competency by speaking out about health injustice. Learn the structural competency skills to move from individual case reviews to systemic analyses of social and structural root causes of health inequities in your practice. For those

seeking more expertise, begin to practice speaking out about social injustice in health care. Talk to your colleagues. Meet with your leaders. Write op-eds, such as through the OpEd Project's Public Voices Fellowship,[14] and academic papers. Join organizations with health activist agendas like Physicians for a National Health Program.[15] Go to public meetings and testify. Like most things in life, practice makes perfect—including speaking up.

Engage with community. Allyship and accompaniment are the natural outcomes of authentic community relationships built and maintained over time. There is a phrase that arose from the disability movement that is apropos of most health activism: "nothing about us without us."[16] Remember, the role of physician activists is to listen, amplify, and support the needs of the community with humility. With regard to transplant activism, while the system made sense from a financial perspective to those within the transplant centers, it was morally unjust to the patients. Once we understood this community perspective and agreed to accompany community members on their journey, we could advocate more effectively.

Utilize narrative. There is power in narrative as well as in data. Narrative + Data + Action = Change is a framework we created that can guide social medicine practice. Social medicine requires that practitioners amplify patients' stories with data and civic activism. The narrative of JM, a 24-year-old uninsured man who had lived in the United States since the age of one and been denied the gift of his mother's kidney simply for financial reasons, amplified the moral case. Data on transplantation demonstrate that Black and Latinx patients are transplanted less frequently than White patients,[17,18] underscoring that the system is unjust. But in this case, civic action in the form of public demonstrations, hunger strikes, creation of the transplant taskforce, and subsequent legislative action was crucial to create the outcome—which improved, but did not completely fix, the system.

Leverage public policy to create social change. In this case, law and other policy changes led to expanded access to transplantation. In Illinois, this successful work on transplantation resulted in new legislation, effective December 2020, to extend coverage to undocumented individuals over the age of 65 through the Health Benefits for Immigrant Seniors Program,[19] thereby expanding the social safety net. If there are political determinants of health, activists must pursue political solutions.

Conclusion

The social medicine skills of structural competency, allyship, accompaniment, and activism are key for health professionals. We have discussed why some clinicians are reluctant to practice activism and provided a roadmap for practicing these skills. JM's case illustrates how activism in service to a community helped a patient equitably access care. Social medicine skills are central to health professionalism. With community members, clinician activists can motivate equity and help all patients get ethically and clinically indicated interventions.

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