

Commentary: Community Knowledge for Equity in Healthcare

Commentaire : connaissances communautaires pour l'équité dans les soins de santé

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Abstract

In their insightful article, Sayani et al. (2021) provide five considerations for developing patient partnerships that are meaningful and inclusive. In this brief rejoinder, we outline three points that push the boundaries of the discussion on diverse patient partnerships and represent challenges faced by our own research team as we aim to build and deepen our approach to community engagement. Firstly, we suggest a shift from patient engagement to community engagement; secondly, we propose a shift from engaging various communities together by labelling them as “underserved” or “structurally marginalized” to engaging specific cultural or geographic communities at specific times; and finally, we suggest deferring to community knowledge.

Résumé

Dans leur article inspirant, Sayani et al. (2021) présentent cinq points à considérer pour l'établissement de partenariats significatifs et inclusifs avec les patients. Dans cette brève réplique, nous abordons trois points qui repoussent les limites de la discussion sur divers types de partenariats avec les patients et qui représentent les défis auxquels notre propre équipe de recherche s'est confrontée au moment d'approfondir la démarche concernant l'engagement communautaire. Premièrement, nous suggérons de passer de l'engagement avec les patients à un engagement communautaire; deuxièmement, nous proposons de passer de l'engagement amalgamé de diverses communautés qualifiées de « mal desservies » ou « structurellement marginalisées » à un engagement culturel ou géographique, à des moments définis; et enfin, nous suggérons de s'en remettre davantage aux connaissances de la communauté.

Introduction

Events during the COVID-19 pandemic have awakened many people in positions of privilege to the realities of those living in circumstances of unearned and unjustifiable disadvantage. Although some of these realities are linked, perhaps indirectly, to the spread of the virus, issues such as systemic racism, ageism and the ongoing effects of colonialism seem to have become a more prominent part of public discussion. If growing awareness about these issues is going to lead to actual change, then privileged stakeholders in institutions of research and policy, such as ourselves, must help make it happen.

In the realm of public health and healthcare, it is not just disparities in access to and outcomes of health interventions between groups that are significant – although they are persistent and extremely problematic. It is also the outright risks to personal safety faced by Black, Indigenous and other Peoples of Colour during encounters with healthcare that must be addressed. In this context, Sayani et al. (2021) emphasize that redressing these injustices in health systems requires the collaboration and leadership of those people who are the most affected by institutionalized forms of oppression. They clarify the importance of centring diverse patient perspectives in research and policy that is oriented toward enhancing health equity. They provide five considerations for developing meaningful inclusive patient partnerships, each of which is framed in practical ways for health leaders to understand and adopt. In this brief rejoinder, we highlight three points that push the boundaries of the discussion on diverse patient partnerships and represent challenges faced by our own research team as we aim to build and deepen our approach to community engagement in our work.

Shifting from Patients to Communities

The concept of the “patient” in the phrase “patient engagement” is problematic. The assumption made in healthcare is that when viewed from a vantage point of the health professions, a *person* is transformed into something new: a *patient*. In a commentary, Neuberger (1999)

advocated for a shift away from the term “patient”. She explained that the word “patient” comes from the Latin word *patior*, which means to passively suffer or bear the weight of a given burden (Neuberger 1999). This legacy of the term “patient” has remained salient throughout the history of healthcare and medicine, creating a foundation for healthcare paternalism that characterizes contemporary health-related education and practice.

The attention to patient engagement in research and policy in recent years has undoubtedly shifted emphasis from the expertise of the healthcare provider to the needs, wishes and experiences of people seeking care. While this has meant that some people have been able to provide input into the organization and delivery of healthcare, this opportunity has not been equally available to all patients. As Sayani et al. (2021) clearly articulate, those who have had the opportunity to participate in this way have tended to be “white, well-educated and well-resourced” (p. 19), leading to a very narrow set of insights about patients’ experiences with healthcare.

However, beyond the unequal distribution of opportunity, other foundational assumptions regarding patient engagement and partnership should also be questioned. Perhaps the most important one is the assumption that the voices of individuals already labelled as passive patients – with no insider knowledge of how the system works – can compete against the deeply entrenched hierarchies through which decisions in healthcare are made. Can individual people providing independent input to committees otherwise dominated by powerful insiders really produce systematic and meaningful change in healthcare?

Through the extraordinary action of some individuals, the answer is, sometimes, yes. But as Sayani et al. (2021) propose, the engagement of community perspectives over individual viewpoints enables a more robust approach to understanding and acting on peoples’ perspectives of healthcare. Community engagement and partnership refers to a diverse collection of practices oriented toward involving community members in projects and services that affect them (Wallerstein et al. 2017). This can mean having community members as co-leaders on a given project, or creating a process of systematically gaining insights from a variety of community members and synthesizing them into overarching implications for an initiative. The central point of our discussion here is that community engagement and partnership refers to the systematic collaboration with several members of a given community affected by the structure and delivery of health services, as opposed to individual people on an ad hoc basis.

From the perspective of some Anishinaabe Peoples, a request for partnership and the sharing of oral history implies the involvement of an entire community. When one asks for collaboration with an Anishinaabe person, they are not just asking for their individual experiences but, rather, the expertise of that person and the history, relations and “community knowledge” of their Anishinaabe worldview. In our own research, we aspire to carry this sentiment forward and embrace the worldviews of the communities affected by the health services on which we are focused. In relation to partnership with Indigenous communities,

this has been referred to as “two-eyed seeing” (Bartlett et al. 2012), wherein research teams embrace both settler and Indigenous ways of understanding. We are not good at this yet. This is an aspirational goal – one that could help us push the boundaries of what can be accomplished for health equity in research and policy.

Shifting from General to Specific Communities

In a crucial paper for advancing our understanding of research on health equity, Katz et al. (2020) examined how using the phrase “vulnerable populations” can inadvertently obscure more effective approaches to enhancing health equity. In our own work, we have moved between various labels for the diverse group of community members we intend to partner with. For example, we have relied on the phrase “underserved communities” to place emphasis on the effort and capability of healthcare systems to adequately serve everyone. Based on feedback from community partners, we shifted to “structurally marginalized communities” to emphasize the active processes of marginalization due to intersecting and institutionalized forms of oppression. But the incisive analysis from Katz et al. (2020) clearly shows that such labels create spaces that people will fill with their own assumptions about what makes people “vulnerable”, “underserved”, or “structurally marginalized”. The vagueness of these terms might do more harm than good as echoed by Sayani et al. (2021).

Relying on such all-encompassing terms conveys an assumption that there is a set of commonalities between specific communities, which might not be so common on a close, second look. Certainly, solidarity between communities facing circumstances of structural disadvantage is important but, as researchers and other health leaders, we probably would do better by focusing on the needs and experiences of specific communities at specific times. For example, one would need to emphasize very different things when promoting cultural safety for First Nations communities in Northern British Columbia than for French-speaking refugee communities in downtown Toronto. We suggest that focusing on specific communities at specific times is an important complement to the diverse patient engagement outlined by Sayani et al. (2021).

Deferring to Community Knowledge

One of the most challenging elements of adopting a community-engagement mindset must be about shifting from a model of scientific expertise to one of community expertise. Sayani et al. (2021) have addressed this in a highly insightful way, outlining the importance of deep reflection about the assumptions we, as researchers and health leaders, bring to our work in healthcare. For example, we have deeply entrenched assumptions about what counts as “real knowledge”, and when we have “enough” knowledge to act. For many of us, the answers to these questions tend to rest on an epidemiological paradigm. Unless something has been demonstrated as existing through a large-scale study – or so the logic goes – it cannot form an evidentiary foundation for making real change in healthcare. However, such a logic relies on what scientists of the past and present have chosen to study. Are they studying the right things?

This scientific humility is at the central core of the effort to shift from a paternalistic, system-centered approach to one that truly respects and reflects the experiences and perspectives of individual communities. Researchers and other health leaders have the means to listen to communities and examine how and why community members have been made to think and feel about the system in particular ways. This is a crucial way in which those of us in privileged positions in public health and healthcare can more adequately co-develop the necessary system changes to enhance health equity. Meaningful partnerships demand scientific humility.

Conclusion

Carrying forward the lessons learned during the COVID-19 pandemic about the importance of partnering with communities in support of health equity will not be easy. Systems of research, health leadership and health policy are structured on a model of expertise that places community knowledge at the bottom of the hierarchy (Cann and DeMeulenaere 2020). This has allowed conventional practices of patient engagement and partnership to be superficial and sometimes harmful. While we work to bring community members in as co-leaders of research and policy initiatives, we also need to work to change the structures and incentives that reinforce this hierarchy. Expanding the conversation to include diverse patient voices and community partnerships is one way of doing so, and we are grateful to Sayani et al. (2021) for getting us started.

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