Can a Focus on Equity, Diversity and Inclusion Transform Health Services Research?

L'accent mis sur l'équité, la diversité et l'inclusion peut-il transformer la recherche sur les services de santé?

COMMENTARY

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ABSTRACT

The new Canadian Institutes of Health Research – Institute of Health Services and Policy Research's Strategic Plan 2021–2026 *(CIHR IHSPR 2021) holds potential. Barriers are anticipated, including that commitments to equity, diversity and inclusion (EDI) are tokenistic. This commentary provides four recommendations to* *support EDI as transformative. First, EDI must start with an honest history of the role of institutions in upholding injustice. Second, performative EDI must be replaced by changes in money, power and resources. Third, data collection alone must never be the end goal of EDI. And fourth, for EDI to be transformative, it must be grounded in praxis, taking direction from communities and movements seeking justice.*

RÉSUMÉ

Le nouveau Plan stratégique 2021–2026 de l'Institut des services et des politiques de la santé des Instituts de recherche en santé du Canada (CIHR IHSPR 2021) présente un certain potentiel. Des obstacles sont anticipés, notamment le fait que les engagements en matière d'équité, de diversité et d'inclusion (EDI) sont symboliques. Ce commentaire fournit quatre recommandations pour soutenir l'EDI en tant que concept de transformation. Premièrement, l'EDI doit commencer par une histoire honnête du rôle des institutions dans le maintien de l'injustice. Deuxièmement, l'EDI de performance doit être remplacé par des changements en matière d'argent, de pouvoir et de ressources. Troisièmement, la seule collecte de données ne doit jamais être l'objectif final de l'EDI. Et quatrièmement, pour que l'EDI soit transformatif, il doit être ancré dans la pratique, en s'inspirant des communautés et des mouvements en quête de justice.

Introduction

Universality is a core principle of the Canadian healthcare system, enshrined in the *Canada Health Act* (1985). Universal access to care when it is needed – regardless of the ability to pay – is deeply embedded in the public's perspectives on our healthcare system and seen as a defining feature of what it means to be Canadian (Soroka 2007). However, alongside this commitment to medicare, Canadians have accepted deep inequities in access to care, health outcomes and the social factors that determine our health. Numerous reports and studies have documented health inequities in Canada, from the *1986 Epp Report*, which noted that "people's health remains directly related to their economic status" (Epp 1986: 3), despite the passing of the *Medical Care Act, 1966* (Government of Canada 2019), two decades prior. A recent study of premature and avoidable mortality in Canada between 1991 and 2016 found that health inequities associated with socio-economic status have persisted or even widened (Shahidi et al. 2020). Canadians who have a low income can experience discrimination when seeking a family physician (Olah et al. 2013), or when accessing specialists, compared to wealthy Canadians (Alter et al. 1999; Dunlop et al. 2000; van Doorslaer et al. 2006). Similarly, Canadians with lower educational attainment can face more difficulty accessing specialist care than those with higher education (Glazier et al. 2009). Other factors that influence who receives health services and the quality of the care they receive include racial or ethnic background, language preference, gender identity and sexual orientation and disability status (Adler and Stead 2015; Gottlieb et al. 2013; Pinto et al. 2016; Weissman and Hasnain-Wynia 2011; Wen et al. 2007).

Health services research plays a crucial role in shaping the design, implementation and performance of health systems and addressing such gaps and challenges. Health services research has been an important means of deepening our understanding of why inequities persist, what role organizational and financial factors play at multiple levels and how healthcare systems work, or do not, for specific populations. The Canadian Institutes of Health Research – Institute of Health Services and Policy Research's *Strategic Plan 2021–2026: Accelerate Health Care System Transformation through Research to Achieve the Quadruple Aim and Health Equity for All*, has a strong focus on all these areas (CIHR IHSPR 2021). The plan commits to fund research that will contribute to the transformation of healthcare delivery systems in Canada to achieve the Quadruple Aim, which includes a focus on improving the health of populations (Berwick et al. 2008; Sikka et al. 2015), and advance interventions that are focused on "improving health equity for all" (CIHR IHSPR 2021: 5). Related, the plan emphasizes support for research at the intersection of health services delivery and population health practice, with a focus on improving health equity. Finally, a key value that is cited as a guide to the plan is a commitment to equity, diversity and inclusion (EDI), defined in the strategy as fairness, representation and valued participation, respectively (CIHR IHSPR 2021).

Root Cause Analysis

A starting point for considering the potential impact of this new agenda for Canadian health services research is whether it can support a root cause analysis that goes upstream of health inequities (Penman-Aguilar et al. 2013; Pujolar et al. 2016). The persistence of health inequities in the context of near universal coverage for key healthcare services is predominantly a product of the social determinants of health. These are "the conditions in which people are born, grow, live, work and age" and the broader social, economic and political systems that create these conditions (WHO 2008). It is impossible for health systems to significantly reduce inequities without integrated action on social determinants, whereby traditional healthcare services that tackle biological concerns and "downstream" concerns are combined with "upstream" steps to address social issues at the individual and community levels (Pinto and Bloch 2017). Triggered in large part by the work of the World Health Organization's "Commission on Social Determinants of Health" and the publication of its final report in 2008 (WHO 2008), major Canadian health organizations have publicly supported upstream action, including the Canadian Medical Association (CMA 2012), the College of Family Physicians of Canada (CFPC 2015) and the Registered Nurses' Association of Ontario (RNAO 2010), among others.

However, beyond declarations and statements, are Canadian health professionals, their associations and organizations and the governments that finance and manage them truly prepared to tackle the social determinants of health? As others have noted, Canada has a history of calling attention to health inequities and putting forward a strong vision for necessary changes but not following through with concrete actions (Bryant et al. 2011; Raphael 2008). Outside of isolated initiatives in a small number of health organizations (Andermann 2016; Bayoumi et al. 2017; Drozdzal et al. 2019; Jones et al. 2017), action on social determinants in healthcare remains rare. Several reasons for this can be hypothesized. It may be difficult to step back from the narrow goals of a single initiative and understand and address the broader political economy in which decisions are taken – specifically, the current neoliberal state that since the 1980s has focused on individual responsibility and market mechanisms to address many social problems and seen the diminishment of collective action (Bambra et al. 2009; Poland et al. 1998; Raphael 2015). It may be that the financial and non-financial incentives do not yet exist for health professionals and healthcare organizations for actions on social determinants at both the individual and community levels. In addition, when policies are proposed to redistribute money away from health services and toward social needs, it is perhaps not surprising that there is opposition, even from those in the health sector who had called for greater equity (Stanbrook 2017; Vogel 2017). Finally, it could be that the closely linked community of health leaders, academics and provincial and territorial policy makers in Canada are not able to understand, speak to and address the needs of people who have been made vulnerable by social and economic policies.

Can EDI Transform Health Services Research?

Skepticism and a critical perspective are, therefore, warranted from universities, research institutions, medical journals and funders when considering the much more recent focus on EDI (Tamtik and Guenter 2020). EDI as a concept, process and set of objectives is related to the goals of reducing health inequities, going upstream and tackling the social determinants of health, but is certainly distinct. EDI is focused internally on an organization (e.g., a university department, a research institute, a funder), the individuals who make up or are affiliated with the organization (e.g., faculty members, students, board representatives) and how these individuals relate to one another. One connection between EDI and the social determinants is that both are concerned with the distribution of money, power and resources. EDI has emerged from a long history of struggle for equality by Black, Indigenous and other People of Colour; women; people with disabilities; and many other communities (Black Health Alliance, Health Commons Solutions Lab and Sinai Health 2020). These are the same communities that historically have been excluded and mistreated by health researchers and health organizations. Related, it is essential to recognize that the contemporary focus on EDI has not emerged as a result of dialogue and reflection within traditional institutions or organizations, but in response to mass movements – notably Black Lives Matter – in pushing for social change in the wake of the murders of George Floyd and many others (Neustaeter 2021; Silverstein 2021).

The potential impacts of EDI as a value applied to health services research can be grouped into at least four areas (Odedina and Stern 2021). First, what are the characteristics of the individuals applying for grants to support health services research? Are they representative of the diversity of the population? Who are the reviewers of applications and are there any systematic inequities in who is successful and the amounts granted? Research from the US suggests racial inequity in grant funding is a distinct possibility (Taffe and Gilpin 2021). Second, in terms of capacity building, are individuals, who are from underrepresented communities and those who have faced historic disadvantage, provided with additional support, mentorship, protected time and resources to become future leaders in health services research? Third, what projects, topics and methods particularly succeed in obtaining funds, and is there an emphasis on calls for health services research to tackle health inequities, particularly issues such as addressing systemic racism? Related, is there a focus on funding authentic community-based participatory action research that seeks to engage those who have been made vulnerable by social and economic policies in the design and implementation of interventions? Fourth, and most important, are the producers of health services research supported to translate findings into policy decisions that support interventions that identify and reduce health inequities, including the anti-racist interventions in health settings (Hassen et al. 2021)?

Recommendations to Support EDI as Transformative

1. *EDI must start with an honest and clear history of the role of science in upholding injustice.* For EDI to be transformative, it must begin with a thorough knowledge of the harm committed by researchers and institutions in the past and present, particularly the impact on Black, Indigenous and other People of Colour (Darroch and Giles 2014; Morton Ninomiya and Pollock 2017; Pinto and Smylie 2013). A knowledge of this troubling history can influence all aspects of research, from the research questions posed to the selection of methods to how data are collected, analyzed and interpreted. While acknowledgements and apologies are important, there must be a commitment to justice and reparations, with both health organizations and health services research funding bodies reporting on the resources dedicated to addressing historic gaps and progress over time.
2. *Performative EDI must stop* (Khazanchi et al. 2021). This means putting a halt to declarations and statements without any fundamental change in money, power and resources being contemplated or implemented. Health organizations, research institutes and funders should commit to a policy of no statements without specific and measurable actions, timelines and transparency.
3. *Data collection alone must never be the end goal of EDI.* All too often, EDI initiatives have focused on the process of measuring the degree of the problem of a lack of representativeness and systemic discrimination in who holds power or is awarded resources. Furthermore, such data, when collected, are often kept hidden from the view of communities and individuals, with the institutional reputation prioritized. If data collection occurs from applicants for funding, employees, faculty or students, there must be transparency so that the numbers can be put in the hands of individuals and communities working for change. Lessons can be drawn from how data that are collected from patients and communities are governed and acted upon. The principles of Ownership, Control, Access and Possession (OCAP®) (FNIGC 2022) regarding Indigenous data are a key part of supporting Indigenous self-governance and sovereignty (Anderson 2019; Pyper et al. 2018). A more recent framework of principles that emerged during the COVID-19 pandemic concerning data from Black and other racialized communities is "Engagement, Governance, Access and Protection" (Black Health Equity Working Group 2021). These approaches can help to ensure that data collection does not become the goal but rather the starting point for accountability, reducing inequities and justice.
4. *For EDI to be transformative, it must be grounded in praxis, "reflection and action upon the world in order to transform it"* (Freire 1970: 51). This is perhaps the most challenging recommendation as it sees health organizations, health services researchers and funders as part of a broader system that either maintains the status quo of inequities and systemic racism or can be part of solutions. However, rather than setting the agenda and taking the lead role, academics, health system leaders and professionals

must listen to and follow the needs of communities and social movements for justice. Although this inversion of power may seem both idealistic and unattainable, community-based participatory action research and patient-oriented research have established a nascent path and set of methods. Related, health services research must be judged with new eyes. Instead of a focus on individual-level metrics that frame science as a series of outputs (e.g., papers, citations, value of grants), we must engage diverse communities in how to assess the value of health services research – for example, considering who benefits from the findings, what the collective impact is and if the research is emancipatory.

Conclusion

These four recommendations to support EDI as transformative for the community of health services researchers that is truly seeking to reduce inequities are just the starting point. Much more, of course, is required of our institutions, associations and governments. Progress will be assessed in whether we have at last narrowed persistent inequities in access, outcomes and quality, fitting with the deep commitment to universality that Canadians cherish.

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