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What Is Missing from “Patient-Oriented Research?” A View from Public Health Systems and Services

Que manque-t-il à la « recherche axée sur le patient »?
Point de vue des systèmes et services de santé



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Abstract

Patient-oriented research (POR) aims to increase patient engagement in health research to improve health research and health services. In Canada, the Strategies for Patient-Oriented Research (SPOR) framework provides guidance for conducting POR. We critically review the SPOR framework through the lens of public health systems and services research. The SPOR framework is primarily focused on engaging individual patients in health research without attention to broader structural forces that shape health and participation in health-care systems. Shifting from patient to public involvement and from patient to community engagement and being explicit about the range of health research that SPOR encompasses would enhance the framework and strengthen the potential of SPOR to improve health systems through health protection, promotion and prevention of disease and injury.

Résumé

La recherche axée sur le patient (RAP) vise à accroître la participation des patients afin d’améliorer la recherche et les services de santé. Au Canada, la Stratégie de recherche axée sur le patient (SRAP) offre des conseils pour faire de la RAP. Nous avons examiné de façon critique la SRAP selon l’angle de la recherche sur les systèmes et services de santé. La SRAP vise principalement à faire participer les patients à la recherche sans égard aux grandes forces structurelles qui influent sur la santé et sur la participation dans les systèmes de santé. Passer d’une participation du patient à une participation communautaire, et exposer de façon plus explicite la gamme de recherches en santé visée par la SRAP, améliorerait le cadre stratégique et accroîtrait son potentiel d’amélioration des systèmes de santé, notamment par la protection sanitaire et la prévention des maladies et blessures.

Introduction

The enhancement and sustainability of public health systems and services has repeatedly been identified as important to improving the health of the public through health promotion, protection, and disease and injury prevention efforts both within the health system and through collaboration with other sectors that impact health (Krever Commission 1997; The Standing Senate Committee on Social Affairs, Science, and Technology 2002). In addition, there have been specific calls to reorient health systems toward health equity to address structural injustices and social conditions that produce poor health (Commission on the Social Determinants of Health 2008; World Health Organization [WHO] 2011). These calls stem from analysis of the rising costs of medical care and the ineffectiveness of the current health system to address health inequities. In an analysis of the economic benefits of public health services, Mays and Mamaril (2017) found that investments in public health significantly offset health system costs, with larger offsets for low-income and low-resource communities. Reducing health inequities through upstream action on the social determinants of health is an economic, social and ethical imperative.

The field of public health systems and services research (PHSSR) emerged to bridge population health research and health systems and services research, with a unique focus on public health services, policies and programs. PHSSR examines “the impact of the organization, staffing, and management of public health systems on access to, delivery, cost, quality and outcomes of population-based services and interventions” (Van Wave et al. 2010). PHSSR aims to enhance the health of the public and reduce health inequities by understanding how public health systems and services work and identifying ways in which these might be improved.

Concurrent with the emergence of PHSSR, there has been a growing focus on patient involvement and engagement in the development and conduct of health research (Brett et al. 2010, 2012; Sacristán 2013). Terms such as patient-centred research, patient engagement in research, patient-oriented research and public involvement are used to capture the growing impetus to involve patients and service users in all types of research. We use the term “patient-oriented research” because that is the predominant term used in Canadian guidance documents (Canadian Institutes of Health Research [CIHR] 2014).

Patient-oriented research (POR) encompasses several aims. Some authors have described the moral aim of POR as the empowerment of patients in the process of research, to ensure more responsive and responsible research that benefits the public (Brett et al. 2010; White and Verhoef 2005). Others have emphasized the importance of optimizing research designs, enhancing validity and improving the effectiveness of knowledge translation and exchange (Bogart and Uyeda 2009; Brett et al. 2012; Caron-Flinterman et al. 2005). The ultimate aims of POR are to improve the effectiveness, efficiency and delivery of healthcare services, programs and policies.

Policy and funding initiatives have been launched to support POR and enhance the shift from primarily researcher-driven to patient-driven research: these include INVOLVE in the UK (<https://www.invo.org.uk/about-involve/>), Patient-Centered Outcomes Research Institute (PCORI) in the US (<https://www.pcori.org>) and Strategies for Patient-Oriented Research (SPOR) in Canada through the CIHR (2014). The aims of SPOR are identified as follows:

An important goal of Canada’s Strategy for Patient-Oriented Research (SPOR) is for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada. Since patients are at the heart of SPOR, they must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians. (CIHR 2014, p. 4)

POR commitments include engaging patients and the public to improve health research and, ultimately, health systems and services. This represents a significant shift toward

acknowledging the value of situational and experiential knowledge as a source of practical wisdom for improving health research, systems and services (Caron-Flinterman et al. 2005).

In this commentary, we critically examine the CIHR SPOR framework from the perspective of PHSSR. We examine three concepts central to the SPOR framework and to PHSSR – patients, patient engagement and health services – through a public health systems and services lens. We identify dominant underlying discourses of SPOR and discuss important contributions from public health and PHSSR that could strengthen the framework and improve the potential for health system improvements.

In the name of “patients” and communities

In SPOR, the “patient” is the focus of engagement or involvement. A patient is defined as “an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends” (CIHR 2014). The strengths of this definition include a focus on experience as a source of knowledge, the engagement of people with lived experience and the inclusion of caregivers, families and friends.

The very nature of the word “patients” as the primary human focus in the SPOR framework intentionally or unintentionally reinforces the dominant societal focus on individuals presenting with a health problem to be treated through acute or chronic healthcare services and, by extension, involving their caregivers and families. Public health does not have “patients” but focuses on primordial, primary and secondary prevention with families, groups and communities. The aims of public health are to promote health, strengthen community action for health, develop personal skills, promote supportive environments, build healthy public policy and reorient the health system toward health promotion and well-being (WHO 1986). Health promotion prevents people from becoming patients, thus reducing the burden of disease that the healthcare system has to manage. Moving upstream to focus on prevention and health promotion has long been a critical recommendation for reducing costs and enhancing health systems in Canada and worldwide (Commission on the Social Determinants of Health 2008).

Absent from the SPOR framework is recognition of the complex social, environmental, economic and policy conditions in which individuals, families, groups, communities and populations are embedded and that impact health through the social locations of individuals and collectives within systems of power and privilege. This “situated-ness” is central to public health thinking and approaches (Commission on the Social Determinants of Health 2008; Sadana and Blas 2013). The term “patient-oriented” implies that “patients” and “academic researchers,” “health service providers” (except informal caregivers) and/or “health policy makers” occupy mutually exclusive groups. This creates a binary or fixed understanding of categories of people, with little to no overlap, empathy or shared perspectives and little understanding as to how each is situated and/or the differences in power based on one’s position.

Along with an emphasis on social positioning, public health emphasizes self-determination, social context and social and environmental conditions that influence health and well-being that are implicated in the production of inequitable health outcomes (Commission on the Social Determinants of Health 2008; Sadana and Blas 2013). The degree to which individuals are autonomous is contextualized by the relative power they hold and their resources and social networks (Commission on the Social Determinants of Health 2008). This portrayal of “patients” as autonomous is rooted in a neo-liberal consumer model of healthcare that personifies patients as rational consumers choosing the best available product. It is also based on an inaccurate presupposition that there is equitable access to accurate, unbiased information and the full gamut of health services. Further, there is a failure to recognize differences in vulnerability based on group or community identification or status within a healthcare system that privileges the ultimate authority of the physician and emphasizes treating illness and injury rather than promoting self-determination and health. These understandings of social position and situatedness are critical to recognizing and addressing power inequities that permeate research and healthcare relationships and should be a fundamental principle of SPOR.

The focus on involving individual “patients” runs the risk of failing to represent groups impacted by structural inequities. When patients are involved, without attention to issues of power and privilege, tokenism and the co-optation of individuals and groups can reproduce systemic and structural inequities that are the root of poor health (Ocloo and Matthews 2016; Shimmin et al. 2017). For example, individuals may be selected to participate in SPOR projects specifically for their tendency to represent and, therefore, reinforce the status quo. Representatives may be chosen who present socially acceptable personas and/or do not threaten the existing power dynamics within the system. Public health approaches draw attention to the determinants that shape health and the constraints that affect participation of individuals, groups and communities. We would suggest, like others, that the use of the term “public” engagement better reflects broader collective involvement of individuals, groups and communities. Use of the term “public” also more readily makes space for consideration of the social, political, economic and historical conditions that impact resources and the ability to participate fully and in meaningful ways (Shimmin et al. 2017).

In the name of “patient” and community engagement

Patient engagement in the SPOR framework is primarily described through the delineation of various individual roles such as committee members and researchers and through guiding principles of inclusivity, support, mutual respect and co-building. We explore two relevant issues from a public health systems and services perspective: 1) use of the term “patient engagement” and 2) lack of attention to well-known and established participatory processes for research.

The focus on patient or individual engagement misses the important role of communities in creating supportive environments for health. In a recent scoping review of the

literature, Manafo et al. (2018) suggested that methods for patient engagement should involve patients early and throughout the research process and should support and value the expertise of patients. Community-based participatory research (CBPR) emphasizes the co-production and democratization of knowledge and action with recognition and valuing of the contributions of communities to the research as a means of generating action to improve health and health services. CBPR, and engaging communities as a source of knowledge in designing, developing, evaluating and researching health services, is central to PHSSR (Bogart and Uyeda 2009; Israel et al. 1998; Minkler 2010). Using a critical public health lens, rooted in the concepts of health equity and social justice, can help illuminate important differences in power between providers, policy makers and patients/communities that are central to authentic and meaningful participation in research. This is consistent with the democratic aims of CBPR.

Further, in relying on existing (and in our view limited) CIHR frameworks, SPOR seeks to engage individual patients and their families without paying sufficient attention to Indigenous wellness approaches and research processes. This is extremely problematic in the context of the Truth and Reconciliation Commission, which has outlined specific calls to action for improving health and healthcare (Truth and Reconciliation Commission of Canada 2015). This follows earlier reports on the failure of the health systems for Indigenous peoples, including the Royal Commission on Aboriginal Peoples (Aboriginal Affairs and Northern Development Canada 1996). These omissions reinforce and overlook important considerations in reorienting health systems and health research. Any attempt to improve health and health systems for Indigenous peoples has to account for the powerful, historical and ongoing colonization of healthcare systems and doing research “with,” not on, Indigenous people, with explicit attention to Indigenous methodologies to enhance cultural appropriateness, efficacy, relevance and fairness of health research, services and systems (Kovach 2018).

To address these issues, we suggest attention to 1) expanding the language of “patient engagement” to community or public engagement, thus including individuals, families, groups and communities; 2) explicitly incorporating principles of CBPR, specially the importance of an action orientation; and 3) paying specific attention to decolonizing health research and processes for the meaningful inclusion of Indigenous peoples, as well as Indigenous research methodologies and protocols.

In the name of “health research”

The SPOR framework refers to “health research.”

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system. (CIHR 2014)

Although this statement could be considered as inclusive of all health research, including PHSSR, such language is also subject to the dominance of an individually focused, bio-medically oriented healthcare system. Like the term “patient,” the use of the terms “health research” and “health services” is subject to biomedical discourses, with the main focus being on “patients” accessing acute or chronic healthcare services, not community-based, population-focused health-promoting care. Biomedical discourses focus primarily on the diagnosis, treatment and cure of diseases, which is the dominant focus within our Canadian health system (which is, in reality, an illness care system). The need for patient involvement in biomedical research has been a main driver of POR, and patient engagement in biomedical discourse is highly relevant to improving healthcare and individual health outcomes (Caron-Flinterman et al. 2005; Sacristán 2013; Shaywitz et al. 2000). However, many public health interventions are social, environmental, economic and policy focused in nature and aimed at changing these health determinants and the broader structural conditions that affect health. Public health approaches and interventions, which are often outside the dominant understandings of health services, aim to promote community or societal health and, in doing so, also promote individual health.

PHSSR, as one type of health services research, has the potential to produce knowledge that contributes to improvements in health systems that, in turn, will improve the health of populations. PHSSR achieves this by studying interventions that change the conditions that produce health inequities. Upstream thinking is needed at the population level to enhance early detection, support and intervention, particularly within vulnerable groups (PHAC, PHN, Stats Can and CIHI 2017). As identified at the outset of this paper, PHSSR is a highly recommended area for health systems improvements, with the potential to offset expensive acute care costs (Krever Commission 1997; Mays and Mamaril 2017; Romanow 2002).

We argue that specifying the full range of health research within the scope of SPOR would greatly enhance its potential to achieve its aims while also improving population health and reducing health inequities. In addition, using language that better reflects the full scope of healthcare functions, from health promotion, prevention and early intervention to diagnosis, treatment and tertiary care, will better position the role of health service users, within the context of their communities, as leaders in transforming the system. To realize health systems improvements, we need to move beyond dominant biomedical and individualized understandings of health and health services. Although the SPOR document does not exclude PHSSR, specific delineation of different types of health research would greatly enhance the potential of SPOR to move beyond dominant understandings to harness the potential of critical new areas of health research, such as PHSSR, to realize both health systems improvements and – more importantly – improvements in the health of populations and reduction in health inequality.

We argue that PHSSR, as a focus of health systems and services research, can improve health and reduce the large excess burden of disease and illness that the health system has

to manage at great expense. Prevention is a hallmark of quality care that contributes to improved health and reduced inequalities in health as well as improved patient satisfaction – nothing is more satisfying than not having the illness or injury in the first place – and reduced costs (Hancock 2017; Ministers of Health and Health Promotion/Healthy Living 2010). Indeed, public health and preventive services are argued to contribute to achieving the “Triple Aim” (Beasley 2009) and thus to the sustainability of the healthcare system (Hancock 2017).

Conclusions

In this commentary, we unpack the central SPOR concepts of patient, patient engagement and health research and argue for an expansion of these concepts in the SPOR framework to enhance potential for improvements in health systems and services. We provide a critical analysis of the dominant understandings of “patient,” “patient engagement” and “health research.” Implicitly, the SPOR framework revolves around individual patients, and, by extension, biomedicine and acute care, without capturing the full range of health research.

The SPOR framework would be greatly enhanced by shifting from patient to public and from patient engagement to community engagement and by delineating a broad range of health research that is inclusive of and extends beyond PHSSR. These shifts are needed for the promise of SPOR to be realized, to address issues of power and privilege in the research process and to avoid unintended consequences. These consequences spring from dominant neo-liberal and biomedical understandings that permeate healthcare systems along with inattention to the social conditions that influence health outcomes and the ability to participate in healthcare research. Individual patients, families, communities and the entire population will be better served by this expanded framework.

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