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Patient-centric culture and implications for patient engagement during the COVID-19 pandemic

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Abstract

Some consider patient engagement as the “holy grail” of healthcare because of its potential to revolutionize how we view and address health system problems. Multiple efforts around the world have attempted to cultivate a patient-centric culture whereby health services are grounded by the needs and preferences of patients. Recently, health service organizations are engaging patients in a wide array of activities including research and quality improvement. There are many ethical imperatives and economic and social benefits to patient engagement such as higher patient self-esteem and trust, and a more cost-efficient system. However, these benefits have been realized in some contexts and not others. Using the 3I framework (ideas, interests, institutions), this analysis examines two ideas that support (ethical imperatives and economic and social benefits) and one that opposes (negative attitudes and perceptions of patient engagement) a patient-centric culture. The first idea identifies the ethical imperatives that bolster the patient engagement movement and shift power and accountability to patients because of their role as taxpayers, users, and consumers of health services. The second idea describes the economic and social benefits associated with patient engagement and discusses why these benefits have been observed in some contexts and not in others. The final idea examines the negative attitudes and perceptions that healthcare professionals may hold of patients and patient engagement. These negative attitudes originate from an implicit belief that patients are separate components of the healthcare system; that healthcare professionals (clinicians and managers/administrators) design, deliver, and improve health services and patients receive them. We discuss the relevance of these three ideas for PE in the context of the COVID-19 pandemic.

Keywords

Patient engagement; patient experience; patient-centred care; barriers and facilitators

Introduction

Some consider patient engagement (PE) as the “holy grail” and “next blockbuster drug” of health care.¹ Around the world, PE has become an expectation in a wide range of activities such as drug development,² health system restructuring,³ health technology assessment,⁴ policy design and evaluation,⁵ and the development of clinical practice guidelines.⁶ In part, this proliferation is due to the ethical imperatives and economic and social benefits associated with engaging patients in health care activities.

Ethical imperatives relate to the democratic principles of participation that the view patients as service users, taxpayers, and consumers of health services. As such, patients have a right to participate in the design and delivery of health services.⁷⁻⁸ Research has also documented a myriad of beneficial outcomes of PE including: higher patient self-esteem⁹; improved relationships between patients, families, care partners, and healthcare providers¹⁰; better health outcomes such as higher engagement in preventive and healthy behaviors¹¹⁻¹²; and a more cost-effective healthcare system.¹³ These

benefits support a strong rationale for integrating patients across the healthcare milieu; to cultivate a patient-centric culture whereby health services are grounded by the needs and preferences of patients. The realization of these benefits, however, is obfuscated with important political, structural, and relational challenges.

Some scholars have found that although patients participate in an array of health care activities, the degree of their participation varies widely.¹⁴ This variation reflects differing goals and expectations of PE, variable expertise of PE practitioners, and the lack of support and resources available for PE.¹⁵ In particular, many activities that involve patients may constitute tokenism, a concept describing engagement that appears on an institutional checklist without devolving power and decision-making capacity to patients¹⁶ and excluding them from the discussions that matter the most.¹⁷ In tokenism, PE is employed as a tool to legitimize existing decisions rather than a goal in and of itself that transforms the design and delivery of health services to be more reflective of a patient-centric healthcare culture.

The literature describes a story of tokenism in PE. Due to the lack of practical support, tools, and resources to engage patients in meaningful relationships,¹⁵ there is confusion regarding which patients to engage, which activities to engage them in, and where and how to engage.¹⁸ This confusion engenders premature or cursory planning efforts to involve patients in healthcare activities, which is a strong barrier to realizing the benefits associated with PE.¹⁹ Without adequate planning, preparation, and organization, patients and healthcare professionals (clinicians, managers/administrators, and researchers) may perceive distinct goals of engagement and emphasize conflicting approaches to achieving their goals.²⁰ As such, instead of collaboration and partnership, the relationship dynamic between patients and healthcare professionals may privilege traditional, normative power imbalance that exists between these groups.²¹⁻²² Since healthcare professionals hold the power to make decisions regarding the planning, delivery, and improvement of health services, a power imbalance may cause healthcare professionals to engage patients through passive or superficial mechanisms that may appear appropriate to them and external stakeholders, but not to patients and their communities.²³ This power imbalance may promulgate differing, and sometimes conflicting, preferences and expectations regarding the goals of PE, which promotes tokenism and other forms of passive engagement.

PE requires a significant amount of time and resources from patients and healthcare professionals. Healthcare professionals commonly report the lack of time and resources needed to train and orient patients as a barrier to involving patients in healthcare activities.^{12,24} Despite the resource demand, there are strong institutional pressures to engage patients. In the United Kingdom, for example, The National Health Service (NHS) Constitution conveys the goal to involve patients in their own care and in efforts to improve the delivery of health services.²⁵ Similarly, in Ontario, the Patients First Act created the precedence for all hospitals to establish and maintain Patient and Family Advisory Committees that discuss hospital planning, delivery, and quality improvement issues.²⁶ Despite these institutional pressures, there is still a gap between patient-centric policies and the lack of practical resources, tools, and infrastructure that support attitudes and behaviors indicative of a patient-centric culture.

Due to the considerable amount of time and resources needed for PE, and the institutional pressures that may sometimes obligate patient-professional relationships without adequate support and infrastructure, tokenism in these relationships becomes an organizational and financial concern. Tokenism is problematic because it may not provide the benefits to patients and the system that justify PE in the first place because it does not meaningfully engage patients in healthcare activities.²⁷ Tokenism may instead lead to the inefficient use of constrained health

care resources in a system that is looking for new and innovative ways to reduce unmanageable healthcare costs.²⁸ Tokenism may also increase mistrust between patients and healthcare professionals¹¹ and create health services not responsive to patient needs and preferences, which are linked to poorer communication processes and lower clinical outcomes.²⁹

Tokenism is also problematic because it contributes to a health care culture that places patient needs and preferences as peripheral to clinical judgement and empirical evidence.²⁸ In an “evidence-informed culture” whereby decisions and policies are guided by evidence, patients appear to have been sidelined in shared decision-making,³⁰ despite the importance of patient preferences in the original model of evidence-based medicine.³¹ This observation highlights a need to integrate patient experiences and preferences as a guiding framework for the planning, designing, and delivery of health services. Similarly, a patient-centric healthcare culture has been identified by some as an overall objective of health service organizations.^{27,32-33}

This paper will analyze the notion of a patient-centric culture that advocates for an integrated approach to PE in which the needs and priorities of health system actors are aligned, resources are used cost-efficiently, and the solutions to concomitant health problems are meaningful to patients.³⁴ Some health system stakeholders believe that healthcare system problems will not resolve if patients do not play a leading role in the initiatives that aim to solve them.³⁵ A patient-centric culture advocates for shifting some power and accountability to patients; it is something healthcare actors may consider striving for due to its ethical imperatives and economic and social benefits. However, because of tokenism and other barriers, there is a need to enhance how patients engage in healthcare activities and streamline the mechanisms through which different healthcare system actors recognize, clarify, and examine how different attitudes, beliefs, and behaviors may problematize PE and a patient-centric culture.³⁴ Using the 3I framework (ideas, interests, institutions),³⁶ this paper will analyze two ideas (ethical imperatives and the economic and social benefits of PE) that support and one idea (negative attitudes and perceptions) that opposes a patient-centric culture. From analyzing the implications of these ideas, this paper will envision what a patient-centric healthcare culture may look like.

Methods

The 3I framework is a tool for analyzing policy processes and decisions. This framework comprises of three components: ideas, interests, and institutions. Ideas are “knowledge or beliefs about what is, views about what ought to be, or combinations of the two.”³⁷ For example, policy decisions made from the informed opinions of

experts may assume that available empirical evidence is not trustworthy; this is an idea that may underscore the policy formulation and deliberation processes. The analysis presented in this paper focuses solely on ideas that support or oppose a patient-centric culture. An analysis of ideas was seen as beneficial for deepening understanding of the tacit beliefs that contribute to the challenges experienced by healthcare stakeholders involved in PE. An analysis of this nature and on this topic has not been published and can reveal nuanced conceptualizations of the barriers to PE. This paper opted for a more nuanced understanding, rather than a broader analysis that may have resulted from an analysis of all three components of the 3I framework.

The second component are interests, “agendas of societal groups, elected officials, civil servants, researchers, and policy entrepreneurs.”³⁷ Interests refer to the stakeholders involved, which depends on the nature of the policy decision. The third component is institutions, “the formal and informal rules, norms, and precedents, and organizational factors that structure political behaviour.”³⁷ Institutions include the cultural mores and expected behaviors determined by society as within norm, and those deemed deviant. There are strong interdependencies between the three components of the 3I framework. The outcomes of a public policy process are a result of the interplay between these components. However, analyzing these components separately can help to delineate important beliefs, values, processes, and rules that underpin a phenomenon.

The 3I framework is a tool used frequently to analyze public policy in political science. Previously, it has been used to explain policy divergence between systems that foster sustainable innovations,³⁸ broader transformations in political economy of systems,³⁹ and the role of economic ideas in public policy.⁴⁰ There have been limited publications that use the 3I framework to examine health policy processes. One exception assessed the usability of the framework for analyzing community integrated management of childhood illnesses, home management of malaria, and removing user fees for antiretroviral treatment in Burkino Faso.⁴¹

PE has proliferated at multiple levels and across the healthcare milieu. We have observed a dramatic paradigm shift to involve service users in planning, designing, service delivery, and quality improvement. This shift has been concomitant with the rise of the number of stakeholder groups involved in PE initiatives or strategies to improve it. As a result, multiple groups (i.e., interests) have contributed to the state of PE today. However, there are important relational, political, and logistical barriers that have been cited as obstacles to cultivating a patient-centric healthcare culture. These barriers may stem from implicitly held beliefs (i.e., ideas) of patients and PE, but there is uncertainty regarding the sources and characteristics of

these beliefs, their mechanisms, and how they influence the goal of organizational patient-centeredness. As such, ideas from the 3I framework was chosen to delineate the implicit values and beliefs that underpin PE. By focusing on ideas, values, and beliefs that seep into and determine the relationships between health stakeholders, this analysis sought to reveal philosophical imperatives that may obscure the overall objective of patient-centred care and provide a rationale for improving the processes and objectives of PE.

Findings: Supporting and Opposing Ideas

Supporting Idea: Ethical Imperatives

Healthcare professionals lead the design and delivery of health services because they have knowledge regarding the organization and management of services and facilities. However, healthcare professionals have one perspective of many that represents the delivery of health services. Incorporating only the perspective of healthcare professionals in healthcare activities misses an important viewpoint; most notably, experiences related to interacting with and receiving health services.⁴² As such, the involvement of patients can broaden the perspectives that guide the design and delivery of health services.

Increasingly, healthcare professionals are recognizing that patients are users, consumers, and taxpayers of the healthcare system.⁷ Accordingly, patients have the democratic right and ethical imperative to participate in deliberations that determine how health services are organized, delivered, financed, and improved.⁸ This view promotes autonomy and agency of patients beyond activities of their own clinical care. PE in organizational activities is an opportunity to distribute power, responsibility, and accountability from certain healthcare professional groups to interprofessional healthcare teams that also includes patients, family, and care representatives. This view recognizes patients as members of interprofessional healthcare teams because they hold important knowledge and experiences that can substantially improve the design, delivery, and responsiveness of health services.⁴³⁻⁴⁴

Including patients as members of interprofessional healthcare teams expands their role from passive consumers of health services to decision-makers, collaborators, and partners. Examining the nature of both healthcare professional and patient knowledge and experience may substantiate the conceptualization of their expanded role. On one hand, healthcare professionals have technical, explicit knowledge acquired through formal education and training that they employ and deploy in medical practice.⁴⁵ The scope of practice of healthcare providers, for example, is largely determined by the breadth and depth of formal knowledge and training.⁴⁶ Regulated healthcare provider groups are required in many

jurisdictions to continue their education and training to be familiar with the most recent evidence and clinical practice guidelines. However, technical knowledge is not the only type of knowledge that guides medical practice. Technical knowledge is inextricable from experiential, tacit knowledge acquired through interactions and experiences in healthcare design, delivery, and improvement.⁴² This type of knowledge represents the nuances of medical practice, for example, the tailoring of bad news to patients that is sensitive to their culture and social location. Experiential knowledge increases overtime and transforms into explicit knowledge through externalization and socialization.⁴⁷ Tailoring information results in the amalgamation of technical and informal knowledge.⁴⁸ Explicit and implicit knowledge are privy to healthcare professionals and constitute a core component of healthcare professional identity that differentiates them from other groups involved in healthcare, such as patients and the public.

Patients also have experiential knowledge that is privy to them and evolves overtime through interactions and experiences with health services. This experiential knowledge is different from the implicit knowledge of healthcare professionals because it represents the perspectives of receiving health services. Some patients interact with health services regularly, and in some cases, for an amount of time equivalent to a full-time job (e.g., chronic illnesses). Experiential knowledge also comes from daily self-management and self-care; the activities of caregiving, accessing, and experiencing frontline care; and interactions with health care providers.⁴⁹ Incorporating patients' experiential knowledge may reveal previously unknown issues, perspectives, and lenses to view the healthcare system.⁵⁰ As a result, fleeting and innovative solutions may be uncovered that are both responsive to patients and their care representatives, as well as aligned with the capabilities of health service organizations.⁵⁰

The essentiality of experiential knowledge in health service design and delivery originates from theories of experience-based co-design, human-centered design, and ladders of citizen participation. These theories espouse the view that service users have indispensable knowledge and experience (i.e., experiential knowledge) that, if incorporated into design and delivery, allows health services to be more appropriate to end-users and their circumstances.⁵¹ In the healthcare system, since patients interact with health services as consumers and users, they may be in a better position than healthcare professionals to delineate how health services can best be organized to meet their unique needs. Some researchers have found that the priorities of healthcare professionals may not have relevance to patients if they are not meaningfully involved in priority-setting activities.⁵² Alignment between the needs and preferences of patients and the design and delivery of health services is an important objective of healthcare

organizations worldwide. This objective is reinforced by public calls of accountability and reduction of preventable medical errors.⁵³ Alignment is related to the responsiveness of health services, which are not only in parallel to the needs and preferences of patients, but also facilitate ease of access and use.⁵⁴⁻⁵⁵ Health services that are responsive to service users have higher uptake, dissemination, and use,¹³ and accordingly, improve clinical outcomes.⁵⁶

Supporting Idea: Economic and Social Benefits.

There are many benefits to engaging patients in healthcare activities and champions of PE commonly cite these benefits as springboards for discussion regarding the role of patient preferences in healthcare. For some, the benefits of PE are a sufficient justification to cultivate a patient-centric healthcare culture. However, as mentioned previously, these benefits have yet to be realized across the healthcare milieu. The recent deliberations facilitated by the Ontario government, for example, to establish the strategic priorities for the healthcare system excluded patients and primary healthcare providers.⁵⁷ This observation indicates that although decision-makers and healthcare professionals may overtly believe in the value of PE, they have yet to internalize it into their actions and decisions.⁵⁸ Analogous to the creativity bias that exist in management science,⁵⁹ healthcare professionals may have a PE bias that seeps into hidden attitudes and behaviors and opposes a patient-centric culture.

Benefits associated with PE can be divided according to those for individuals/groups and those for health service organizations. Individual/group benefits include higher patient satisfaction with health services,⁶⁰ higher patient self-esteem and self-efficacy,¹² improved accountability in healthcare providers,⁶¹ improved relationships between patients, family, care representatives, and healthcare professionals,⁶² and higher engagement in preventive health behaviors.⁶³

Organizational benefits include the development of tools and systems that are more aligned with patients' needs and preferences,⁹ simpler and more accessible care pathways and management structures,⁹ healthcare professional attitudes that are more favourable to notions of PE and patient-centered care,⁶⁴ lower number of admissions in some hospitals,⁶⁵ a more cost-efficient health service organization,¹³ and improved clinical outcomes.⁶⁶ Related to the individual/group and organizational benefits are the pitfalls of not engaging patients in health care activities. Gruman and colleagues (2010) reported that the potential consequences of not engaging patients may include a higher prevalence of preventable medical diseases and errors, lower health and well-being of patients, increased health disparities between groups, and the use of limited healthcare resources inefficiently.⁶⁷

The benefits to PE and the adverse consequences of no PE present a rationale for integrating PE in healthcare activities and cultivating a health system culture that is patient-centric. However, these benefits may be associated with meaningful PE, which is a nebulous concept loosely defined in the literature but may refer to partnership, collaboration, and shared power.⁶⁸⁻⁶⁹ It may be the case that efforts to engage patients may not observe the aforementioned benefits if patients are engaged instrumentally, symbolically, or tokenistically. For example, patient safety initiatives have originated from institutional pressures to reduce preventable medical errors.⁷⁰ Many of these initiatives, however, have not been sustainable, effective, or transferable, which some scholars have conjectured to be due to the exclusion of patients from the design and delivery of such initiatives.⁷¹

The gap between evidence and medical practice has noteworthy implications for health service organizations seeking to implement innovation and change. For example, one recent systematic review found that organizations identified “low-performing” based on patient outcomes and quality of care metrics are financially-driven whereas “high-performing” organizations are motivated by patient needs, preferences, and priorities.⁷² Moreover, some researchers have estimated that two-thirds of all efforts to implement change by organizations have not been successful.⁷³ On this note, Patrick and colleagues (2018) asserted that without the meaningful engagement of patients in organizational initiatives, constrained healthcare resources are utilized to create structures and processes that are not relevant to patients and accordingly, have poor implementation in health service organizations.⁷³

Reviews of the literature has found that collaborative, authentic, and mutually beneficial PE may reduce healthcare costs by tailoring health services and clinical interventions to the needs, preferences, values, beliefs, and experiences of patients that use them.⁴² Accordingly, tailored health services and interventions may have higher legitimacy to a wide array of audiences, and enhanced use, uptake, sustainment, and sustainability.¹³ Previous research has also found that patients are more likely access health services if they believe that services are designed by individuals with lived experience of their disease.⁷⁵ In this way, incorporating the lived experience of patients increases the sensitivity of health services to patients’ values and preferences, which may improve patient well-being adherence, self-management, and clinical outcomes.⁴² These health services increase patients’ trust in the health care system and healthcare providers, which also improves clinical outcomes.⁷⁶

Opposing Idea: Negative Attitudes and Perceptions. Research has found that some healthcare professionals are reticent to engage patients in healthcare activities. This

reticence may come from negative perceptions, expectations, and attitudes concerning patients. Although there has been no effort to synthesize the sources of negative attitudes that healthcare professionals hold, different areas of the literature have explicated four sources. First, healthcare professionals may believe that patients lack the technical knowledge and experience to contribute to healthcare activities.⁷⁷ Since the design, delivery, and improvement of services are complex and multifaceted, patients require resources, support, and preparation to understand relevant complexities and to contribute meaningfully.²⁴ Healthcare professionals commonly report lack of time and resources to support patients through the engagement process.¹² In some instances, patients may not be provided training or preparation to support their engagement in a healthcare activity. Dudley and colleagues (2015) note that without training or preparation, patients often serve in responsive roles that are “impromptu and more informal” and involve patients only when challenges emerge that cannot be resolved through professional knowledge and experience.⁷⁸ In such roles, patients are often expected to contribute to complex decision-making processes without the necessary knowledge, jargon, and understanding of the context and factors that surround the initiative. This expectation can create confusion among patients regarding their role and the goals of PE; and promote traditional power imbalance between healthcare professionals and patients that promote tokenism and passive forms of engagement. Moreover, since patients do not have the same level of technical knowledge or experience regarding the structure and function of the healthcare system as healthcare professionals, they require additional support to orient themselves in a way that renders meaningful engagement in healthcare activities.

Second, some healthcare professionals may believe that patients do not have the ability to competently express themselves during complex decision-making,¹⁹ which appears to be an essential skill for patients to engage in healthcare activities. From the perspective of healthcare professionals, van den Bovenkamp and colleagues (2009) identified the following characteristics of PE that is meaningful, useful, and relevant: (1) patients are able to look beyond their personal experiences and relate to overall health system structure and function, (2) patients require strong negotiation and deliberation skills, and (3) patients should be able to express themselves in a cogent and competent manner.⁷⁹ The latter two characteristics indicate an expectation that healthcare professionals hold about patients’ abilities to discuss, deliberate, and speak professionally with members of the healthcare team. However, this expectation is problematic because patients often come from a variety of backgrounds, some from outside the purview of healthcare, and as such may not immediately appreciate, acculturate, or adapt to the professional vernacular and mores of healthcare. Patients

commonly report language differences,¹⁹ and differing views about engagement processes and activities compared to healthcare professionals.¹¹ Especially in situations where there is limited support and training, some healthcare professionals may perceive patients as lacking the ability to competently express themselves because they do not speak in the professional language most familiar to them. In such situations, research has found that healthcare professionals who convey a willingness to engage patients despite language differences,⁶⁴ exemplify favorable attitudes towards patients and PE,⁹ make an explicit effort to acknowledge the benefits associated with PE,⁵⁶ respect patients through the engagement process,¹¹ and value patient contributions to healthcare activities lead to more meaningful PE.⁶

The belief that patients are unable to express themselves competently is related to a third belief that patients are in a dependent position due to their medical condition, and therefore their meaningful, authentic, and collaborative engagement in decision-making may be challenged.⁸⁰ This belief may stem from the notion of patients as passive consumers of health services, which may bolster the idea that patients are separate components of the healthcare system with clearly defined roles: healthcare professionals design, deliver and improve care, and patients receive it.⁸¹ However, the clear delineation of roles and responsibilities is problematic and unrepresentative of healthcare structure and function. For example, high-performing health service organizations require extra-role activities and behaviours, also known as organizational citizenship behaviour, in order to function optimally.⁸²⁻⁸³ Instead of “blaming patient factors” for the failure of organizational initiatives, which one study found to be a characteristic of low-performing organizations, high-performing organizations are motivated to support patients through the engagement processes.⁷² Patients can also fulfill many extra-role behaviours by offering a different perspective to view healthcare problems and their concomitant solutions.⁵⁰

The research discussed in this paper highlights the argument that to realize the benefits associated with PE, patients must be integrated into the healthcare system milieu, which means that they should be perceived as inextricable components of healthcare activities. Viewing patients as inextricable may transform the notion of patients as passive consumers to decision-makers, collaborators, and members of interprofessional healthcare teams. This view grounds the philosophy of a patient-centric healthcare culture. Increasingly, the literature discusses patient professionalization and consumer leadership as emerging concepts that illustrate the evolving roles of patients from passive consumers to members of interprofessional healthcare teams.⁸⁴⁻⁸⁵ These concepts may support the internalization of patients as acculturated components of the healthcare system that may address the many barriers which stymie a patient-centric healthcare

culture. For example, the time required to engage patients becomes integrated into daily medical activities, similar to the situation of new healthcare providers (e.g., Physician Assistants in Ontario).

Finally, some healthcare professionals believe that patients are “noncompliant,” conflicting, problematic, and troublesome. Healthcare professionals perceive these patients as using the PE platform to voice their complaints regarding the healthcare system, without providing substantive and meaningful suggestions to improve health services.⁸⁶⁻⁸⁷ This belief may prompt some healthcare professionals to seek patients who they believe would acquiesce to existing views, preferences, and decisions.²³ In this way, PE may not lead to the benefits identified in the literature, and instead sustain existing power relations that maintain the status quo and reinvents the wheel of quality improvement. Tokenism and the exclusion of patients from decision-making can bolster the negative experiences of patients who contribute their time and energy to engage in healthcare activities. Consequently, studies have found that some patients report decreased motivation and commitment to initiatives that involve patients,⁷⁵ feel that their experiential knowledge is not valued to the same degree as healthcare professional technical and implicit knowledge,⁷⁹ and increased mistrust between patients and healthcare professionals,¹⁹ all of which are linked to poorer health outcomes.

By excluding patients deemed “problematic” and including those who are likely to acquiesce to the decisions already in place, the primary purpose of PE may become a function of legitimacy to the decisions determined by healthcare professionals, which conveys a masquerade of PE, in other words, tokenism.²⁸ However, instead of realizing the benefits to PE, tokenism may advance the same perspectives, philosophies, and experiences, that rebrands rather than transforms the design and delivery of health services to be more aligned with and responsive to the needs and preferences of patients. This is especially problematic since healthcare systems around the world are seeking new and innovative ways to reduce unmanageable, rising costs. On the other hand, healthcare professionals committed to the philosophy and ethical imperatives of PE create more meaningful opportunities for engagement that may confer the benefits associated with PE.⁸⁸

Discussion

In a patient-centric healthcare culture, the attitudes and activities of the healthcare system are grounded in the needs and preferences of patients. Worldwide, there have been efforts to cultivate a patient-centric culture. However, these efforts have been problematized with multiple barriers. This policy paper used the 3I framework (institutions, interests, ideas) to discuss two ideas that support and one idea that opposes the development of a

patient-centric culture. The first idea described the ethical imperatives of PE associated with the role of patients as users, taxpayers, and consumers of health services. This role advances a strong rationale to integrate patients as decision-makers, collaborators, and members of interprofessional healthcare teams. The second idea highlighted the individual/group and organizational benefits of PE. This section also discussed the potential pitfalls of not engaging patients in organizational initiatives. The final idea discussed the different sources of negative attitudes and perceptions that healthcare professionals may hold of patients. This section reinforced the notion of patients as decision-makers, collaborators, and members of interprofessional healthcare teams that may support the realization of the myriad of benefits associated with PE. Overall, this paper explicated hidden issues in power imbalance and hierarchy that problematize the PE movement. This paper also answers why, despite the best efforts and intentions, a patient-centric culture has not been cultivated. As such, this paper encourages continued dialogue, discussion, and deliberation regarding the role of patients in healthcare.

Implications of this Discussion for the COVID-19 Pandemic.

The current SARS-Cov-2 pandemic has imposed an increased burden upon healthcare systems worldwide, pushing them to the limits of their capacity and forcing them to utilize all available health resources. As such, the ethical imperatives described in this paper are much stronger during this pandemic which in turn, leads to an even greater need for PE. The overburdening of healthcare systems and the lack of sufficient resources to meet the demands of the population coupled with social distancing requirements and the highly contagious nature of the disease necessitate the restructuring of existing health services. Despite substantial reorganization, the expectations with regards to maintaining a high quality of these services remain from patients and the public. Failing to incorporate the perspectives of patients in this reorganization may hinder these services from reaching their maximum efficacy and desired quality at least from a consumer standpoint which is problematic because it might contribute to a number of potential consequences identified in this paper.

The SARS-Cov-2 pandemic has called for rapid transformations of health services. The most prominent of these is the transition from in-person healthcare centres and clinics to reliance on eHealth and virtual care delivery. Although telemedicine may have, in a way, bridged physical and geographic barriers and removed inequities by enabling individuals to obtain health services at their home,⁸⁹ these rapid and unaccounted changes may have also contributed to the proliferation of inequities among the population. The shift to virtual care was quick and was primarily driven by logistical and resource constraints

without genuine consideration of diverse patient preferences. For example, recent research has demonstrated that most individuals, if given a choice would opt to receive health services via telephone instead of video care.⁹⁰ However, some systems have allocated resources to video-to-home visits without much deliberation over the diversity of preferences, creating inequities for those wanting to access care through alternate mediums. Moreover, in addition to possessing a computer and email, eHealth and telemedicine require a certain level of technological literacy including knowledge of video conferencing software, e.g., Skype, Cisco, Webex, and Zoom, which older individuals may lack.⁹¹ Ensuring equitable access to healthcare would necessitate the development and implementation of programs aimed at improving technological literacy.⁹² Sidelining the views of patients may partly explain why the switch to telehealth was made without the provision of support on computer and technology literature, which is essential for effectively engaging in virtual care, leaving older patients at a clear disadvantage within the healthcare system. Diminishing these inadvertently introduced inequities is a complicated process that requires significant effort over a long duration of time. Inequities that are inadvertently introduced may lead to downstream effects that are largely unknown even to healthcare providers but may hold the potential to keep the quality of care at a lower than optimal level.

At the same time, drastic changes in the delivery of healthcare which are sustained over several months may impact patients' expectations. A group of patients may eventually become accustomed to comprehensive virtual care, particularly in instances where this has led to positive experiences. They may in turn want telemedicine to exist as a potential option after the pandemic due to the ease with which it can be accessed. However, whether healthcare systems have the infrastructure to fulfill these expectations will vary and will likely not be possible in several regions around the world. Furthermore, the sustainability of these services, particularly post-pandemic has likely not been adequately considered. Thus, modifying health services in accordance with patient preferences may not be possible.

This paper demonstrates that negative provider attitudes towards patients may act as a potential deterrent to PE. This barrier may have been amplified in the context of the SARS-CoV-2 pandemic such that negative attitudes towards both patients and PE may be more pronounced due to uncertainty and additional stress regarding COVID-19. For example, healthcare providers often express that patients lack technical knowledge and experience. This gap may be further intensified during outbreaks when providers are dealing with a novel infection and are still unsure of the most appropriate treatment plan themselves. Furthermore, tools to support patients during the engagement process are already limited, but they are

especially exhausted during pandemics. The dearth of adequate engagement tools subsequently reduces the willingness to engage patients in decisions about their healthcare. There is a need to develop and introduce appropriate mechanisms for PE during pandemics, which is a direction for future research.

Given the uncertainty and severity of the situation, ethical imperatives and social and economic benefits may not support PE in the same manner as they did prior to the pandemic. While there may be stronger ethical imperatives or an elevated need for PE, other priorities may take precedence over the creation of a patient-centric culture. Physiological, social and economic outcomes have always been attributed greater significance than patients. Improvements in these domains may be increasingly prioritized after they have endured powerful blows due to SARS-Cov-2. Having a considerable amount of attention and support directed towards these outcomes, may push PE aside, leaving it largely ignored.

Limitations of this Paper.

Although this paper analyzed three ideas, there are other ideas that may further complicate the development of a patient-centric culture. For example, the representativeness of patients is a common barrier to meaningful engagement reported by both patients and healthcare professionals.^{6, 20} This barrier may also stem from confusion surrounding the conceptualization and application of representation in healthcare activities. It may also contribute to negative attitudes and perceptions that healthcare professionals may hold of patients, exemplified by their negative experiences with patient interest groups some of who may use PE as a platform for advocacy rather than quality improvement.⁸⁶ Negative experiences from these groups may cause healthcare professionals to generalize to the entire patient population, which may engender some of the observations mentioned in this paper such as including patients who are likely to agree with the decisions already in place.

This paper analyzed only “ideas” from the 3I framework. A separate analysis on institutions and/or interests and actors may contribute to the ensuing discussions on a patient-centric culture. In particular, the role of policy documents and statements of health service organizations as “institutions” may reveal nuances of why tokenism becomes the norm rather than the exception. I conjecture that perhaps institutions attempt to adapt to external calls for accountability through diffusion of innovation and isomorphism (i.e., low-performing organizations becoming similar to high-performing organizations). However, as this paper recommends, a patient-centric culture needs careful foresight, deliberation, and participation by all healthcare system actors. Although this paper identified multiple economic and social benefits, these benefits may be problematized by relational and political factors in health service organizations that limit the uptake of

meaningful engagement. For example, poor planning and training before an engagement activity may lead to less meaningful and effective PE, which may lead groups, healthcare professionals and patients alike, to attribute a lack of effectiveness and meaningfulness to the practice of PE as a whole rather than the contextual factors that surround the specific patient engagement activity. Similarly, different healthcare professional (i.e., “actors” and “interests”) groups can also help to illuminate some of the issues mentioned in this paper. In lieu of integrating care, for example, examining the interests that prevent the integration of patients may enable a more nuanced understanding of what a patient-centric culture may look like.

Conclusion

The development of a patient-centric culture has a powerful rationale: ethical imperatives and economic and social benefits. As this paper describes, to achieve patient-centeredness, organizations should work to internalize the ethical imperatives of PE; identify, appraise, and resolve tokenism in initiatives that involve patients; provide tailored support, information, resources, and guidance before and during the engagement process; and be willing to learn from the environment by collaborating with diverse stakeholder groups including patients. PE can become the “holy grail” and next “blockbuster drug” of healthcare if there is considerable, concerted effort to identify and address the ideas that oppose a patient-centric culture and privilege the ideas that support it.

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