

Harnessing Patient Engagement for Healthcare System Change

WHITE PAPER - WORKING DRAFT

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In this white paper, we address the ways that patients attempt to influence healthcare system change through individual and collective advocacy, and consider how healthcare organizations can harness that patient involvement to create systems and structures that genuinely place the patient at the centre of care. We examine individual level advocacy by first exploring some of the current, existing tensions between a previously physician-centred care system and the newer approach of patient-centred care, and then drawing on perspectives of individual complaining behaviour and (dis)satisfaction from the marketing literature to understand how, within a patient-centred healthcare context, health organizations can benefit by effectively tending to this dynamic. Having established these individual level dynamics, we then investigate the broader socio-political collective dynamics that facilitate this patient-centred trend. Last, we present a case study of a mid-sized healthcare organization that has effectively tended to both individual and collective level issues in order to arrive at lessons learned.

UNDERSTANDING PATIENT-DRIVEN ADVOCACY

Patient-centred care has rapidly become the new paradigm within healthcare organizations. The concept pervades practical discussions about quality and efficiency of care and the organizational structure necessary to enact such a patient focus, as well as more philosophical deliberations about the roles of and relationships between patients and doctors. From a definitional perspective, patient-centred care seems simple enough: it is care that is centred around the patient, a model in which healthcare providers partner with patients and families to identify and satisfy the full range of patient needs and preferences (Planetree and Picker Institute 2008). A broader perspective argues that the originators of the concept were driven primarily by moral arguments based on a deep respect for patients as "unique living beings, and the obligation to care

for them on their own terms; thus patients are known as persons in context of their own social worlds, listened to, informed, respected and involved in their care – and their wishes are honored...during their health care journey" (Epstein and Street 2011).

Accompanying this rise of patient-centred medicine, with its goals of improved quality, safety, and efficiency, as well as an expanded role for the patient in the equation of healthcare delivery, has been a concurrent transformation of the individual, who was previously simply a member of society, into a "consumer" – of commercial products, of public goods and services, and also of healthcare. As identified by Bardes in an editorial in the *New England Journal of Medicine* (2012, 782–83), "if the patient is reconceived as a consumer, new priorities take center stage: customer satisfaction, comparison shopping, broad ranges of alternatives, choice, and unimpeded access to goods and services." While perhaps overly simplistic in his description of the priorities of a patient in a healthcare "service" encounter, Bardes is nonetheless correct when he identifies that this shift towards "patient as consumer" sets up a conflict between "a Ptolemaic universe revolving around the physician [against] a Copernican galaxy revolving around the patient" (2012, 782–83), and that the favouring of one party over another fails to recognize the need for an ongoing, functional, and trust-based relationship between the two in order to achieve both patient goals as well as broader societal health goals.

And yet, this conflict between the desire of physicians to dispense treatment in the way that they feel is superior versus the happiness (or lack thereof) of the patient with that treatment is not new. What is new is the increasing visibility of patients who feel the need to express displeasure at (real or perceived) substandard care, at the same time as there has been an explosion in the media that shares that sentiment, ranging from within small social groups to a broader, sometimes global, scale. In order for organizations to cope with and manage this feedback, it is important to understand what we have learned from years of studying both consumers and organizations about how and why individuals

behave the way they do when they are unhappy with the provision of a service, and the implications of those behaviours for the service-providing organization.

In this white paper we identify and examine the various ways that patients express displeasure, both informally and formally, with the healthcare they receive and the providers they encounter on their healthcare journey. We also examine the dynamic created when this patient voice becomes amplified by the use of social media, which has the effect of drawing in a broader range of stakeholders as patients express their healthcare experiences. Finally, we present a case study in which a healthcare organization has undertaken the challenge of developing true patient-centred care, and look at how patient concerns have been structurally integrated into the organization to improve the patient experience.

INDIVIDUAL LEVEL PATIENT-DRIVEN ADVOCACY

Patient Complaining

We first examine individual level patient-driven advocacy by discussing what we know from the marketing literature about patient complaining and dissatisfaction. In marketing, we have always known that consumers complain when they are unhappy and, in fact, that complaining is an important part of social life. Complaining can be broadly defined as “a behavioral expression of dissatisfaction” (McGraw, Warren, and Khan 2015), and in the context of marketing has typically either been expressed as direct communication of that dissatisfaction to the service provider via in-person complaints, calls or letters, or word-of-mouth conversations with friends and family. Over the years, however, the reach of negative experiences and dissatisfaction has expanded, whether through traditional media interested in airing (and sometimes obtaining redress for) major service failures, or through digital forms like social media and websites where consumers (including patients) can expound at length about their dissatisfying encounter with a service provider. Depending on the forum, these complaints can be directed at a small number of people an individual knows personally, or at a wider range of individuals they may want to “warn” about their interactions with a service provider, through to a disclosure of appalling treatment that receives national or international attention and widespread media coverage.

A variety of reasons or purposes for such complaining behaviours emerged in a recent review of consumer complaining behaviour (McGraw, Warren, and Khan 2015). People may complain to simply make small talk or to vent frustrations, which can help reduce the detrimental emotional effects of coping with negative thoughts and feelings as a result of a product failure or negative service encounter. People also complain in order to influence the perception

and behaviour of others, either for their own or others’ benefit. Complainers may want to warn people about a negative experience so that they may avoid a similar fate, they may want to obtain redress, which could range from a simple apology to something more material such as a refund, or they may simply want to receive sympathy and/or moral support. Complaining, however, is not always beneficial for the complainer and can have unintended consequences. People who complain frequently or about what others perceive as “trivial” matters are frequently viewed negatively – as grumpy, argumentative, or boring. Other times, people believe that complaining will not have the effect that they are hoping for, or they do not have time to seek redress. Due to these costs of complaining, people sometimes do not complain even when they are greatly dissatisfied (McGraw, Warren, and Khan 2015).

Patient Complaining in a Healthcare Environment

It is important to recognize, however, that much of our understanding about consumer complaining, as described above, comes out of a context that is not at all similar to that experienced by patients in a healthcare environment. First, a commercial context is frequently characterized by competition – if consumers are unhappy, they will first complain, and if that complaint is not addressed then they will take their business elsewhere. As a result, organizations are primarily motivated out of self-interest, as they must make consumers happy or risk financial loss. In healthcare, however, particularly in Canada, it is rare for patients to have the flexibility of being able to choose healthcare providers. In many cases, patients are aware that they are lucky to have a primary healthcare provider who will see them on a somewhat timely basis and provide regular care; switching to another provider is often difficult, if not nearly impossible, and this has been made more so with governmental systems (e.g., in Ontario) that require patients to un-enroll from one provider before being able to switch to another. For patients who have ongoing health issues that may need regular or emergency care, the risk of having a period of time without a regular provider is often too great to bear, and thus patients are essentially forced to stay with a provider regardless of their level of satisfaction.

Secondly, while occasionally expensive and certainly frustrating, the vast majority of marketplace transactions that stimulate complaining behaviour are not critical to consumers’ immediate or long-term emotional and physical well-being. The same cannot be said for a healthcare environment, in which many patients only engage in interactions with their healthcare provider when they are unwell. That provider is, at least in some sense, what stands between a patient continuing to feel unwell or being provided with some immediate relief (or hope for some future relief as a result of further testing and consultation with a specialist) from the discomfort they are experiencing. As a result, it is reasonable to assert that a patient may feel that they have to maintain a positive relationship with that provider at all costs, regardless of their desire to complain

about their treatment. In this way, the costs of complaining about some aspect of treatment may be very salient to the patient, and extreme dissatisfaction may need to occur before the patient is willing to risk a deterioration in the physician-patient relationship by expressing dissatisfaction with some aspect of care. They may fear being labeled a “difficult patient,” and having their future healthcare concerns affected as a result. Since the physician acts as a gatekeeper to specialists and advanced forms of testing that the patient would not otherwise be able to access, these are not unreasonable concerns. The author of an essay on the impact of doctor disillusionment with our current medical system recounts hearing countless stories of patients in pain who worry that asking for more pain medication “will be construed as entitled meddling” (O’Rourke 2014). It is therefore not altogether surprising that, if a patient is dissatisfied with some element of their care and feels like they are unable to secure redress from the provider themselves, they will want to vent that frustration to other people, either face-to-face or via social or traditional media, as a way of coping with the negative thoughts and feelings that McGraw, Warren, and Khan (2015) have identified as one of the causes of complaining behaviour. Depending on the severity of the perception of mistreatment, such negative feelings may range from simple frustration and disappointment to anger, humiliation, worthlessness, and even abandonment, and have deep and lasting psychological effects (Boodman 2015).

But this increased likelihood that an unhappy patient will engage in indirect rather than direct complaining is ultimately a bad thing for the provider, as it fails to allow providers to address problems as they occur and instead forces them to be reactive when those problems get a broader airing. At that point, an organization is more likely to be engaging in crisis management, rather than working to actually address the original issue, and very often the focus on the patient is lost in favour of managing impressions among a larger community of stakeholders. It is due in no small part to the hope of becoming proactive rather than reactive to patient complaints that more and more healthcare organizations are attempting to measure patient satisfaction, through tools such as the Patient Experience Survey being developed by Health Quality Ontario to assist primary care providers in assessing potential problems within their practices. In the United States, Medicare has taken the lead in requiring hospitals to collect information about patient satisfaction, with the federal government and some private insurers considering these survey results when setting reimbursement levels for hospitals (Boodman 2015). It is to the topic of patient satisfaction and how it relates to patient experience that we next turn.

Patient Satisfaction and Patient Experience

In marketing, we have been examining customer satisfaction (and lack thereof) since the late 1970s. It is now well recognized that satisfaction has both cognitive and affective components, each of which contribute to a consumer’s global judgment of (dis)satisfaction. The cognitive component is most often

described in terms of expectation disconfirmation theory, which explains how individuals compare expectations against perceived performance to both directly and indirectly (through disconfirmation of beliefs) affect judgments of satisfaction. The emotional component of dissatisfaction arises as a result of an assessment of what that shortfall between expectations and reality means for the consumer’s values, goals, and beliefs, and possibly also from attributions made as to why that shortfall occurred (Giese and Cote 2000). The more central those values, goals, and beliefs are to the individual, and the more impact the shortfall has on their well-being, the stronger the emotional response generated in response to that dissatisfaction is likely to be. In the context of healthcare, given the centrality of physical well-being to overall well-being, the experience of dissatisfaction as a result of a healthcare encounter is likely to be emotionally acute.

Using the principles of expectation disconfirmation theory, we can approach management of patient satisfaction from two possible routes: attempting to increase patient perceptions of performance, and/or managing patient expectations. If we assume that improved performance (which in the healthcare context can reasonably be interpreted as “curing” a patient, or at least improving their well-being as much as possible) is the goal regardless of concerns about patient satisfaction, then we can put that aside and focus on managing patient expectations. It is in the latter area that the greatest change has occurred in recent years. In particular, there has been a marked increase in patients who want to feel empowered in their healthcare choices and involved in decisions about their care, rather than simply receiving wisdom dispensed to them from doctors, often with little explanation. A common expectation of this new breed of empowered patients is that they are partners in their healthcare, and when that expectation is not met or they are made to feel that that expectation is unreasonable, it is unsurprising that they are disappointed and ultimately dissatisfied with their care – and they are more likely to complain as a result.

Measurement of patient satisfaction has taken several routes. Some organizations focus on what can be termed “process” or “operational” concerns, such as in-clinic wait time, friendliness of reception and nursing staff, comfort of reception area, cleanliness of exam room, and so on. Still others concern themselves with broader “relational” questions that are more in line with measuring patient expectations of a positive healthcare experience, such as the physician listening to a patient’s concerns and treating them with respect, spending enough time with them, and encouraging them to ask questions. A recent study indicates that patients’ care experiences will shape their perceptions of their relationship with their provider, independent of simple satisfaction measures, and that the stronger the relationship with the provider, the better the interpersonal continuity of care (repeated visits to the same provider), which is often considered a major goal of primary care (Beeson 2006; Tabler et al. 2014). Anecdotal data also suggests that satisfied patients are more likely to comply with treatment plans suggested by their doctor, more likely to

assume an active role in their care (i.e., be more empowered), and more likely to continue medical care with their current physician; this echoes the results of the study described previously with respect to the relationship between satisfaction and continuity of care (Beeson 2006). While discussion of how to best assess, measure, and deliver a superior patient experience is still in its infancy, it is clear that there are likely to be both organizational and medical benefits to determining how to best engage a patient in care in ways that more closely address their varied medical, social, and personal needs.

Patient-centred care reduces patient complaining behaviour, which would typically occur behind the backs of healthcare providers as patients voice their displeasure to a broader audience. With patient-centred care, better channels of communication are forged between the patient and healthcare provider. Further, patient-centred care leads to higher levels of patient satisfaction that will lead to better interpersonal continuity of care, greater patient compliance with treatment plans, and improved patient engagement in their own care. In addition to these important benefits, embracing patient-centred care also benefits healthcare organizations in the more macro-political environment. We will now examine the collective level issues that arise, contrasting it with the foregoing discussion of how patients as individuals approach healthcare advocacy.

COLLECTIVE LEVEL PATIENT-DRIVEN ADVOCACY

It is important to note that the dynamic surrounding patient complaining behaviour and dissatisfaction does not only concern the patient-healthcare provider relationship. Healthcare organizations have come to be immersed in a social and political environment that comprises a growing number of diverse social actors with an array of interests. The Internet and social media have given rise to a form of communication that empowers individual patients to connect to a network of social actors made up of individuals, small groups, and formal organizations, all of which present various narratives surrounding the nature of healthcare provision. Empowered by digital communication, this wide spectrum of social actors poses new challenges to healthcare providers. As one illustration, healthcare providers not only must track and report on formal government mandated measures of patient satisfaction, but must also consider patient satisfaction measures and reports from a growing and diverse list of “informal” but influential websites that might seemingly be unrelated to healthcare. Increasingly, patients turn to Facebook pages, hospital reputation websites, and even “Trip Advisor,” all of which provide patient-driven commentary on experiences with various healthcare providers.

More traditional perspectives of activism regard organizations as typically confronted by politicized and organized social activists who see themselves as “outsiders” in relation to the target system. These organized activists protest

what they consider to be problems within the dominant economic, political, and ideological systems with which they see traditional organizations, such as healthcare providers, as being complicit (Glickman 2009). Traditional tools of activism involve lobbying governments, boycotting, and engaging in formal protests as activists seek to trigger change to the dominant system. This traditional perspective regards change to dominant institutions, such as healthcare, as being triggered by activists who have a particular passion for and concern about a given social and political arrangement. These activists are seen to mobilize people into a collective effort to change the current social order so as to bring about a more desirable state of the world (Den Hond and Bakker 2007; Fligstein and McAdam 2012).

However, digital technology has enabled a democratization of communication, challenging some of the basic assumptions underlying the traditional view of activism and change in the healthcare system. The “average” patient is now able to access information from any part of the globe with an ease never before possible. Likewise, the online environment provides this patient with the ability to find an audience for their views in a forum previously only accessible to an elite few. For instance, an individual patient’s blog espousing some concern about the healthcare system can attract an audience of a size and form never possible before the digital age. These democratized forms of communication challenge the more centralized and unified structure of past activist movements.

What emerges is considered a “field” of social actors who take each other into account in their attempts to achieve both instrumental ends (such as specific changes to certain healthcare practices) as well as existential ends (such as individual meaning making and identity building). All of these ends are achieved through a confluence of actions between social actors within the field. However, rather than a “consensual frame that holds for all actors [there are] different interpretive frames reflecting the relative positions of actors within the strategic action field” (Fligstein and McAdam 2012, 89). The field comes to comprise a diverse range of social actors and roles, bringing a range of interests, perspectives, experiences, and expertise. In this field, the line between the “experts” and the “average person” becomes blurred as all social actors share the same tools of communication. What differentiates the voice of one social actor from another is not necessarily expertise, but rather the skill to navigate this social media space. The social actor with the best blog or Facebook page and the ability to distribute and share commentary using the Internet and social media may arise as an influential player in the field. Furthermore, these social actors may not necessarily be driven by well-defined instrumental objectives, but rather by self-identity building projects, such as the pursuit of recognition for one’s own points of view, and the corresponding social status that recognition affords within a given field.

Therefore, the healthcare organization is not being confronted by a unified and elite class of activists demanding some common end. Instead, organizations

find themselves as but one social actor having to navigate a complex field of a whole range of social actors, presenting healthcare providers with a complex and even confusing social terrain. While the diffused and seemingly confusing nature of this terrain may tempt healthcare providers to ignore this space, there are reasons that emerge as to why this may be a perilous choice when one considers the underlying social change that inadvertently arises from this social dynamic. We next consider this dynamic in more detail.

As noted previously, patients turn to social media to present their complaints about their healthcare experience to a broader audience. In order not to come across simply as a “complainer,” these patients will instead work to construct themselves as worthy of having a voice to be heard. Therefore, patients will want to legitimate their voice over that of healthcare “experts.” As such, patients will work to present themselves as insightfully aware of the intricacies of some aspects of the healthcare system. These knowledge claims may be based on their own direct experiences with healthcare providers, on their own “research” as they search for information online from other contexts, or on their examination of the experiences of others combined with their own research. Either way, the field comes to be characterized by patients who are working to construct themselves as “in-the-know,” insightfully aware of the arrangements underlying the healthcare system. In this identity pursuit of the “in-the-know” citizen worthy of their voice being heard, these “patient activists” will inevitably and inadvertently not only confront healthcare organizations, but also end up informing and confronting each other with their diverse range of views and opinions. Healthcare organizations that follow these field level narratives may experience great frustration as they hear vast amounts of “misinformation” being espoused. It would be understandable for these organizations to be tempted to jump into the field in an effort to “set the record straight” and “educate” patients as to the “facts.” To do so, however, is to miss an unexpected and seemingly stealth form of social change that is occurring.

As patients present and debate their positions based on their own “research” and experiences, a social trend towards the legitimacy of “local knowledge” and a simultaneous refutation of “expert knowledge” is emerging. Local knowledge refers to the knowledge claims that arise from an individual’s own experiences, perspectives, and insights into a given situation, which is contrasted against the “expert knowledge” that is handed down from authoritative organizations. In this context, there are two problems with this expert knowledge. First, the acceptance of this hierarchical knowledge would be completely counter to the social actor’s endeavour to construct themselves as a knowledgeable individual whose own claims are worthy of legitimacy. To accept expert knowledge claims would present the social actor as a cultural dupe, hoodwinked by the “system,” and thus violate the identity of an in-the-know individual whose own knowledge is worthy of attention. Second, these hierarchical, expert knowledge claims are often met with suspicion and presumed to be tainted with agendas and interests of control. Therefore, the fundamental nature of the social change that emerges from this field dynamic is the increasing

legitimacy of “local knowledge” claims and the simultaneous de-legitimation of “expert knowledge.”

Healthcare providers must re-examine their roles within the fields to which they unwittingly belong. To ignore the field is perilous as patient activists construct narratives and views to which healthcare providers become completely out of touch and uninformed. To attempt to dominate the field by seeking to “educate” or “correct” what providers view as misinformation will simply violate the core nature of the social movement in such attempts to supersede local knowledge with expert knowledge. Such domineering actions will also subvert the legitimacy of an individual’s complaints and therefore further contribute to the healthcare provider-patient problems raised above. This can only be met with more resistance by the patient. However, to understand and work within this field dynamic can present a tremendous opportunity for healthcare providers. Patient-centred care can not only involve lowering complaint behaviour while increasing rates of satisfaction, it can also involve engagement with, rather than refutation of, the “local knowledge” of patient activists.

Having now discussed both the individual and the collective approaches to advocating for a patient-centred healthcare system, the following case study presents one healthcare organization that has enacted system-wide reforms to create a patient-centred environment, not only at the level of the individual patient, but also in the broader field.

CASE: TRANSFORMING PATIENT EXPERIENCES THROUGH PATIENT-CENTRIC CARE

Putting patients at the core of the service delivery model overturns conventional healthcare approaches in which the patient is often considered as separate from the healthcare delivery team. In the same way that commercial organizations seek to understand and satisfy customer wants and needs, considering patients as customers pushes healthcare organizations to develop a deeper understanding of patient needs in order to provide experiences that are valuable from the patient’s perspective.

Over the last few years, a large, regional healthcare institution in Eastern Ontario has embarked on a program to develop a patient- and family-centric healthcare service delivery approach in line with a customer-oriented philosophy. Conceptually, the patient- and family-centred initiative establishes patients and families as co-creators of healthcare outcomes by including them as partners in the decision-making processes. In addition to reinterpreting the role of patients and families in individual healthcare delivery, the organization has also created a new role of patient experience advisor, which occupies a unique, multifaceted, voluntary position. The advisors are recruited from individuals in

the local community who have direct knowledge of the patient experience at the healthcare institution, either as patients themselves, or as family, friends, or acquaintances of patients. These advisors volunteer to serve in a decision-making capacity within the institution, to provide a patient perspective on organizational issues that have material impact on the experience of patients, including the hiring of new staff. The creation of these new positions legitimizes the value of the “local” knowledge of patients and their advocates, as well as acknowledges the role of the patient as a partner in their own healthcare. Through the patient advisors, the organization is able to integrate informal feedback within its institutional structure so as to proactively address patient needs as well as legitimize patients as important stakeholders within the organization.

The changing stakeholder relationships amongst healthcare staff and patients in response to the patient-centric model of care reveal the challenges associated with organizations implementing customer-centric transformational practices. We outline some of these challenges below.

Challenging Existing Power Structures

The move to patient-centric care, as well as the creation of the patient advisor role, was a direct challenge to existing power hierarchies within the organization. Many of these hierarchies are legacies of the healthcare sector as a whole, while others are particular to the individual departmental arrangements specific to the organization. In these hierarchies, physicians occupy a privileged position relative to nurses, who in turn often leverage greater authority than social workers, respiratory therapists, and other members of the organization. The movement towards a patient-centric model shifts these power dynamics because the emphasis is not placed on status claims linked to healthcare roles, but rather on the degree to which those roles provide value as determined by the patient. No particular provider role is privileged relative to others, and non-provider roles such as religious figures or family members may hold greater influence.

As key members of the healthcare decision-making team, patients, their families, and patient advisors have a voice in the ways in which the organization delivers healthcare services. This presents challenges to traditional, often paternalistic, modes of healthcare delivery and organizational decision making, in which patients and families are assumed to be passive and deferential to the authority of physicians, nurses, and other healthcare staff. Patient advisors sit on internal committees that deal with all aspects of the organization’s operations. This involves more than just transparency; by bringing voice to their experiences at the decision-making table, patient advisors attune the organization to patient values and concerns in ways that focus groups, feedback forms, and surveys simply cannot achieve. The trade-off is that entwining patients and families in such an intimate way with organizational decision making means

the organization must be willing to work effectively with those individuals to achieve common goals, and to determine how to reconcile and manage patient goals that may not align with organizational priorities. Healthcare staff in this organization report that they increasingly view their conversations with patients, families, and patient advisors as negotiations in which all sides present their case, and outcomes are driven through mutual understanding and compromise. While in some cases this is not different from traditional dialogue between healthcare providers and patients, increasingly the pathway to agreement is a fluid approach in which evidence-based medicine and processes act as only one pathway to achieving goals. This approach is atypical, given the evidence that many patients futilely seek to be more engaged in decisions related to their care, but are often rebuffed by their medical care providers (O’Rourke 2014).

Patient-Focused Outcomes

Healthcare has been focused on reducing risk and preserving life, but patients are voicing their preference to, in some cases, pursue riskier courses of treatment in the hopes of achieving outcomes that they deem preferable. In one case, a young mother diagnosed with early-stage cancer opted to pursue alternatives to Westernized medical approaches, only to return later with an advanced form of the disease that was no longer treatable. By including patients and families in the decision-making process, the healthcare provider has to adjust their interpretations of, and expectations for, success. The healthcare staff had been trained to follow courses of treatment that would minimize risk to patients, particularly of death, and so often limited the options presented to reflect this training bias.¹ In contrast, a patient-centred approach would require including the patient in the decision making, and accepting that patients, as in this case, will sometimes prefer riskier courses of action. Some healthcare providers will react by distancing themselves from the decision-making process by making treatment choices entirely the patient’s responsibility. However, if providers choose to dissociate themselves from patient choices rather than opting to delve into the deeper meanings patients associate with courses of treatment, then patient experiences have not been improved, and patient empowerment (which implies truly informed consent) has not been achieved. True patient-centric approaches involve all staff associated with healthcare delivery actively listening to understand a patient’s desired outcomes as representative of a patient’s value system, and resisting the temptation to layer on value systems based on professional education or training.

1. This tendency to privilege medical preferences over other patient concerns and the attendant negative effects it can have on quality-of-life (especially in the case of terminal diseases) is discussed eloquently and extensively in physician Atul Gawande’s best-selling book *Being Mortal*.

Communication Flows and Transcending Boundaries

Management and operations practices have infiltrated healthcare institutions as these organizations seek to become more efficient and effective, as well as accountable to their key stakeholder groups. One consequence of this operational focus is the silo structure that many healthcare organizations employ. In this model, departments are structured as distinct from one another, and separated within the physical space the organization occupies. This structuring extends to the various boundaries, both physical and virtual, that exist between healthcare organizations such as hospitals and primary care providers, such as family physicians. As patients traverse the boundaries within and between healthcare organizations, the patient-centric focus requires that the organization with which the patient interacts be constantly providing feedback to all other members of the service delivery chain. Within the organization studied, healthcare staff found that there were significant communication breakdowns at the points where patients transcended these boundaries. These breakdowns are now identified as missing or incomplete records of care or treatment. A patient-centric model focused on patient experiences and outcomes will attune the healthcare organization to ensure these trans-boundary barriers are removed.

One role within the organization that appears to be underutilized in assisting with boundary issues is the social worker. Individuals in this role are frequently engaged with patients at multiple points during the service delivery process, and have a holistic perspective on patient values and concerns, including those that transcend purely health-related issues. For example, one social worker discussed how a severely ill patient was more concerned with the administration of their disability insurance payments than with following their treatment conditions. This concern was due to the financial situation of the patient's dependent family members. Once the administration of payments was coordinated by the social worker, the patient was able to focus on their treatment plan and their health subsequently began to improve. Despite this patient-centric focus, the degree to which other healthcare staff within the service delivery chain engage with information provided by the social workers is variable, and there are disproportionately few social workers working within the organization relative to other healthcare positions.

BROADER IMPLICATIONS FOR HEALTHCARE ORGANIZATIONS

Day and Moorman (2010) urge organizations, public and private, not-for-profit and for-profit, to engage in what they call an "outside-in" strategy. This involves the organization's leadership coming to understand the value sought by their key stakeholders and then structuring the organization to ensure the ability

to deliver this value to those stakeholders. The fundamental argument is that an organization that is unable to deliver value to its key stakeholders will be constantly sidetracked by issues that deflect attention away from the organization's core purpose. Therefore, an "outside-in"-driven healthcare organization would be a patient-centred organization. However, it is important to recognize that a patient-centred care system does not necessarily mean a patient-"driven" system; as one writer comments, "the patient, unlike the customer, can't always be right, though few of us want to hear that" (O'Rourke 2014). It is important to recognize and legitimize the "local" knowledge of patients, while balancing it with the "expert" knowledge that the patient is unlikely to have.

To become "outside-in"-driven, the organization must tend to three imperatives: its structure, culture, and metrics. We will examine each one of these imperatives in the healthcare sector context, drawing on the above case study to illustrate.

Organizational Structure. An "outside-in" organization first looks to its key stakeholders to understand the needs that they have and the problems they are looking to solve. To achieve this understanding, the organizational structure must be focused on and attuned to understanding stakeholders' needs rather than focused on internal organizational arrangements. The key structural imperative to achieving this is for the organization to break down its internal silos and allow for cross-functional team coordination. As demonstrated in the case study above, the needs of patients do not necessarily fit into predefined organizational silos. A patient's medical needs, social needs, spiritual needs, life goals, financial concerns, family dynamics, and so on, all interact. Many healthcare organizations, however, are structured around internally driven arrangements that most likely mirror professional hierarchies. Consciously breaking down these internally driven structural constraints in order to design healthcare systems that reflect the inter-related dynamics of each patient would be a major step towards delivering patient-centred care.

A second important structural consideration is establishing those organizational roles that help to facilitate an integrated approach to patient care. In the case study above, the role of the social worker was emphasized as a key player in helping the healthcare organization transcend professional boundaries in order to ensure the patient receives value in all aspects of their healthcare concerns. Beyond social workers, the organizational structure must formally include those whose role is specifically designed to transcend these internally driven professional boundaries.

A third structural consideration is having formal organizational mechanisms that integrate the patient voice into all aspects of organizational decision making and operations. The organization outlined in the above case study used patient advisors. There are, of course, many other roles and mechanisms that can be used to ensure the integration of the patient voice throughout the organization. Some for-profit organizations are increasingly turning to "Chief

Cultural Officers" (McCracken 2011), people trained and tasked with the job of scanning and engaging the social media environment to understand the kinds of social changes (such as the trend from expert knowledge to local knowledge) that may provide opportunities for the way in which the healthcare organization delivers value to patients.

Organizational Culture. Organizational culture refers to the beliefs and norms that guide day-to-day activity within the organization. A patient-driven organization would have a culture in which organizational members firmly believe in and embrace the core principle that decisions about organizational practices must be made from the patient's perspective, and that everyone in the organization, regardless of their position and rank, has a role in delivering this value. But it is not only changes in patient empowerment and the increased impact of patient satisfaction measures on financial performance that are driving this cultural shift. Physicians are also experiencing a crisis that spans their profession; according to a 2012 survey, nearly eight out of ten American physicians rated themselves as somewhat or very pessimistic about the future of the medical profession, and only 6 percent of doctors surveyed in 2008 rated their morale as positive, compared with 85 percent in 1973 (O'Rourke 2014). Increasingly, it is being recognized that what can be a deep divide between patient and physician, with correspondingly poor health outcomes and dissatisfaction on the part of the patient, as well as disillusionment and frustration on the part of the physician, may be addressed by training doctors not only in the physical and technical aspects of medical care, but also the emotional and psychological ones. Driven by an increased emphasis on patient-centric care, as well as insiders within the healthcare system who were encountering patients recounting "devastating" interactions with doctors that were not just "innocuous, but often experiences that were profound and deeply affected [their] lives" (Boodman 2015), a range of programs have been developed to train physicians (and other healthcare providers) in delivering medical care with empathy. Studies have linked empathy to greater patient trust in the physician, increased patient satisfaction, decreased physician burnout, a lower risk of medical errors and malpractice suits, and demonstrably better health outcomes and medical efficacy (Boodman 2015). For instance, a study found that the rate of severe diabetes complications in patients of doctors who rated high on a standard empathy scale was 40 percent lower than in patients with low-empathy doctors, an effect comparable with the benefits seen as a result of the most intensive medical therapy for diabetes (O'Rourke 2014). As such, starting in 2015, the Medical College Admission Test will contain questions about human behaviour and psychology, in recognition that being a good doctor "requires an understanding of people, not just science," according to the American Association of Medical Colleges (Boodman 2015).

Such training is just one illustration of how a cultural shift within an organization can have substantial benefits for multiple stakeholders, and yet result in relatively small costs. The need for such a philosophical shift is not an easy one to identify or to determine how to implement, but as accountability

for healthcare metrics continues to focus on not only medical outcomes but also patient perceptions, such a cultural reorientation may be the best way to authentically connect with the true needs and values of multiple organizational stakeholders.

Organizational Metrics. Finally, the organization must be geared towards gathering key indicators that reflect the organization's performance in delivering value to patients and their families. Even patient advocates recognize that, to a certain extent, the measures of patient "satisfaction" currently in place are incomplete at best and deeply flawed at worst. Take, for instance, the patient satisfaction survey data collected by the U.S. Centers for Medicare & Medicaid Services. Consistent with the idea of managing to measurement, most hospitals have improved in the areas the surveys track, such as how clean and quiet their rooms are and how well doctors and nurses communicate, but the surveys have resulted in little shuffling in the rankings of high- versus low-performing hospitals (Rau 2015). In some cases, small variations in patient responses (which are well-recognized as being a normal part of using surveys as a research tool) can have drastic financial impacts; in determining how much to reimburse, the government only gives credit when patients say that they "always" got the care they wanted during their stay (such as their pain was "always" well-controlled). If a patient indicates that the hoped for level of care was "usually" provided, it doesn't count at all, and on a scale of 0 to 10 for rating a hospital stay, an organization must get a 9 or 10 in order for Medicare to fully reimburse them (Rau 2015). This approach to measurement fails to reflect or appreciate the complexities associated with self-report measures of any service experience, let alone a healthcare experience that takes place over an extended period of time, across multiple individuals, and which could reasonably be assumed to be affected by emotional and physical factors that may have little to do with the experience itself.

This approach also highlights a limitation of the assumption that only things that are quantitatively measurable are "real" and thus can be managed and controlled. That this perspective dominates within healthcare organizations and their assessors is not altogether surprising, given the typical "evidence-based" approach of traditional medicine. But many social science disciplines (including marketing, organizational behaviour, sociology, and anthropology) have demonstrated that there is much to be gained in true understanding by employing qualitative methodologies that yield "thick description" (McCracken 1988), making them better suited to fully exploring complex and ongoing interactions, such as those commonly observed in a typical "patient experience." Medical researchers could thus benefit from taking a cross-disciplinary approach that would better capture the occasionally intangible nature of the "patient experience" in order to truly embody the "outside-in" philosophy espoused by Day and Moorman (2010).

CONCLUSION

As identified here, organizations involved in healthcare delivery and policy can no longer afford to focus on organizational or systemic priorities at the expense of ignoring the patient voice. As primary stakeholders in the healthcare system, patients are becoming more empowered and more vocal about what they expect from healthcare providers and from the system itself. There are a variety of ways that organizations can integrate patients into organizational decision making and priority setting, thereby harnessing patient engagement for optimal healthcare system change.

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