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Framing the Conversation on Patient Experience

How does patient experience fit into the overall healthcare picture?

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Abstract
Understanding the experience of patients provides insight into health care as well as being a crucial first step towards partnering with patients to drive improvement. Increasingly, health care organizations gain feedback from patients about their experience through surveys. Patients are also turning to other avenues, including the internet, to document their experiences.

Although long recognised as a domain of quality, evidence of the link between patient experience and clinical outcomes has emerged more recently. Organizations that succeed in improving patient experience have adopted a strategic approach to patient focus that incorporates both patient feedback and consumer engagement.

Adopting a patient perspective sees leading organizations moving beyond 'episodic' care approaches to an extended patient continuum. The use of patient portals and access to electronic records foster a much needed two-way communication.

For the patient's and provider's perception of the care continuum to coincide, the 'continuum' definition needs to expand to complement population health management. Similarly health care delivery models and payment models will need to change to reflect the care continuum.

Patient experience fits into the overall healthcare picture more today than it ever has. As population health management, accountable care, and healthcare reform mature, the efficacy of those efforts depend more and more on how well providers can integrate the design of patient experience and empowerment into the expanding care continuum.

Keywords
Patient experience, consumer engagement, care continuum, patient portals

Introduction

To live up to the mantra of 'nothing about me without me' in health care[1], we need to understand the current experience of patients as well as partner with patients to drive improvement in health care.

Listening to and learning from patient experience is the first step. Taking the next step of engaging patients and families to improve care delivery has led to a range of outcome benefits for health care organizations committed to a 'client focus'.[2]

Learning lessons from approaches to 'experience' by other industries can prove useful to health care organizations. Listening to 'customers' to improve service provision implies that the service values feedback about the customer's experience. The move away from the industrial economy view of the 'product' as the service outcome to a modern view that what a customer receives at the end of a service encounter is 'the experience' may be considered central to the rise of patient experience in health care.[3] This 'Experience Economy' theory by Pine and Gilmore suggests that organizations should create engaging, personal and memorable experiences for 'customers.'

Capturing patient feedback about health care provides insight into the extent to which patient expectations of care have been attained. As 'consumers' of health care services, it is important to acknowledge that we all start from a different level of anticipation. Indeed, research about patient experience has taught us the importance of 'assuming nothing' as assumptions by health care professionals can lead to what has been called "patient preference misdiagnosis."[4] A number of studies about patient experience demonstrate that a gap often exists between 'what patients want' and 'what doctors think patients want'.[5] Even though clinicians think it is

important to ask patients about their expectations, they often fail to do so.[6]

It is important to consider the range of methods that are being used in health care to learn about the patient experience. The use of surveys to capture patient experience has become wide spread, with findings consistently highlighting important issues that health organizations need to address from the patient's perspective including coordination of care, pain management and respect for preferences.[7,8]

While health care organizations increasingly gain feedback from patients about their experience through surveys, patient experience scores can present a limited picture of care. Detailed information about specific aspects of patients' experiences are likely to be more useful for monitoring performance of hospital departments and wards in particular.[8] Listening to patient narrative stories about care experiences can provide insight into expectations of care, often in a manner that health care professionals may find more engaging.[9]

Increasingly, patients are publically expressing their views about experiences with health care on websites such as *Patient Opinion* and rating clinicians on sites such as *Angie's List* and *Healthcare Reviews*. There is evidence to support that patient views expressed online correlate with ratings from conventional patient experience surveys.[10]

A focus on staff experience is equally important for health care organizations.[11] An understanding of the link between patient experience and the way staff experience their work environment is also slowly gaining recognition. Research has demonstrated that positive staff experience is associated with positive patient experience. The association is positive for witnessing and reporting of errors and negative for working extra hours and stress.[12] Consequently, improving patient experience through patient-focussed approaches increases employee satisfaction, and improves employee retention rates.[13]

Ultimately, at the centre of really understanding patient values and preferences is establishing a healing relationship between clinicians and patients and patients' families grounded in strong communication and trust.[14]

In this paper we examine the central place that patient experience is now playing in the overall health care picture, having moved from 'nice' to 'necessary'.

Recognition of Patient Experience as a Key Domain of Quality Care

The basic premise that focusing care around the patient and responding to patient's needs and preferences ('patient-centered care') as a key domain of quality in health care has been established for over a decade.[15]

In the late 1980's, researchers started investigating the core components of such care. In 1993, the Picker Institute identified eight domains: respect for patient preferences and values; emotional support; physical comfort; information, communication and education; continuity and transition; coordination of care; involvement of the family and friends, and access to care.[16] Further research has supported these core concepts.[17,18] Respect for patient needs and preferences has been confirmed by the International Association of Patient Organizations as the most consistent element of definitions of patient-centered care.[19]

This original research from Harvard University helped to place the consideration of patient care experience as integral to the overall quality of care received by a patient, with 'patient-centeredness' included as a dimension of quality in its own right. The ground work of the IOM *Crossing the Quality Chasm* report greatly contributed to gaining broad support for the importance of 'patient experience' within healthcare.[15] In the United Kingdom, the National Health Service (NHS) "next stage" review recognized the experience of patients as one of three dimensions of quality.[20] The other two dimensions were clinical effectiveness and safety.

While health care service organizations recognize the importance of 'patient-centeredness', many struggle with how to move beyond the rhetoric towards improving patient care. Organizations find it difficult to involve patients and learn from their experience.[21-23]

Even with 'customer focus' as a key domain of quality, health care has not yet fully embraced using patient feedback as a driver of quality improvement. A potential driver in the USA has been the FY 2013 introduction of the Hospital Value-Based Purchasing program including incentive payments for performance in patient care experience scores.[24] In this model, 'patient experience' comprises 30 percent of the total bonus payments. The remaining 70 percent is for performance in the 'clinical process of care'.

Link Between Patient Experience and Clinical Outcomes

A range of individual studies over the years has investigated the association between patient experience and clinical outcomes. Evidence points towards 'good patient experience' and 'good clinical quality' going hand-in-hand. Several studies now indicate that hospitals that perform well on patient care experience surveys also do better on clinical metrics. A review of over 306 hospital referral regions defined by the *Dartmouth Atlas* indicated

that hospitals with lower overall ratings by their patients also tended to have lower technical quality measures.[25] Jha et al.[26] concluded that hospitals with high levels of patient-reported 'care experience' provide higher quality clinical care across a range of conditions Higher patient ratings of experience of care have also been associated with lower mortality in patients with acute myocardial infarction.[27]

Strong relationships between patient experiences and technical measures of quality and safety were noted by Isaac et al. in a study of 927 US hospitals, including better patient experiences being associated with lower infections due to medical care.[28]

A recent systematic review by Doyle et al.[29] has highlighted the positive association between self-reported patient experience, clinical outcomes and resource utilisation (e.g. impact on length of stay). The business case for organization-wide approaches to improving patient experience has been mounting.[13]

Gradually, we are witnessing patient feedback being used at a service and systems level to drive patient-focused approaches to quality improvement. Measurement of quality of care, however, has traditionally focussed on access issues (e.g. waiting times) and clinical care process (e.g. disease-specific indicators or overall mortality).[30] Accompanying the recognition of 'domain of quality' status has been an increasing interest in the patient experience of care as an indicator of quality. This comprehensive approach to quality has extended further into the development of patient reported outcome measures (i.e. PROMs) to complement clinical outcome reporting, including such measures as patient feedback about post-operative outcomes.

Whilst most patients report positive experiences of care, a number of patients have poor experiences and may ultimately lodge formal complaints. Indeed, there are lessons here as well with studies indicating that a small number of doctors are often responsible for the majority of patient complaints[31,32] and that 'complaints' are associated with other measures highlighting gaps in care.[33]

Patient surveys consistently report the need for improvement in clinician communication skills and teamwork. Such feedback can provide another early warning system for safety issues as patient perception of poor communication is associated with elevated adverse event rate.[34] Patient perspectives on safety are highly correlated with patient experiences of care.[35]

Patient feedback is also a positive predictor for staff participation in hand washing and for Methicillin-resistant Staphylococcus aureus (MRSA) infection levels - seemingly a better predictor than feedback tools used with clinicians and managers.[12,36]

Approaches to improving patient experience should not only focus on health care providers and service delivery. Patients who can better manage their own health care, as indicated by higher levels of knowledge, skills and confidence, also report higher patient experience ratings than patients less confident in managing their own care.[37] Such findings reinforce the importance of building patient-provider partnerships to enhance overall health care.

Engaging Patients in the Drive for Higher Quality Care

Being informed about the patient experience of care is a crucial first step towards actively partnering to drive improvement in health care quality. Taking the next step appears to be where many health care organizations stumble.

In a 2013 editorial, Richards et al.[38] emphasised the importance of engaging with patients -who have experienced care - in the quest for improvement. "And how better to do this than to enlist the help of those whom the system is supposed to serve—patients? Far more than clinicians, patients understand how services could be better designed to help them." The authors highlighted that such partnership "must be seen as far more than the latest route to healthcare efficiency. It's about a fundamental shift in the power structure in healthcare and a renewed focus on the core mission of health systems." Similarly, Leape et al.[39] identified 'consumer engagement' as one of five key factors as yet unfulfilled in most organizations and hence a deficit preventing the transformation of safe care delivery.

Traditionally, patient engagement in health care has focussed on the involvement of individual patients and centred on self-management for chronic conditions and shared decision making for treatments. Empowerment and partnership with patients requires taking engagement to a new level. It requires a mind shift by health care providers towards considering patients as true members of the care team.

While many health care organizations have attempted refocusing care to become more 'patient-centered,' the outcome is often isolated pockets of excellence. A more comprehensive, organization-wide approach, fundamentally linked to organizational success, is required.[40] Patients and family have also been identified in this strategic approach as 'an invaluable asset and resource for improving patient safety.'[41]

Strategies for engaging patients in health care improvement range from listening to individual patient stories, patient rounding, patient representation on governance and committees through to experience-based co-design of new processes and facilities.[42,43] "Patients as

Teachers" provides one such model that incorporates patient experience into service design and professional education. Internationally, programs have emerged to support patient engagement in health care improvement, such as Partnering With Patients (Clinical Excellence Commission, Australia), Point of Care (The Point of Care Foundation, UK; formerly of The Kings Fund) and Patients Accelerating Change (NHS Clinical Governance Support Team, UK). Leading health care organizations also provide exemplars for patient engagement - such as Griffin Hospital and MCG Health Inc. - whilst groups such as Planetree aim to facilitate patient-focussed care through forming healing environments in a collaborative community of healthcare organizations.

It is important to note that organizations that have succeeded in fostering patient-centered care have gone beyond traditional frameworks for quality improvement - based on 'clinical measurement and audit' - and have adopted a strategic organizational approach to patient focus incorporating both patient feedback and consumer engagement.[2,18]

The Extended Patient Continuum

Historically healthcare providers have focused on the time patients are presenting for a visit, contacting the organization, hospitalized for care or procedures and discharge follow-up. Communication has been about marketing, preparing for your visit and onsite services. This is a small percentage of that patient's journey. From a patient's perspective, their patient care continuum begins from the first time they consider where they are going to get their care. This extends to not only the onsite visits but also to where they pick up their prescriptions, how they are going to manage their care at home and how each of their care encounters plays a part in their overall health.

When we think of the patient's perception of their care continuum in its entirety, we recognize their actions are greatly influenced on what and when they access healthcare services and by what means and how this affects their care. Traditionally, organizations have provided general health information to patients via educational documents provided at the time of the encounter along with the various care plan summaries provided by EHRs. With the advent of meaningful use, patient portals and other electronic and mobile tools, two-way communication has increasingly been available; however the information that is available is often very generalized or is a very specific reporting of a healthcare encounter. Personalizing information for patients based on demographic, disease, co-morbid conditions and personal preferences for communication based on their behavioural characteristics or personal motivators has not yet been widely developed. There are many different applications, portals and mobile devices that address part of the patient's continuum but few have been adopted to encompass the entire continuum of care.

The impact of patient portal use on health outcomes is unclear, according to a systematic review of studies.[44] Moreover, the researchers said, the evidence to date shows that portals are unlikely to have substantial effects on efficiency and utilization of services, at least in the short term. After combing the literature, researchers were able to identify only 46 fairly high-quality studies that addressed how portals "tethered" to EHRs related to health outcomes, patient satisfaction, and adherence; efficiency or utilization; patient characteristics; and/or attitudes or barriers to or facilitators of use. These included 14 randomized controlled trials, 21 observational studies, and 11 descriptive studies. Results of the studies were mixed. "We did identify examples in which portal use was associated with improved outcomes for patients with chronic diseases such as diabetes, hypertension, and depression, but these studies generally used the portal in conjunction with case management," the authors of the review paper said.

It is understandable that the focus of many providers has been to ensure their patient portals meet Stages 1 and 2 of the Meaningful Use Incentive Program. Doing so however is not synonymous with designing a patient portal that is patient-centric. Stated another way, patient portals have not been designed or implemented to focus on patient engagement. Portals are much more focused on information sharing than on facilitating information exchange.

A recent HIMSS survey found that two out of three people would consider switching to a physician who offers access to medical records through a secure site. But only one in five practices actually offers access to medical records through a patient portal, according to Derek Kosiorek of the Medical Group Management Association.[45]

The portals that many practices have set up are offering basic statistics, current medications, upcoming appointments, and the like. There is much that practices could do on these sites to grab a patient's attention and provide much needed education on a variety of important issues.[46]

Glenn D. Steele Jr., MD, president and chief executive officer of Geisinger Health System, says "We have a series of expectations, even in the biggest compartments that are most well-capitalized, the hospital-centrics; we have a series of expectations that up until recently were pretty simplistic: that if you put an electronic health record in it would automatically improve badly engineered and badly transacted systems. It doesn't work that way."[47]

Those statements, when taken together, seem to make a strong argument to suggest that the application of technology, even costly technology does not pass the test of being both necessary and sufficient when it comes to improving patient outcomes, engagement, and experience. The answered question is how to get people involved in their own health. Technology alone is not the answer. If you look at what percent of the US population today has a personal health record it's only about 6 percent.[48]

In addition the personality, strategy and objectives of each organization, locality and availability of community resources is variable, thus not well acclimated to having a "one size fits all" care continuum.

Measured or not, patients have experiences at each touch point across the continuum. Unplanned, unmanaged and unmeasured experiences result in very low satisfaction. When the patient's perceived care continuum exceeds the scope of the provider's actual care continuum, the patient's experiences of those touch points the provider missed will yield a series of poor experiences. Those poor experiences can cause undesired outcomes.

For the patient's and provider's perception of the care continuum to coincide it is required that the definition of the continuum expand to complement population health management. Approaches and technologies that are being considered for population health management should be evaluated as to what role they can play to enhance the care continuum, thus facilitating best practices and driving innovation to improve effectiveness for patients and their population fraction.

Many factors go into making patient engagement initiatives successful. Whether through training staff or incorporating new technologies, each approach requires a strategic organizational commitment to work effectively. Patient engagement starts with giving patients the tools they need to understand what makes them sick, how to stay healthy, and what to do if their conditions get worse. It means motivating and empowering patients to work with clinicians—to be active participants in their care by asking questions, knowing their medications and medical history, bringing friends or relatives to appointments for support, and learning about care that may be unnecessary." With new technologies on the rise that aim at making the patient experience as engaging and educational as possible, health care providers can equip themselves with the tools necessary to help keep their patient populations out of the hospital.[49]

This is not surprising since the patient care continuum and population health share several common goals: improving education, care, quality, and safety and moving away from transactional care towards a continuity of care model. Expanding and improving the continuum of care for the patient, when applied again and again among the patients that comprise the population, by definition improves population health.

We recognize that the term population health is currently being used by some health care organizations to describe the clinical, often chronic disease, outcomes of patients enrolled in a given health plan. Certainly an enrolled patient group can be thought of and managed as a population, but defining population health solely in terms of clinical populations can draw attention away from the critical role that non-clinical factors such as education and income play in producing health.[50] There is no population to manage without the patients who make up that population.

As the deployment of the care continuum continues to expand the roles of primary care and specialty providers will need to change accordingly. The current role of the primary care provider is that of wellness evaluation, episodic care, treatment, individual practitioner, face-to-face care, managed care interaction, payment for service, production, and treatment.[51] In the future, the primary care provider's role will be much more pivotal as a care coordinator for health and wellness care across the continuum, treatment and prevention and oversight of the care team using tele-medicine and eVisits, provider-payer partnering, patient empowerment[52], all while being paid for performance and accountable for quality and outcomes, and.

Healthcare Reform and the Expanding Patient Experience

The Affordable Care Act (ACA) makes provisions for government-payer exploration regarding what may best align the interests of patients and providers to promote health and reduced intervention. With a few exceptions, the overwhelming majority of health care reimbursement is still allocated for provider visits, interventions and hospitalizations. The change from the current model to these new payment systems will not occur quickly since the tools, interventions and sunk costs associated with the old model still exist.[53]

Corporate wellness programs have shown a reduction in overall healthcare costs.[54] A comparison of a disease-management and lifestyle management program found that the disease-management programs alone resulted in cost reductions of $134 per month and 29 per cent drop in hospital admissions among its participants. The employees who participated in both the disease and lifestyle-management programs saved $160 each month and hospital admissions fell 66 percent.

In order to change the traditional healthcare model and effectively reduce healthcare costs, the patient continuum

must expand to include prevention, employee wellness and lifestyle changes as well disease management. Predictive analytics is moving from traditional analytics/reporting solutions that provide a snapshot of past intervention to solutions that provide an accurate picture of the present and a prediction of future trends. The power comes with *prescriptive analytics,* which would include evidence, recommendations and actions for what the patient needs to do next in the continuum of care via two-way communication channels (web, mobile, social).

The shift from pay-for-service to pay-for-performance in healthcare means that healthcare organizations and providers must approach care delivery in a different way, moving from diagnostic care to preventive medicine. Part of the challenge of adopting a forward-looking approach is having the right tools, namely health IT systems with the ability to predict what's next.[55] Currently, the potential for predictive analytics in healthcare appears high. In fact, the limit to its applicability looks to be based more on what healthcare organizations want to do rather than what the technology is capable of. The healthcare analytics market is expected to exceed $17.1 B in 2016.[56] As the analytic capabilities of healthcare organizations expand to become more predictive, the resultant proactive decision making will enable them to better meet the needs of patients across the care continuum and effectively meet their expectations.

At the 2014 Healthcare Information and Management Systems Society's 2014 conference, Aetna CEO Mark Bertolini remarked that healthcare needed to move "as far away as possible from the hospital". This is an increasingly predominant thinking in that the three pillars of the "Triple Aim" in healthcare are to lower cost per capita, improve population health and improve patient experience. In response to the ACA, many healthcare organizations have formed Accountable Care Organizations (ACO). These organizations are characterized by a payment and care delivery model that seeks to tie provider reimbursements to quality metrics and reductions in the total cost of care for an assigned population of patients. In measuring ACO success factors, a recent study indicated 88 percent identified clinical outcomes as the first important measure and patient satisfaction the second at 68 percent, patient engagement at 48 percent and patient compliance at 36 percent.[57] The emphasis on patient experience and patient engagement as a key success factor for ACO's and models focused on population health will bring attention to those touch points outside of the traditional healthcare model.

To be successful during an era of changing health reform, providers must give patients consistent messages about how to manage their care at all touch points. Providers have the opportunity to create two-way communications that are consistent and personalized to the needs of the individual and the specific point of interaction in their care. Patient stories which span an entire continuum of care are useful in identifying the many ways that patients interact and how issues outside of their care management, (i.e. psychosocial, financial) impact how and when they choose to interact with the system.

Patient experience fits into the overall healthcare picture more today than it ever has. As population health management, accountable care, and healthcare reform mature, the efficacy of those efforts will depend more and more on how well providers can integrate the design of patient experience and empowerment into the expanding care continuum. As that integration improves, so will the ability of providers to meet their dual missions of improving the health of individuals and their communities.

Proactive Office Encounters ensure that no matter where patients access care, we are able to address all of their health care needs through a personalized, evidence-based approach. Our goal is to help patients get and stay healthy.[58] The premise that actively engaging healthcare users and their families can improve outcomes and reduce healthcare costs depends highly on the experiences of those users and their families. In the same way that a satisfied, engaged patient is likely to take more ownership of their care, adopt a healthier lifestyle, and be more proactive in their treatment, a dissatisfied patient, one whose experience with any of the touch points is poor, is more likely to disengage, and to eschew responsibility for their individual health.

That same metric works the same for populations. More patients having better experiences and living healthier lifestyles moves a community's health in a positive direction, thus improving outcomes and controlling costs.

Summary

Healthcare organizations are increasingly focusing their efforts on patient experience and engagement. As the CEO of Children's National Health System said, "I think the important perspective at Children's National is that we make the patient experience about the entire family. The interactions that are important to us are not only with the patient – the child - but also the parents, the extended family, and the siblings".[59]

The "Triple Aim" of reducing costs per capita, improving patient experience and population health all require an engaged patient to improve clinical outcomes. To be successful in the new era of health reform, organizations will have to take engagement to a new level and consider patients central to the care team. Strategic focus on patient feedback all along the care continuum will be essential to continually improve the health of populations. Wellness, prevention, predictive analytics and focus on

clinical outcomes will be required to move from an era of treating disease to engaging patients in healthy behaviors that maintain their highest quality of life.

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