

How to effectively engage patients and families in quality improvement: a deep, transparent partnership

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Introduction

Increasingly, healthcare organizations are leveraging the unique perspective of patients and families to drive organizational change. As recipients of care, patients and families are well-positioned to add immense value as equal partners in efforts to advance health-care quality.

However, what is important is not just the engagement of patients in quality improvement, but how one engages them. Even with the best intentions, it is the ‘how’ that can be most challenging, as most recommendations end at high-level concepts, leaving quality improvement teams wondering how to most effectively engage their patients and families in a tangible and concrete way [1].

A multidisciplinary team at a large health system undertook a quality improvement initiative utilizing the ‘Plan-Do-Study-Act’ methodology for continuous quality improvement [2]. As part of the evaluation of improvement efforts, physician, nurse and patient advisor leadership for the initiative assessed together the lessons learned on how to better engage patients and families in quality improvement. From an initial brainstorming of observations, the leadership team organized and streamlined to three key principles towards most effectively engaging patients and families in quality improvement. Here we illustrate these principles, as gleaned from the system-wide sepsis improvement effort at MedStar Health.

MedStar Health sepsis improvement effort

More than 1.7 million Americans get sepsis each year and 270 000 die from it, yet approximately a third of people have never heard of sepsis—which is critical given that 87% of sepsis cases begin at home [3, 4]. In the current coronavirus disease 2019 pandemic, addressing sepsis has become all the more important. MedStar Health, a 10-hospital health system in Washington DC and Maryland, created a system-wide sepsis improvement effort to address early identification and treatment of sepsis, with multidisciplinary leadership from the physician, nurse, and patient/family advisor perspectives.

The choice to prioritize sepsis was two-fold. Our outcomes and process data and the perspectives of frontline providers

indicated an opportunity for improvement. Specifically, our processes for screening and early identification were varied, and sepsis contributed to more than half of inpatient mortality. We also engaged the system-level MedStar Health Patient and Family Advisory Council on Quality and Safety (PFACQS®), which is composed of eight national patient and family advisors for the purpose of quality and safety improvement. The Council has a charter to guide focus and establish infrastructure, and PFACQS® members are recruited through social media, grievance databases and word of mouth referrals, and selected through an interview process with senior leadership, where the number one question is understanding why they want to serve. A toolkit is available to support best practice, which includes governance structures, staffing and membership guidelines, sample charters, and recruitment and interview processes for establishing and sustaining a PFACQS® [5]. The experiences of PFACQS® members who suffered loss from undetected sepsis heavily influenced the decision not only to prioritize sepsis, but also what specifically to address within sepsis improvement. It was clear through PFACQS® member stories that the public lacked awareness about sepsis prevention, signs and symptoms, and when to seek treatment. This lack of awareness further hindered screening and early identification efforts. Thus, simply inviting a patient or family member to attend a meeting to ask their perspective was not enough. Rather, deep integration of that perspective was key to drive the initiative.

Providers must make themselves vulnerable and transparent to patient/family representatives in order to truly engage them in improvement efforts

The framework of MedStar Health’s PFACQS® is to create a robust engagement between patient/family and clinician/staff through partnered improvement efforts focused on discrete projects. One of the authors (A.N.) is a PFACQS® member of 5 years whose son had died of sepsis, and he was invited as an equal member of the sepsis improvement team. He attended every monthly system-wide committee meeting

for a period of more than 2 years, alongside nurse/physician champions for each hospital, and system-level quality, IT, coding/documentation, infection prevention, pharmacy and respiratory. He actively participated in reviewing process data and debating how to improve sepsis care right alongside clinical leaders. He joined walk-throughs to discuss sepsis care with frontline workers, viewed the dashboards tracking our metrics such as time from sepsis alert to antibiotic administration, shared his story of loss and designed educational materials for providers and patients.

His thoughtful, probing questions were also critical to break through logjams and move work forward. For example, in one meeting, clinicians across MedStar Health's 10 hospitals were engaged in a debate on how they utilize vital signs, patient history and lab values to trigger sepsis diagnosis and treatment. Most hospitals did not have a sepsis screen in emergency department (ED) triage. Of those that did, they asked different questions to assess suspicion for sepsis (such as change in mental status or presence of infection), and any subsequent workflows based on a positive screen also differed (for example, triggering automatic labs or clinical escalation/rapid response). After an hour, little progress was made on defining a care pathway to be used across all 10 hospitals, as clinicians were hesitant to create a standardized screening and escalation protocol when there was no definitive gold standard. Because of the extremely varied current state, it was also difficult to evaluate what worked and what did not.

Our family advisor raised his hand. 'I lost my son to sepsis. Are you saying that I need to figure out which hospital has a better screening process, and drive past the others?' This prompted an immediate response from one of our ED providers who apologized for his loss, thanked him for his perspective and commented that we needed to do better, to try something. Our family advisor encouraged the group to try a care pathway and evaluate its impact, and not be paralyzed by the lack of a 'gold standard'. As a result of this discussion, a workgroup was formed to create a standard nurse triage screen that was embedded in the electronic medical record for use across the hospitals, along with an automated trigger for a stat lactate lab if certain signs were present. Our family advisor attended the triage form design meetings, and his forthright comment as to the location of the sepsis screen, 'If sepsis is such a high risk why wouldn't you place that screen right at the beginning of the form?' resulted in a priority position on the form.

There was no doubt about the power of our family advisor's voice to centre the team to focus on the ultimate goal of our efforts—to improve patient care. And importantly, that voice was authentic and not coached or influenced. After each sepsis improvement meeting, we solicited the input of the team members to determine what was working well and what was not. A common theme that emerged was the open collaboration and honesty to tackle such nuanced issues. Team members felt comfortable to debate, to listen and then to try to improve in an iterative manner.

Involve patients and family members early and often

From engaging clinicians to educating communities, the impact of having that patient voice was undeniable, and it was critical to include our family advisor from the very first

improvement committee meeting. That way, he was seen as an integral part of the team, where he helped shape and prioritize the ongoing initiative, rather than just reacting to what had already been developed. He offered ideas for provider education and community engagement and also brought in colleagues through the PFACQS® network to participate in health fairs, speak at grand rounds and provide input to processes and documentation.

As anyone in quality improvement knows, change is hard. Clinicians were grateful to hear directly from families and survivors about their experiences with sepsis during conferences. They commented that there are few opportunities to engage in dialogue with survivors, and the resulting emotional connection motivated and drove them to continue their work. Involving PFACQS® representatives was also crucial in developing a public awareness campaign. Bringing the patient perspective into educational materials made them more engaging, relevant and impactful, and PFACQS® representatives disseminated them at community events, health fairs, senior centres and skilled nursing facilities. To complement these materials, PFACQS® members also created videos of their stories to be shared with the public. The first video, 'What YOU Need to Know About Sepsis', illustrated contrasting stories of early identification and treatment of sepsis, through the eyes of one father who lost his son to sepsis and another father whose son survived sepsis [6].

Allow patients and family members not only to have a voice, but to determine how they want to use that voice

Rather than telling our patient and family advisors where they could contribute to the sepsis effort, we asked them how they wanted to contribute and doing so led to impactful efforts not traditionally considered in the quality improvement rubric. One four-extremity amputee sepsis survivor wanted to do more than conferences, brochures and community events. With the support of MedStar Health, she helped develop legislation in Maryland that led to a state-wide sepsis awareness campaign.

Summary

Quality improvement stands to benefit from early and deep integration of patients and families in all aspects of improvement. Multidisciplinary leadership, rotating facilitation of discussion, inclusion of diverse stakeholders, and transparency with processes and outcomes can help create a culture that encourages the unencumbered expression of diverse thoughts. The engagement of our patient and family advisors catalyzed standardized screening processes in our hospitals that did not exist previously and were otherwise met with some scepticism and resistance; multipronged health-care worker and public awareness campaigns; and state-wide legislation. The PFACQS® campaign resulted in enhanced awareness such that patients arriving at EDs across the system would mention sepsis by name and voice their concern for possible sepsis.

A known driver for reduced sepsis mortality is early identification and early treatment. Our internal analysis demonstrated a statistically significant decrease in the

mortality index and mortality rate post-implementation of our automated lactate lab trigger. The ED triage screen further afforded a mechanism for even earlier diagnostic testing and identification for possible sepsis; post implementation of the ED triage screen, a 25% decrease in median time to first diagnostic test was realized.

These efforts undoubtedly contributed to the 14% reduction in risk-adjusted mortality that we saw from April 2017 to April 2019 (calculated from the Vizient Clinical Data Base/Resource Manager) and forged a new way to partner moving forward.

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