

Grant Final Report

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Symposium on Patient Engagement

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Structured Abstract

Purpose: The Symposium on Patient Engagement, funded with an AHRQ conference grant, aligned with three of the Agencies research portfolios - patient safety, health IT and prevention and care management. The grant aims were to: 1) utilize a multidisciplinary expert panel to develop a national consensus-based white paper defining roles of nurses in fostering consumer/patient and family engagement; 2) involve a diverse group of health professionals in a national conference to promote patient engagement policy research and strategy setting; and 3) incorporate the knowledge of expert panel, conference presenters, and attendees in structuring the profession's strategic plan of action for increasing nurses' effectiveness in patient engagement.

Scope: The Nursing Alliance for Quality Care (NAQC) identified a need to study nurses' roles and skills that foster patient engagement and to heighten awareness among nurse leaders of patient engagement's importance.

Methods: NAQC commissioned a national expert to draft a white paper on nursing's roles in fostering successful engagement, convened a panel of experts in patient engagement to review and improve the white paper, and developed and implemented a national conference to educate nurses and identify best practices for engagement.

Results: Conference presenters and participants, in addition to 22 national nursing organizations and consumer groups, provided substantive comments incorporated into a final White Paper – *Fostering Successful Patient and Family Engagement: Nursing's Critical Role*. This document includes two models and a Strategic Plan for moving both the profession and health care systems forward in embracing and supporting patients and their families in sound decision-making about their own health and health care.

Key Words: nursing; patient engagement; patient safety

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Final Report

Purpose

The specific aims of this grant were to interact with the larger national nursing community and other health-related disciplines with expertise in patient engagement to:

- Activate an expert panel to develop a national consensus-based white paper defining the roles of nurses in fostering successful consumer/patient and family engagement in every setting and aspect of health care, including decision-making, care coordination, and self-care management;
- Involve a diverse, interdisciplinary group of health professionals in a national consensus-based conference and follow-on activities promoting significant patient engagement policy research and strategy setting that will ultimately improve the patient/consumer healthcare experience; and
- Use the expert panel and conference activities, along with the White Paper to develop a strategic plan for the nursing profession that included consensus-based recommendations and action steps that nurses and nurse leaders can use to facilitate patient engagement.

Scope

Health Care today is costly and complex. Advances in medicine provide the opportunity for people to live longer, but many patients will face chronic health issues that require sustained interaction with the healthcare system. Care is delivered in an increasingly complex environment that may involve multiple specialists and delivery sites offering an array of diagnostic tests and treatments. Patients must assimilate information needed to make complex care decisions, and then they must comply with regimens related to diet, medication, rehabilitation, wound- healing and more (Center for Advancing Health, 2010). Studies show that patients with chronic conditions have better outcomes when they engage in self-management, collaborative care, and shared decision making (Hibbard and Greene, 2013). Such patient activation also improves behaviors related to exercise, medications, and healthcare planning (Dixon, Hibbard, and Tusler, 2009). Patients and providers need new ways to define and implement such desirable behaviors.

With the passage of the Affordable Care Act in 2010, the business case for high quality, safe, and coordinated care gained strength (Mostashari, 2011). Currently the United States spends more per capita on healthcare than any other nation yet lags behind others on healthcare access, cost, and coverage (Schoen et al., 2010). Health care organizations that have adopted a patient centered care approach have a lower cost per case and a shorter length of stay, decreased

malpractice claims and increased market share as well as higher than average patient satisfaction (Charmel & Framptom, 2008).

The current health care environment is complex, fragmented, overextended and inconsistent in the quality of care it provides. Even in the face of significant innovations in health care services and technology, the reality is that health care delivery, whether in inpatient or primary care settings, is fraught with medical errors, safety concerns, and failures to provide quality. While dramatic improvements in access to health coverage through the Affordable Care Act are imminent, this will occur at a time when the system unintentionally does harm to many it intends to cure. Such problems were documented by the Institute of Medicine more than a decade ago. Despite national efforts by hundreds of organizations and institutions, minimal progress has been made (Landrigan, 2010), prompting recent national initiatives by the national Partnership for Patients to reduce harm to patients by 40% and reduce all hospital readmissions by 20%, two agendas embraced by the more than 5000 healthcare institutions and entities participating (US Department of Health and Human Services, 2012).

So why did NAQC choose to focus on patient engagement as a priority? From the perspectives of patients and family members, and from the views of health care organizations and professionals, preventing harm and reducing readmissions both appear doable through more complete and effective engagement of patients, regardless of setting. Certainly patients and families cannot be expected to fix the health care system. But their voices, their growth in making more knowledgeable well-informed health decisions, and the certainty that they will have their values, preferences and choices heard can positively impact a health care system willing to listen and learn. Nurses see all too frequently the examples of medication errors where patients and families questioned the administration of a medication to no avail, and the tragedies of families and patients who insisted to deaf ears that something was seriously wrong, only to have the family member suffer grievous consequences due to the failure of a health care team to respond appropriately. Patients and families can and do speak up, but their voices have not proved to be sufficient to protect themselves. It is up to health care professionals and health systems to listen and respond appropriately.

Nurses are the professionals who are the eyes and ears of the health care system. Nurses, as the most trusted of all professionals (Gallup, 2012) are considered by patients to be the safety net. Patients depend on their nurses to speak up within the system, to the physician and others on the team, by advocating that a “time out” occur to prevent a wrong site surgery, by coordinating care upon discharge (Jencks, Williams and Coleman, 2009), by insisting that the right medications be ordered or by taking the time to validate what the departing physician really meant when s/he ordered a procedure or delivered a diagnosis. Often patients are not given information on test/treatment benefits, risks and options that would make “patient consent” authentic. Health professionals’ expressed concerns about this are reflected in the “Choosing Wisely” campaign of the American Board of Internal Medicine and its partners (Cassel and Quest, 2012). Nursing as a profession has an ethical obligation to support patients and families being successfully engaged and heard in every health transaction. Nurses at all levels, in all care settings and in their work and lives in communities, support engagement by all consumers of health care. There are 3 million nurses in the United States, on average one for every 100 individuals. Neighborhoods, faith-based communities, schools and others rely on their knowledge and often their volunteer services.

Nurses can be strong enough to question the appropriateness of a medication order that flies in the face of the patient’s condition. Yet we know that a variety of factors have reduced nurses’

willingness and effectiveness to be this strong voice on behalf of patients who depend on them. This document details a set of strategies that will support every nurse as an advocate, will educate each nurse regarding techniques that foster well-informed decision-making by patients and families, and will demand that the health care system stop, listen, translate effectively, and respond appropriately to keep patients safe from harm due to medical error or insufficiently responsive health care professionals.

Engagement, including informed decision-making that is supported by strong nurse advocates, can and should be the rule rather than the exception in every health care encounter. Regardless of whether the nurse's role is to provide direct care as a primary care provider or at the bedside, to lead others in the provision of that care, or to establish policy, nurses are positioned to do what it takes to make it easy and clearly beneficial for patients and families to engage. Nursing leaders create the context in which patient and family engagement will be successful.

Methods

Preparatory work by the NAQC, including research on the existing state of the science in patient engagement, laid a framework for the development of the proposed national consensus-based conference, White Paper, Strategic Plan development and follow-on activities. Through an environmental scan and literature review, the NAQC Patient Engagement Subcommittee had examined the relevant terminology and concepts in this field.

Prior to the NAQC work on this initiative, patient engagement had been defined as “actions individuals must take to obtain the greatest benefit from the health care services available to them” (Gruman, 2011). Despite the frequent use of this term in the healthcare community, the NAQC scan revealed a lack of clear definitions for patient engagement and, despite a growing base of research on the subject, a dearth of guidance on how to implement best practices in the clinical setting. Based on this scan and review, the NAQC Board of Directors developed a set of *Guiding Principles for Patient Engagement* for nurses to use in relating to patients/consumers regarding patient engagement. The NAQC recognized this as a first step toward addressing the gaps that emerged from the scan and then proposed to work with an expert panel to prepare a draft white paper and recommendations. It was also clear that the larger nursing community needed to be enlisted in better understanding the importance of the role of nurses in fostering successful patient and family engagement. Combining a national educational conference that could simultaneously be used to gain feedback and consensus from its participants regarding a White Paper would potentially move the nursing community forward.

Organizations that have succeeded in introducing and fostering person-centered care have gone beyond mainstream frameworks for quality improvement, which are based on clinical measurement and audit, and have adopted a strategic organizational approach to patient focus. Best practices include having an engaged leadership, a strategic vision, focusing on staff satisfaction, and changing the organizational culture from a ‘provider-focus’ to a ‘patient-focus’ (Luxford, Safran & Delbanco, 2011). Others have focused on the patient experience of care, shared decision-making and even preference sensitive conditions. The approaches used to achieve the aims of this grant initiative were built upon these lessons learned. The NAQC “conference used various formats to bring together the evidence and the stakeholders to

determine the direction of nurses in supporting progress in patient engagement. The approach to achieving the specific aims of the initiative incorporated extensive pre-symposium work, including formation of an Expert Panel and drafting of a white paper, and continued in a highly interactive format through the conference and into post-conference feedback activities.

With policy making as part of its mandate, the NAQC filled a unique role in hosting this national conference and driving the development of a consensus-based white paper. As evidenced by its member base of 22 organizations, which includes consumer groups such as AARP, Consumers Advancing Patient Safety, and Mothers Against Medical Error and nursing organizations such as the American Nurses Association, American Academy of Nurse Practitioners and the National Council of State Boards of Nursing, the NAQC has earned the trust of diverse stakeholders. The conference built upon themes established at its April 2011 symposium on Nurse-Led Medical Homes which was attended by 180 nurses from over 100 institutions nationwide and its 2012 Conference on Nursing Leadership Roles in ACOs: Opportunities and Challenges.

As a process, the White Paper and Strategic Plan emerged from the national consensus process as identified below. This document, initially drafted by a national expert on patient engagement, was honed through a national consensus process supported in part by grant 1R13 HS21600-01 from the Agency for Healthcare Research and Quality (AHRQ). This consensus process included:

1. A Panel of Experts which met to review the first draft and to dialogue about the content of the second draft. Experts were drawn from across the country representing the best thinking on patient engagement from a theoretical framework as well as from a consumer view, nursing view or other provider perspective. Nurses representing advanced practice, senior nursing leadership, education, research and regulation, as well as nurses at the bedside, spoke to multiple settings and populations in need of improved care and successful engagement. (See White Paper Appendix for attributions).
2. A national consensus conference that was planned and implemented, featuring national experts on patient engagement, to raise the level of knowledge about nursing's contributions to patient engagement. A central feature of this two-day conference was conducting listening sessions to elicit feedback from every attendee and expert speaker regarding the content of the White Paper, which was then incorporated into a third draft.
3. Reviews of all drafts with concomitant feedback by members of the Nursing Alliance for Quality Care, its Board of Directors, and the NAQC faculty and staff team.
4. Preparation and review of final drafts which were disseminated to the NAQC member organizations and the NAQC Board of Directors for approval and support.
5. Wide dissemination of the final document within the national nursing community to enlist endorsement of its strategic plan and support for implementation.
6. Dissemination of the final document widely to other health care entities, health care professional disciplines, consumer groups and stakeholder groups to share strategies.

Results

Principal Findings

The cornerstone of this initiative is the final product, the White Paper, *Fostering Successful Patient and Family Engagement: Nursing's Critical Role*. The culmination of the work of the experts, the nursing community, the conference presenters and participants all contributed to its worth. As a result of the many months of discussions, feedback, writing and rewriting, this White Paper represents an aspirational view of the impact of nurses in improving the capacity of consumers, whether patients or families, to advocate for their own values, beliefs and preferences in making decisions about health and health care. The significance of nursing taking on the complexity of defining patient and provider roles in engagement, the long, medium and short term outcomes for consumers as a result, serves as a frame for other disciplines. The White Paper presents a different definition of patient engagement, based upon extensive feedback from both experts and clinicians. The discussions also led to the development of two models which provide the larger context for the importance of engagement. (See Figures 1 and 2 in White Paper). The White Paper also laid out a national strategic plan with action steps for the profession to tackle, in order to not only enhance the skills and behaviors of nurses in working with patients and families, but also to support nurses in advocating on behalf of patients within the health care systems in which engagement must occur.

Conference Feedback

The 119 who attended the conference had high praise for not only the development of the White Paper but also the quality of the conference presentations, discussions, posters and feedback about how critically important nurses are to achieving successful patient engagement, regardless of setting, condition or population. Eighteen educational sessions were provided and a total of 15.75 contact hours were approved and available for those sessions (See Conference Program). Overall program evaluations were very high for every speaker and for the conference as a whole. The average rating for all podium presentations was 4.72 on a scale of 1-5, with 5 being the highest. The lowest average rating for any podium presentation was 4.45, with all others averaging between 4.52-4.96 on a scale of 1-5. The average rating for all poster presentations likewise averaged 4.73 with a range of 4.62-4.87 on a scale of 1-5. Remarks from attendees reflected appreciation for the exceptional quality of the speakers, the thought provoking and professional nature of the conference, the candid conversations and dialogue of the Listening Sessions, and the level of networking available. Attendee evaluations indicated that they found the speakers and poster presenters to be highly knowledgeable and effective in the content areas being addressed.

Synergies

This grant coincided nicely with the funding from the Robert Wood Johnson Foundation, allowing NAQC to continue to move the consensus process through the NAQC organizations, seeking input from them repeatedly. It supported the efforts of NAQC as an entity to complete

the final approval process for the document and has provided NAQC a logical leadership opportunity for the ongoing work outlined in the White Paper. The synergy between the two grants has provided a mechanism for NAQC to disseminate the White Paper and the Principles for Patient Engagement, both products of NAQC. Even more importantly, it has provided an opportunity for NAQC to create value and visibility within the larger health care community. The Centers for Medicare and Medicaid Innovation's Partnership for Patients have been very eager to see the outcome of this work, as have the NQF-sponsored National Priorities Partners. As a result, several of the Quality Improvement Organizations (QIOs) and the Hospital Engagement Networks (HENs) have sought out NAQC to share this work within their organizations.

Dissemination Activities

The patient engagement symposium content has remained active on the NAQC website to allow participants to continue discussions and collaborations after the symposium. The intent was to prepare the consensus-supported white paper for broad dissemination to the nursing community and other relevant stakeholder groups. The final paper was distributed directly to all NAQC organizational members and all symposium speakers and participants. It also appeared in final form on the NAQC website and has been widely disseminated by the NAQC member organizations to their constituents. NAQC staff and members will also pursue publications arising from the conference and the recommendations and findings summarized by the white paper.

NAQC Sustainability

NAQC has committed to continuing the work outlined by the White Paper's Strategic Plan. During the same time period as this grant work, NAQC had to make some decisions regarding its long term sustainability. As a result of many months of deliberations, the management of NAQC has moved to the American Nurses Association, where its activities could more easily be supported through simultaneous work by relevant ANA staff. The transition of support for NAQC from George Washington University to ANA occurred in April 2013, and was completed with the transition to a new ANA hosted website in July 2013.

Challenges

While it is critical to "divide the work" and thus "conquer," it is also important for those working on this very important initiative to be in regular and in-depth communication. Key shared messages will be needed. NAQC and others have committed to take on a role to track progress, not only within individual strategic areas, but across them. NAQC member organizations are beginning the process of identifying and tackling those areas of the strategic plan most suitable to their own strengths. As they do so, it is essential that the profession present a clear and united front in completing this transformational work.

References

Cassel, C. K., & Guest, J. A. 2012 Choosing wisely: Helping physicians and patients make smart decisions about their care. *JAMA*, Vol 307 (17), 1801-1802.

Center for Advancing Health. (2010). A new definition of patient engagement: What is engagement and why is it so important. Washington, DC.

Charmel, P. A. and Frampton S. B. (March, 2008). Building the business case for patient centered care: Patient centered care has the potential to reduce adverse events, malpractice claims, and operating costs while improving market share. *Health Care Financial Management*, 62(3), 80-85.

Dixon, A., Hibbard, J.H., Tusler, M. (2009) How do people with different levels of activation self-manage their chronic conditions? *The Patient*. 2(4): 257-68.

Gallup, *Honesty/Ethics in Professions* 2012. <http://www.gallup.com/poll/1654/honesty-ethicsprofessions.aspx> on Feb 24, 2013.

Gruman, J. The evidence for and experience of engaging in health care. (2011, May 18). Center for Advancing Health. The Institute for Clinical Systems Improvement's Colloquium on Health Care Transformation. St. Paul. Retrieved October 2011 from <http://e-patients.net/archives/2011/06/jessie-gruman-at-icsi.html>.

Hibbard, J. H. and Greene, J. (February, 2013) What the evidence shows about patient activation: Better health outcomes and care experiences; Fewer data on costs. *Health Affairs* 31 (2), 207-214.

Jencks, SF, Williams, MV, Coleman, EA, 2009, "Rehospitalizations among patients in the Medicare fee-for-service program" *New England Journal of Medicine*, 364(16):1582.

Landrigan, C. 2010. Temporal Trends in Rates of Patient Harm Resulting from Medical Care. *New England Journal of Medicine* 363:2124-2134.

Luxford, K., Safran, D., Delbanco, T. (2011). Promoting patient-centered care. *International Journal for Quality in Health Care*. 23(5): 510-515

Mostashari, F. (2011, July 20) HITECH: Then, now and the future. Presentation at the University of Maryland-Summer Institute in Nursing Informatics, Baltimore, MD.

U.S. Department of Health and Human Services. 2012. National Strategy for Quality Improvement in Health Care 2012: Annual Report to Congress. (AHRQ Report). Rockville, MD.

List of Publications and Products

Publications

Sofaer S, Schumann M. *Fostering Successful Patient and Family Engagement: Nursing's Critical Role*. Washington: Nursing Alliance for Quality Care, March 25, 2013. At <http://www.naqc.org/Main/Resources/Publications/March2013-FosteringSuccessfulPatientFamilyEngagement.pdf>

Summary of Evidence: Family Participation in Rounds. Davidson J.E., Falk, N.L., Kleba, P., Jan Bull. 2013. At <http://www.naqc.org/Main/Resources/FamilyParticipation-Rounds.pdf>

Press Releases

Nurses Push for Increased Patient Engagement, at <http://www.naqc.org/Homepage-Category/NAQC-News/PatientEngagement-March2013.html> March 25, 2013.

Nursing Alliance for Quality Care Moves to American Nurses Association, appears at <http://nursingworld.org/FunctionalMenuCategories/MediaResources/PressReleases/2013-PR/NAQC-Moves-to-ANA.pdf>

Products

“Nurses’ Contributions to Fostering Successful Patient Engagement,” November 12-13, 2012, Washington. Attended by 120 registrants in person. Attendees represented 57 organizations. Examples of organizations represented include AARP, Children’s National Medical Center, the Department of Veterans Affairs, and the US Army. Program included 13 sessions, including one

keynote, two listening sessions inviting participation of conference attendees, and a poster session.

Conference booklet appears at
<http://www.naqc.org/Main/Resources/2012-NursesContributionsFosteringSuccessfulPatientEngagement.pdf>

Conference Evaluation Summary available separately.