Patient and Family Engagement Summit

Needed Changes in Clinical Practice

Ellen Swartwout, PhD, RN, NEA-BC
Karen Drenkard, PhD, RN, NEA-BC, FAAN
Kathy McGuinn, MSN, RN, CPHQ
Susan Grant, MS, RN, NEA-BC, FAAN
Ashley El-Zein, MPH, BA

Patient and family engagement is a strategy to enhance healthcare outcomes through strong clinician-patient partnerships. A new care delivery process, in which the patient is the driver of the healthcare team, is required to achieve optimal health. A summit partially funded by a seed grant from the Robert Wood Johnson Executive Nurse Fellow Alumni Foundation was held with interprofessional colleagues and patient representatives to identify needed clinical competencies and future practice changes. Recommended shifts in the care delivery process included a focus on patient strengths, including the patient as a valued team member, doing care "with me" and not "to me," and considering all entities or providers including the patient, as equal partners.

Interprofessional education and practice are emerging as important methods to prepare healthcare teams to provide optimal care.[1,2] Changes to the US healthcare system and components of the Affordable Care Act put clinicians at the core of transitioning how care is delivered to, and received by, the populations they serve.[3] A call for patient-centered care during a time of health reform has clinicians transforming practice to move the locus of control to the patient and partnering with patients and families to enhance self-care management.[4,5] Furthermore, a systematic review examining patients' participation in their healthcare identified the clinician-patient relationship as key to improving involvement.[6] To meet this goal, clinicians must transform the way they practice. Changing mindsets is a challenge, as most clinicians are prepared and educated as scientists focused on problem solving. Clinical roles are shifting from a silo-based approach to a more collaborative approach among patients and interprofessional colleagues.[7,8] Historically, patients have been socialized to be passive recipients of care rather than partners in care, underscoring the fact that not only clinicians' roles must change, but also patients' roles must change.

The O'Neil Center, whose mission is to advance the science of patient and family engagement (PFE), received a seed grant from the Robert Wood Johnson Executive Nurse Fellowship Alumni Association to lead a 1-day summit to identify and explore changes in education and practice needing to occur across disciplines to meet the new care delivery paradigm. In collaboration with the American Association of Colleges of Nursing (AACN) and Emory Healthcare (EHC) system, the summit convened a multidisciplinary group of clinicians and thought leaders from the education and clinical practice arenas, as well as several patients. Table 1 outlines the expected outcomes and specific objectives of the summit. The overall goal was to begin the conversation among academia, practice, and patients to examine the type of relationships needed to deliver care in which patients take a critical role.

Significance

Research shows that patients who are more active in their care experience improved outcomes and lower healthcare costs.[9-12] Healthcare organizations are

Author affiliations: Vice President, Research & Analytics (Dr Swartwout), and Senior Vice President, Chief Clinical Officer, Chief Nurse (Dr Drenkard), O'Neil Center, GetWellNetwork, Bethesda, Maryland; Director of Special Projects (Ms McGuinn), American Association of Colleges of Nursing, Washington, DC; Executive Vice President, Chief Nursing Officer (former Chief Nurse Executive, Emory Healthcare) (Ms Grant), Beaumont Health, Dearborn, Michigan; Research Consultant (Ms El-Zein), O'Neil Center, GetWellNetwork, Bethesda, Maryland.

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Correspondence: Dr Swartwout, O'Neil Center, GetWellNetwork, 7700 Old Georgetown Rd, Bethesda, Maryland, 20814 (*eswartwout@getwellnetwork.com*).

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Table 1. Summit Objectives and Outcomes

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Objective 1	Identify the necessary competencies needed to foster the transition in the care delivery process to more effectively engage patients in their care
Objective 2	To outline components of a curriculum needed for both academia and the practice setting to further this effort
Outcome 1	The development of an outline of a curriculum for the role of the nurse and healthcare team in the emerging trend of patient engagement that will complement the QSEN curriculum
Outcome 2	The assimilation of knowledge by key leaders within the healthcare industry specific to the concepts of patient engagement and the future role of the nurse and healthcare team
Outcome 3	The potential formation of an ongoing advisory council to the O'Neil Center focused on curriculum development and advancement of patient engagement as a core knowledge requirement for nurses and healthcare providers

expected to achieve the triple aim of providing quality care and improved health at a lower cost.[13] One approach to help reach the triple aim is more effectively engaging people in their own care.[4] Healthcare organizations are just beginning to recognize the value of PFE. However, challenges remain to fully implement patient engagement strategies. A recent survey of US hospitals on PFE practices showed that less than half were highly engaged in 9 of 25 practices.[14] Although healthcare organizations believe PFE is important for improving care, 51% surveyed indicated that the main barrier to implementing PFE practices was competing organizational priorities followed by lack of time to establish and implement patient and family advisory programs.[14] Another study found that when patients were actively involved in their care and participated in quality improvement initiatives, improved outcomes were reported, primarily related to transparency and information sharing.[15] Furthermore, a study that examined patient activation levels and their impact on health outcomes found that higher levels of patient activation corresponded with reductions in average length of stay, increased compliance with treatment plans, and improved laboratory values for patients with diabetes or high cholesterol.[12] Based on early evidence, PFE can be a powerful tool to achieve better care and population health management. Involvement of the interprofessional team with patients to design the future of care is critical for this shift to occur.

Healthcare systems are recognizing the increasing need to partner with patients and families to improve care delivery and health outcomes. Some examples of practices underway at healthcare organizations include involving patients and families in clinical rounding, sharing patients' medical record information with them, participating in shared decision making, using decision aids for determining what option of care meets the patient's needs, including patients as part of quality improvement and research teams, and the developing patient and family advisory councils.[16-19] Nurses are in a unique position to lead efforts to engage people in their care because of their frequent presence in patients' lives across the continuum. Furthermore, a shift is occurring in patient and family willingness to be more involved in the healthcare journey. Recent research showed that patient and family attitudes toward involvement in healthcare are changing from a passive to a more active role.[20,21]

Care providers have a responsibility to help facilitate this shift in healthcare and will play a central role in supporting the engagement of their patients. This can be accomplished through techniques such as shared decision making, motivational interviewing, and enhanced discharge planning. The integration of shared decision making between providers and patients has shown improvement in patients' knowledge about their condition, greater understanding of possible risks, improved adherence to prescribed treatments, and improved self-care behaviors.[7] Studies examining the effects of shared decision making have shown enhanced quality of life and reduced symptoms.[12,22]

Motivational interviewing can be an effective strategy to support PFE and health behavior change due to the strength of the patient-provider relationship. Done correctly, motivational interviewing utilizes communication strategies that promote a collaborative partnership and positively affects health behavior change among patients who receive it.[7,23,24]

Conceptual Framework

The summit was based on the Interactive Care Model (ICM), a care delivery process model focused on the changes that need to happen in the clinician-patient relationship to better engage people in their healthcare.[25] Grounded in systems theory, and set in the context of healthcare organizational readiness to change, community resources, and population health management, the model depicts the relationship between clinicians and people at the core of creating a new normal. It details 5 stages of interaction between patients and providers: assessing capacity for engagement, exchanging information and care options, planning,

determining appropriate interventions, and evaluating the effectiveness of engagement interventions.[25] At each stage of the care delivery process, bidirectional interactions that need to occur in the clinician-patient relationship are identified to further engage people in their care.[25]

Summit Approach

Planning Team

A planning team was created that included representatives from O'Neil Center, AACN, and EHC with expertise in clinical care delivery and healthcare administration. The planning team consisted of 5 individuals who represented nursing, leadership, academia, and clinical expertise. An outside facilitator worked with the planning team to design summit activities to achieve desired objectives (Table 1). The team met regularly and identified interprofessional PFE experts in the academic and practice setting, along with patients, to participate in the summit. The summit was held on May 1, 2015, at the O'Neil Center headquarters in Bethesda, Maryland.

Summit Participants

The identified PFE experts were invited to participate in the summit based on their subject matter expertise and experience in delivering care and leading organizational change focused on patient-centered care and patient engagement. Summit participants included a broad base of experts and consisted of 17 representatives from nursing, pharmacy, and academia; patient- and family-centered care organizational leadership; research and executive leaders in the practice arena; and patient advisors. Prior to convening the summit, information about the Quality & Safety Education for Nurses (QSEN) patient-centered competencies and a chapter on the history of patient- and family-centered care were distributed to all summit participants via e-mail.[26-28]

The chief nursing officer (CNO) of a large integrated healthcare system identified potential patient representatives to discuss the summit plans and determine if there was interest to attend the summit. Several were members of patient and family advisory councils, and another patient whose use of technology helped him to identify lifesaving information about his condition agreed to attend the summit and share his inspiring story. Patient and family advisors work in partnership with system leaders, staff, and physicians on councils to build the voice of the patient and family into the care experience. Through their experience and service on the advisory council, the patients were familiar with the healthcare system, had been recipients of clinical care, and desired to give back to the system. These individuals shared that they want to help shape and drive improvements in care delivery and tackle complex issues such as fragmented systems of care, providing appropriate and meaningful information and education, and personalizing care experiences. The patient representatives would help identify what clinician behaviors were important to them in order to encourage them to take a more active role in their healthcare. They would also identify the barriers and challenges they had experienced that curtailed their desire to be fully engaged in their healthcare.

QSEN Competencies

The planning team decided that the creation of a comprehensive curriculum outline for the role of the nurse and the healthcare team to support engagement was an essential outcome of the summit and would be based on the framework of the QSEN project. The prelicensure QSEN competencies and the graduate-level QSEN competencies are curriculum models for prelicensure and graduate nurses in quality and safety best practices. The overall goal of QSEN is to address the challenge of educating and preparing future nurses with the knowledge, skills, and attitudes (KSAs) necessary to continuously improve the quality and safety of the practice setting.[26,27,29] The QSEN project has demonstrated positive outcomes to ensure faculty are prepared to incorporate quality and safety education throughout nursing curricula.[26,27,29] For this summit, the focus was to build further upon the QSEN patient-centered care focus area with PFE engagement practices in mind. Thought leaders leveraged their knowledge and expertise to build on the QSEN patient-centered care competencies for the role of the interprofessional team in patient engagement. Table 2 includes the patient-centered care KSAs used to guide the summit.[26,27]

Summit Activities and Meeting Design

The overall intent of the summit was to have a day of dialogue with key stakeholders to explore what clinical behaviors can foster patient engagement to inform future research. Several strategies were utilized to achieve summit objectives (Table 1). First, an overview of the ICM was presented to set the context for what the future of PFE could become.[25] Second, a discussion about the model components and vision was conducted to address the transition of practice to better engage people in their care. Third, 1 patient representative described his experience with a terminal diagnosis and explained how being involved in his care and using technology to find information and act on it saved his life. A key take-away from his experience was the need to move to an open network of knowledge exchange.

Table 2. Subset of KSAs With Patient Engagement Focus for Patient-Centered Care Competency[26,27]

QSEN Patient-Centered Care Competency: Recognize the patient or designee as the source of control and full partner in providing compassionate and coordinated care based on respect for the patient's preferences, values, and needs.	
Knowledge	1. Examine common barriers to active involvement of patients in their own healthcare processes 2. Describe strategies to empower patients or families in all aspects of the healthcare process 3. Examine nursing roles in ensuring coordination, integration, and continuity of care
Skills	1. Assess the level of the patient's decisional conflict and provide access to resources 2. Engage patients or designated surrogates in active partnerships that promote health, safety and well-being, and self-care management
Attitudes	1. Respect patient preferences for degree of active engagement in care process 2. Respect the patient's right to access to personal health records

Participants then formed small groups to examine PFE's current state and explore future possibilities through an exercise called "A Bus on a Journey." Each group considered what PFE looks like now, discussing both progress and current barriers. They discussed what the future would look like if patients and families were truly engaged in their care and who would be needed on the bus to make this happen. Each group drew its concept using a roadmap and populated the bus with key stakeholders. Groups also identified detours, bumps in the road, and smooth highways to depict challenges as well as areas that are progressing toward the envisioned future.

An exercise called "FutureScape" tasked each participant with conceptualizing a vision for how to take action to get to the desired future state. After each person presented a vision, teams formed to review the data, categorize recurrent themes, and begin to outline the competencies and curriculum necessary to make the future state a reality. Each participant completed prereadings and used his/her experience to help shape the future curriculum. The group work yielded rich information and diverse perspectives that helped guide summit outcomes. This experience was in line with the positive results of using interprofessional teams in quality efforts. One research study showed that applying learning theory to clinical practice teams using facilitated sessions led to successful outcomes for change management.[30] These facilitated activities set the stage for valuable discussion, exchange of experiences, insights, and inquiry surrounding both individual and group ideas for the transition that needs to occur to realize a new care delivery vision.

Summit Outcomes

Group Exercise

The 2 core objectives of the day, to identify the needed competencies and outline the components of a curriculum to more effectively engage people in their care, were achieved through both the group and individual exercises. Some of the common themes identified from the "Bus on a Journey" exercise for the future state of healthcare included the need for multiprofessional health teams that include patients and family members, individualized care based on patients' preferences, values, needs, and beliefs, and the ability to have evolving iterative shared learning between provider and patient. Other themes that emerged were focused on a person's ability to have easy access to the healthcare system and health information. Table 3 presents the needed shifts in the care delivery process identified from this summit activity.

Individual Exercise

After completing this group activity, each individual participant was tasked to identify the "FutureScape" of the healthcare system related to PFE. Each participant used his/her current experience as a basis and projected what he/she predicted the healthcare system to be in the future. Common themes based on the individual work were categorized by participant category including practice, leadership and research, academia, and patient and family members, as shown below.

Table 3. Needed Shifts in Care Delivery Process

From	To
A focus on patient deficits	A focus on patient strengths
A focus on disease	A focus on quality of life
The patient as spectator	The patient as a team member
The patient as an individual	The patient as a part of a family and community
Doing "for/to me"	Doing "with me"
The illusion of certainty from healthcare providers	A sense of discovering the right solutions together
An isolated, closed system	An inclusive, open system
A hierarchical structure	All entities as equal partners

Practice

The intent is that the practice environment will continue to change to better engage people and their families in their care. The participants from the practice arena emphasized the need to understand the healthcare system as a whole, including payment systems, resources, and outcomes. Some of the common themes identified were meeting people where they are at, providing care in a way that matters most to the people receiving it, and performing breakthrough research to build high-quality care at lower costs.

Leadership and Research

Healthcare leaders and researchers participating in the summit all placed the patient at the center of the future of healthcare. Several of the driving factors in the successful implementation of PFE in healthcare were identified as developing advocacy programs for individuals, clinicians, and the system as a whole; understanding and driving public policy to support the changes needed; and using technology as a key resource for information, education, and communication. Other key themes included enhancing practice and academic partnerships, developing incentives for people engaged in their health, and using data to drive value and quality of care.

Academia

Several shifts in academia need to occur to transform education to focus on PFE. This group identified the need for a global focus on person-centered health by providing competency-based models of education, improving collegiality among professions, and enhancing interprofessional competencies. Other themes identified were enhancing the learning continuum for providers related to PFE, identifying the ingredients for ideal health, and engaging patients and families into the development of health education.

Patient and Family

The patients and family members participating in the summit provided insight into the future of healthcare. Key themes identified were recognizing patients as experts in themselves, collaborating with patients and their support systems, and ensuring that patients are at the center of the healthcare system. This group recognized the need to enhance academic education for healthcare professionals as well as to work with providers to gain their buy-in to the patient as the key driver in his/her own health. They also recognized the need for individual people to gather information and develop competency in their own health. By understanding that everyone is in the healthcare system together, patients desired the ability to have full access to sharing data and including patients in the education of providers and other patients in the system by sharing stories and providing real-life examples of practice.

Essential Elements for PFE

Throughout the daylong summit, participants were challenged to suggest how to move from where healthcare is today in the current model to where it needs to be in the future to position patients at the center of the care process. This included concepts such as developing an equal partnership between clinicians and patients. Clinicians and patients need to work together to discover the best options, taking into consideration what matters most to patients and seeing patients as people who are part of families and larger communities. The recommended concepts were based on 7 different areas as necessary competencies for healthcare providers: alignment of values, techniques and processes to accomplish goals, coaching and mentoring to support patient engagement, communication in multiple modes, teaching and evaluation of knowledge, tools and technology to support engagement, and outcomes that are measureable. Participants identified these as essential elements for transitioning the future of healthcare where patients and clinicians from all disciplines are part of the healthcare team (Table 4). These results incorporated the information gathered from the summit participants and lay the groundwork for further development of these competencies and methods for measurement.

The summit was the 1st step in working with patients and the interprofessional team to expand on the needed competencies and education to define the "how" of transitioning the care delivery process. In the PFE roadmap developed by the Gordon and Betty Moore Foundation and the American Institute for Research, 8 strategies were identified to reach this goal.[31] Of these, clinician-leadership preparation and patient-family preparation for engagement were identified as components to address in bringing about this change.[31] This summit identified several competencies to support the redesign of care delivery to include patients and families as key stakeholders.[31] Feedback from participants indicated that the summit experience was positive, and for the planners, outcomes were supportive of the objectives. However, participants emphasized that they want to see this work move forward in tangible ways, and they voiced that beginning the conversation was essential to starting the work of PFE.

Implications for Nurse Executives and Leaders

There are implications for nurse executives in practice and education as it relates to strengthening the KSAs of PFE. On the education front, a consideration would be to expand the QSEN patient-centered care competencies[26] to a deeper level for prelicensure and

Table 4. Patient Engagement Curriculum Outline and Competencies

Patient Engagement Category Curriculum Outline	Competency Statements
Values	1. Demonstrate empathy and a nonjudgmental attitude 2. Show compassion for patients and families 3. Understand the patient's values, preferences, community, and lifestyle 4. Demonstrate respect for the patient's culture 5. Conduct motivational interviewing with patients to identify why they want their health 6. Assist with facilitating patient and family decision making
Techniques and processes	1. The use of appreciative inquiry to understand the patient's needs 2. Conduct a strength assessment for the patient and build upon the patient's strengths 3. Facilitate the change management process for the clinician's and patient's role in healthcare 4. Demonstrate the use of conflict resolution in clinical practice 5. Identification of strategies to talk with patients, family, and healthcare providers 6. Connect patients with community resources
Coaching and mentoring	1. Model partnership behavior 2. Have presence and intentionality in all patient/family/clinician interactions
Tools and technology	1. Utilize and educate patients on using health applications and health gadgets 2. Conduct data analysis and design an analytic plan that uses patient-provided information
Teaching and evaluation	1. Assess a patient's level of health literacy and teach the identified gaps 2. Evaluate the patient's readiness to learn and adjust teaching plan accordingly 3. Evaluate a patient's readiness to comprehend the information 4. Adopt the utilization of decision aids to assist patients in determining their healthcare journey path
Outcomes	1. Identify benchmarks for outcomes management 2. Use technology as a tool to assist with outcomes measurement

graduate education and continuing education content for PFE. In addition, a review of the AACN Essentials of the Baccalaureate[32] around PFE KSAs might also be conducted. A standard curriculum for PFE could be developed to guide interprofessional undergraduate and graduate coursework as well as continuing education for healthcare providers.

In the practice arena, the CNO carries broad responsibilities to determine shifts in thinking to improve the entire delivery system in addition to operational responsibilities. Nowhere is this more important than determining how to ensure that patients and families are the source of control and full partners in their care. The concept of more fully including people in their care requires a change in thinking at both the administrative and care delivery levels. Consequently, the CNO has an opportunity to craft and design, as well as implement and evaluate, necessary changes. For example, using the ICM[25] to guide practice processes of care would encourage the shift to more effectively assess patients' engagement capacity and ensure that exchange of information is happening effectively. Appropriate interventions are considered and targeted based on the person's capacity to be engaged. Evaluating the patient outcomes at the patient and system level will be a guide to the CNO on developing plans for required changes. Executives and managers need to exercise skills that include leading change efforts, developing work plans, managing project plans, and developing accountability structures that include monitoring and evaluation of progress toward goal attainment.[33] In a delivery model where patients are actively involved in their care, this means designing systems that include patients in every part of the process. It includes training and development for clinicians so they have the KSAs necessary to effectively engage patients. It also means redistributing the care hours into new activities that may not have been addressed in the past, such as assessing patients' capacity for engagement, exchanging information with patients, cocreating care plans, and teaching people how to be effective managers of their care. Nurse executives can leverage existing resources to manage time constraints. Working across boundaries and integrating other projects with care delivery changes, clinical training, and annual competency may help ongoing work efforts. Lastly, the alignment of healthcare nurse executives with education nurse leaders will foster partnerships between academia and practice that will benefit the patients. Meeting the challenges of delivering patient-centered care with fully engaged patients presents an exciting opportunity to improve care.

Conclusion/Next Steps

It is clear that a shift in thinking is emerging regarding the patient's role in his/her own care journey.

A complementary shift in thinking includes the role of the clinician in the patient's care journey. Rather than the clinician serving solely as the expert provider of care, a new role of navigator, coach, partner, and advocate is necessary. Key skills for providers include effective teamwork and collaboration, participating in an exchange of information with patients, and communicating with respect to ensuring that the patient is the driver of the care process. In order to fully integrate these shifts into practice, these competencies should be included in the design of care delivery systems including a focus on patient strengths, including the patient as a valued team member, doing care "with me" and not "to me," and considering all entities or providers including the patient, as equal partners. Results of this summit begin the work of determining the competencies that the interprofessional care team will require going forward. Further work is required so that the next level of determining the required KSAs can be explored. Aside from replicating these focus groups, additional research should be conducted to determine the differences in clinician attitude and the corresponding impact on patient outcomes. Including patients in this work is critical. The creation of a curriculum for engaging patients and families could have application in interprofessional prelicensure and graduate programs as well as ongoing continuing education.

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