Task Force on Patient and Family Engagement

Executive Summary

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences and, in some cases, lower costs.[1-3] Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.[3-5] Because of the potential for improved health outcomes and patient satisfaction, patient and family engagement has emerged as a critical strategy for improving the performance of our health care system. The American Institutes for Research defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[6]

Patient and family engagement strategies have shown such promise that they have been incorporated into many recent efforts to improve health care quality.[7-12] Research shows that patients who are more engaged in their care have lower medical costs, fewer hospital admissions, and improved health outcomes, such as a healthier diet, increased levels of physical activity, and weight loss for patients with diet-related chronic diseases.[12,13] However, a recent survey of American health care consumers found that one in three consumers is disengaged in their care.[14]

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Nationally and locally, many efforts are underway to increase patient and family engagement. In North Carolina, Community Care of North Carolina (CCNC), the Medicaid program's primary care case management contractor, and the North Carolina Quality Center (NCQC) have been at the forefront of patient and family engagement efforts. The North Carolina Institute of Medicine (NCIOM) received grant support from The Duke Endowment to convene a task force on patient and family engagement in order to build upon current efforts in North Carolina. The NCIOM Task Force on Patient and Family Engagement was created in collaboration with the NCQC within the North Carolina Hospital Association, CCNC, the North Carolina Medical Society, and the Foundation for Nursing Excellence. The Task Force was charged with identifying and examining evidence-based, evidence-informed, and promising strategies for increasing patient and family engagement.

The Task Force was chaired by Kimly Blanton, a patient family advisor with Vidant Health; Melanie Bush, assistant director of policy and regulatory affairs with the Division of Medical Assistance in the North Carolina Department of Health and Human Services; and Dr. Warren Newton, director of the North Carolina Area Health Education Centers Program and professor and chair of the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine. The Task Force included 46 additional task force and steering committee members representing patients and family members, youth, caregivers, providers, insurers, health systems, community-based organizations, local health agencies, and several divisions within the North Carolina Department of Health and Human Services. The Task Force met monthly from February 2014 to January 2015 for a total of 12 meetings.

After reviewing best practices and evidence-based strategies for increasing patient and family engagement in direct care settings, hospitals, health systems, the community, and through policy, the Task Force developed and refined a set of 17 recommendations that will catalyze patient and family engagement and improve health and health care systems in North Carolina.

Patient and Family Preparation

At all levels of engagement, patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care. To engage patients and families, it is necessary to provide them with the skills, knowledge, and confidence to be effective partners in their care.

Recommendation 3.1: Educate and Train Patients and Families about Partnering and Engaging (PRIORITY RECOMMENDATION)

North Carolina Area Health Education Centers should lead a collaboration of state agencies, community organizations, faith-based organizations, and payers to identify and implement model curricula and tools for educating and training patients and family members about partnering and engaging with their health care providers.

Most of the time, patients and families are managing their health and wellness on their own. Peer support—which refers to linking a patient with another individual who has some level of training and knowledge from personal experience with a condition—coupled with education and training, can provide additional resources to strengthen the individual and family and better prepare them to engage more fully in their health care.[15,16]

Recommendation 3.2: Increase Availability of Peer Support

Organizations that provide care management services should encourage health care systems and payers to recognize the critical aspect of peer support, build peer support into their systems, and facilitate linkages to existing peer support groups, online networks and resources, and condition-specific support groups.

Clinician and Leadership Preparation

In order for the benefits of patient and family engagement strategies to be realized, health care providers and health care leadership must understand the key concepts of patient and family engagement, utilize engagement strategies, and understand how to support and encourage the cultural transformation that patient and family engagement requires. Providers and health care system administrators need to understand not only the concept and importance of patient and family engagement, but also how to effectively engage patients and families. However, few providers receive training on patient and family engagement.

Recommendation 4.1: Incorporate Patient and Family Engagement Techniques into Health Professional Training (PRIORITY RECOMMENDATION)

Health education programs, both pre-service and in-service, should educate health care providers on how to provide patient- and family-centered care and how to engage patients and families in their care. Patients and families should be included in designing and implementing these trainings.

Recommendation 4.2: Amend Health Professional Licensure and Certification Requirements to Include Patient and Family Engagement Skills as a Core Competency

Health professional licensing boards and associations should consider incorporating concepts and skills for patient- and family-centered care and patient and family engagement as a core competency that is included in initial licensure requirements, as well as maintenance of ongoing certification requirements.

Care and System Redesign

Redesigning system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the health care team is necessary to facilitate patient engagement. In order to redesign care and systems, it is important to implement communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns. Redesign may also include structuring care processes to support and value shared decision-making, involving patients and families in care planning and self-management, sharing information, and providing specific engagement opportunities.

Recommendation 5.1: Make Patient and Family Engagement a Goal of Health Care Systems

The North Carolina Hospital Association and all health care systems in North Carolina should encourage and support patient and family engagement at all levels of health care systems by making patient and family engagement one of the goals of their organizations, implementing evidence-based strategies to enhance patient and family engagement, and assessing the impact of patient and family engagement strategies.

Recommendation 5.2: Support Patient and Family Engagement through Health Care Organization Policies and Processes (PRIORITY RECOMMENDATION)

The North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina Community Health Center Association, and other partners should promote policies and processes that support and encourage patient and family engagement including welcoming and supporting patients and families and establishing policies and procedures that promote patient and family engagement in all aspects of their health care experience.

Family caregivers are an important member of a patient's health care team and should be recognized as such by health care providers. Almost half of family caregivers perform medical tasks such as wound care and operating complex medical equipment.[17] Many of these family caregivers are not trained in these tasks prior to the patient needing their support. These caregivers need training and skills to facilitate their engagement.

Recommendation 5.3: Recognize Caregivers as Members of the Health Care Team

Health care organizations should adopt policies that recognize the role of caregivers as members of the health care team including documenting family caregivers, acknowledging their role as part of the care team, and identifying caregiver support resources.

Organizational Partnership

When fully realized, patient and family engagement extends beyond the direct care experience and influences all aspects of health care organizations. There are many ways health care organizations can integrate patient and family perspectives and experiences into their governance structure and organizational decision-making. Creating opportunities throughout health care organizations for patients and family members to influence decisions can help ensure health care organizations are meeting the needs of the communities they serve.

Recommendation 6.1: Include Patients and Families on Health Care Organization Boards and Committees

Health care organizations should appoint a minimum of two patients (or family members) to boards and advisory committees within their organizations. To the extent possible and practical, patients (or family members) should represent the diversity of the community served by the health care system. Patients (or family members) should receive training and mentoring to help prepare them to be productive board and committee members.

Creating a patient and family advisory council (PFAC) is another strategy to ensure the needs and concerns of patients and families are heard and used to inform decision making. PFACs are teams of patients and families working with providers and staff to provide an opportunity to engage patient perspectives in the planning, implementation, and evaluation of health care services and programs.[18]

Recommendation 6.2: Engage Patients and Families in the Governance and Operation of Health Care Organizations (PRIORITY RECOMMENDATION)

Health care organizations should develop patient and family advisory councils (PFACs) to provide input into the governance and operation of health care at all levels. PFACs should represent the community that the agency or health care organization serves.

Measurement, Research, Transparency, and Accountability

Data can be used to inform patients and families about the success of efforts by health care providers to embrace patient and family engagement, and can drive consumer decision making. A key strategy to increasing patient and family engagement is for an organization to create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.[6]

Recommendation 7.1: Measure the Impact of Patient and Family Engagement

The North Carolina Hospital Association, in partnership with the North Carolina Medical Society and organizations that provide care management services, should work with patients and families to develop patient and family engagement measures, and collect and disseminate data in hospitals and ambulatory settings across the state.

Patient and family engagement in health care will ultimately require improved access to information. Some patients want information such as the cost of care, how often a doctor or hospital performs a certain type of procedure, or the complication rate. Such data is collected by both health care providers and payers (insurers) and may be available for the most common procedures, but may also be difficult to access, as well as not always easy to understand. As patients become responsible for more out of pocket costs, patients have shown more readiness to partner in their care, use available tools, and find ways to lower their costs.[19] While taking care to use principles of health literacy and shared decision-making, efforts should be made to provide patients with more information about costs of health care, which will help them select higher value care that better meets their needs.[20]

Recommendation 7.2: Encourage Health Care System Transparency (PRIORITY RECOMMENDATION)

All health care systems and providers should ensure information on services, cost, and quality is easily accessible to consumers in print and electronic formats.

Recommendation 7.3: Encourage Health Care Payer Transparency

Payers should provide, on their websites and in their written materials, information that is easily understood by consumers on covered providers and common procedures, including data on costs, quality, safety, and patient experiences.

Recommendation 7.4: Provide Health Care Cost Information to the Public

The North Carolina General Assembly should collaborate with the North Carolina Department of Insurance, health care systems, and insurers to create a statewide, mandatory data reporting system to enhance pricing transparency for medical care

and health care services. This collaborative effort should include input from additional stakeholders on database use and access. Participating stakeholders should include employers, health care providers, academic and industry researchers, and patient and family advocacy groups.

Transparency around quality and costs is one method to help consumers make more informed choices about their health care. Another potential method is collaborative documentation or charting. Collaborative charting refers to a spectrum of shared medical record keeping between the health care provider and the patient. Collaborative documentation is a promising technique for engaging patients and families in care.

Recommendation 7.5: Increase Collaborative Documentation

Health care organizations should examine opportunities to increase collaborative documentation aimed at increasing patient and family engagement. The North Carolina Quality Center and the North Carolina Hospital Association should continue to provide consultative support to health care organizations implementing collaborative documentation.

Legislation, Regulation, and Partnership in Public Policy

There is significant opportunity in health care to align legislation, regulation, and public policies with the principles of patient and family engagement, while improving health outcomes and quality of care. Payers of health care services wield enormous influence over available health care services based on reimbursement policies. There are many opportunities for health care payers, employers and other organizations to promote and support patient and family engagement through member education, reimbursement policies, and health care plan design.

Recommendation 8.1: Advance Patient and Family Engagement through Payer Policies (PRIORITY RECOMMENDATION)

Payers (insurers) should consider changes to health plans and policies that support patient and family engagement. Those changes may include creating new payment options, developing member advisory committees, and providing more accessible information to consumers.

Health care organizations are leaders in their communities, employ large numbers of people, and have a unique perspective on the importance of maintaining a healthy workforce, all of which make them well suited to implementing comprehensive worksite wellness programs. Worksite wellness programs are an evidence-based approach to engage employees in their health care.

Recommendation 8.2: Implement Comprehensive Worksite Wellness Programs that Include Patient and Family Engagement Support (PRIORITY RECOMMENDATION)

Health care organizations should, with employee input, develop and implement comprehensive worksite wellness programs that include employee engagement strategies. They should encourage other community employers to as well.

There is an opportunity for broader patient and family engagement at the policy making level. Just as health care organization policies benefit from the active involvement of patients and families, federal, state, and local health policies benefit from the involvement of patients and families in the policy making process. Including patient representatives in public decision-making can improve trust and confidence in the health system as a whole. In addition, inclusion of patient experiences in creating organizational and public policies may lead to higher-quality and more effective decisions.

Recommendation 8.3: Ensure Patient and Family Representation on Boards with Broad Policy Making Power (PRIORITY RECOMMENDATION)

Local boards of health, health professional and licensure boards, health insurance companies, mental health managed care organizations, and administrative units and entities in state government that execute state health-related policies should include, at a minimum, at least two trained patient and family representatives on their boards.

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