In addition to preparing patients, families, health care providers, and leadership to engage patients and families, our health care organizations must be designed to create environments where engagement is expected, welcomed, and facilitated.[1] Such environments provide concrete opportunities for patients and families to engage in their care; support and encourage the partnership between providers, patients, and families; and implement processes that allow patients' and families' voices to be heard. Creating such environments will require dedicated work on the part of health care providers and organizations. Necessary changes may include implementing communication mechanisms that help clinicians elicit and understand patient perspectives and concerns; structuring care processes to support and value patient and family engagement; and providing specific engagement opportunities. These changes in care and system design support patient and family engagement and the goals of better population health, better quality, and, potentially, reduced costs.[2]

Our health care organizations must be designed to create environments where engagement is expected, welcomed, and facilitated.

Culture change

An organization's culture is a combination of the organization's implicit and explicit goals and a shared set of values and beliefs that characterize how people work together to achieve these goals. Health care providers and systems have many potential goals (e.g. to improve the health of patients, to be a leading academic health center, to be the leading regional health care provider, to meet the health care needs of the community, to meet the needs of the patient) and values (e.g. excellence, safety, quality, respect, caring, teamwork).[3-8] Changing an organization's culture often requires revising existing mission, vision, and values statements. During this process of change, leadership must provide incentives and drive behaviors to align with the new mission, vision, and values.[1]

In studying several health care organizations known for improving patient engagement, researchers identified several facilitators and barriers to promoting a culture supportive of patient engagement. Facilitating factors included strong committed senior leadership, clear communication of strategic vision, active engagement of patients and families throughout the institution, sustained focus on staff satisfaction, active measurement and feedback reporting of patient experiences, and culture strongly supportive of change and learning.[9] Barriers identified included resistance to changing the culture from "provider focus" to "patient focus" and the length of time for transition or change.[9] Changing health care culture to encourage patient and family engagement at all levels is challenging and requires commitment from leadership, a strategic vision, planning, and participation of all stakeholders.[1]

Developing Processes to Support Patient and Family Engagement

Leadership is needed to drive culture change for the redesign of health care systems and care models. In addition to aligning mission, values, and vision statements to embrace patient and family engagement, the American Institutes for Research's *Roadmap for Patient and Family Engagement in Healthcare Practice and Research* outlines a number of tactics that leadership should consider as they work to focus their organizations on patient and family engagement. The first tactic is the implementation of communication mechanisms that help elicit, understand, and respect patient and family perspectives and concerns.[1] As discussed in Chapter 4, motivational interviewing and shared decision making are strategies that health care providers and system leaders can use to engage patients and families. Other tactics include creating universal advance directives, conducting advanced care planning with patients and families, and having a point person on staff with whom patients and families can contact with any concerns.[1]

Health care systems can incorporate strategies that welcome patients and families as active and participating members of the health care team.

Health care systems can also develop processes to involve patients and families in care planning and support them in self-care. With the right tools, health care providers can document patients' health goals in their medical records, help identify strategies for reaching those goals, and provide support for patients. This may require staff training and coaching, additional time during visits, new tools to measure implementation, and/or technology to support implementation.[10,11] In order to implement such methods, health care systems must develop processes to support and enable the use of these strategies across the health care continuum. Additionally, health care systems can incorporate strategies that welcome patients and families as active and participating members of the health care team through messaging in their facilities. A strategy that is easy to implement is using posters and other forms of media which invite patients to prepare for and engage in the health visit. For example, the Ask Me 3 strategy uses a visual cue to encourage a patient or caregiver in thinking about what he or she hopes to accomplish before the visit.[12]

Family engagement cannot occur if the family, as defined by the patient, is not welcomed as a partner in the patient's care. Currently, many hospitals across the state have restrictive visiting policies, especially in intensive care and other higher level inpatient units.[13] Often the reasons for such policies include concerns about confidentiality, infection control, patient safety, security, patient and family needs, and the impact on staff.[14] These reasons are based on tradition rather than science.[14] Research shows that isolating patients from the people who know them best during their most vulnerable times places them at risk for medical error, emotional harm, inconsistencies in care, and unnecessary care.[15,16] For example, family presence in adult critical care decreases anxiety, increases satisfaction for patients and families, and is not associated with increased infection rates.[17,18] Families are usually more aware of changes in cognitive function than hospital staff, and therefore are a valuable resource during hospitalization. Families should be respected as part of the care team—never viewed as visitors—in all types of health care encounters.[14] This means that families should be welcomed during outpatient visits, inpatient visits (including around-the-clock access), bedside change of shift, physician rounding, resuscitation, and other times at the discretion of the patient and family. Health care systems can facilitate family engagement through developing family presence policies that encourage families to take part in care visits and participate as active members of the health care team.[1] Additional tactics may include conducting bedside shift change reports with patients and families as part of the team and implementing patient- and family-centered discharge planning.[1]

One North Carolina Hospital System Has Embraced Family Engagement

Vidant Health System, based in Greenville, North Carolina is one of the Better Together campaign's exemplar hospital systems, profiled for its work in family engagement.[19] Although successful efforts to advance patient- and family-centered care began at the system's Children's Hospital and Regional Rehabilitation Center in the late 1990s, these efforts did not automatically advance throughout the health system. A defining moment with senior leadership occurred when a hospital employee and her family shared their experience of being treated as visitors and the adverse effects that experience had on them. From there, the leadership implemented new family friendly systems and processes. Leadership listened and engaged with staff. Workgroups with patients, families, and staff from every department mapped out steps needed to become a health care system that fully embraced patients' families.[19]

The Task Force reviewed strategies for health care system process redesign and recommended mechanisms and processes to support patient and family engagement. To fully engage patients and families, health care systems must implement processes to encourage and support patient and family engagement throughout the health care continuum. Therefore, the Task Force recommends:

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 their systems by:

a) Incorporating patient and family engagement as a leading goal of their organizations.

b) Implementing evidence-based strategies with fidelity, to enhance patient and family engagement at multiple levels within the organization.

c) Assessing how patient and family engagement strategies impact patient experience and outcomes, costs, and staff morale, using both qualitative and quantitative evidence.

d) Convening a stakeholder forum to share best practices among health systems.

e) Identifying a leader for patient and family engagement within their organization who can serve as a point of contact and a resource for patients, families, and the community.

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:

a) Welcoming and supporting patients and families as partners in care through communication and messaging. Patients and families should be involved in the design and implementation of patient engagement communications planning.

b) Examining and revising policies and procedures to promote patient and family engagement throughout the health care experience. Such policies and procedures may include those impacting access, coordination of care across multiple sites, organizational transitions, bedside rounding, family presence and visitation policies, shared decision making, care coordination, care transitions, and end of life planning.

c) The health care team should develop care plans based on patient and family goals, with patient and family input.

d) Fostering a work culture that supports increased empathy and improved listening and communication skills on the part health care providers.

Recognizing and Supporting Family Caregivers

In addition to ensuring that families are welcomed throughout a patient's health care experience, health care providers should recognize, acknowledge, and support family members who provide direct care support to patients. In 2012, there were approximately 65 million family caregivers in the United States providing care for family members across the lifespan.[20] Almost half of family caregivers perform medical tasks, such as wound care and operating complex medical equipment.[20] 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. Family caregivers are an important member of the patient's health care team, and, as such, should be recognized by health care providers.

Family caregivers have a unique relationship with the patient. To ensure the best care for patients, health care providers need to recognize and support this relationship. Many health care organizations and systems, however, are not designed to support the relationship with family caregivers. Family caregivers are typically welcomed at health care visits and some information about the patients' care and needs is often shared, however, this is not always the case. Health care systems should develop policies that specify families as important members of the health care team and ensure families are welcomed during patient visits.[1] The family caregiver may not have access to the patient's medical record, even when the patient would like that information shared. Some families have managed to gain access to medical records, through the Health Insurance Portability and Accountability Act (HIPPA), with appropriate legal paperwork (power of attorney). However, many families continue to need help in navigating access to medical records.

Health care providers should recognize, acknowledge, and support family members who provide direct care support to patients.

Several organizations nationally and in North Carolina provide training and support to family caregivers. AARP, the Red Cross, and many local organizations such as county cooperative extension offices and area health education centers offer trainings for individuals caring for older family members.[21] AARP and Area Agencies on Aging offer the Power Tools for Caregivers course at no cost. Power Tools for Caregivers is an evidence-based program of 2.5 hours sessions for 6 weeks that improves self-care behaviors, management of emotions, confidence in coping with caregiving demands, and utilization of community resources. It has shown a positive impact on caregiver health for a diverse group of caregivers, including those in rural areas, ethnic minorities, adult children of aging parents, spouses/partners, and caregivers at differing stages in their caregiving roles, living situations, financial status, and educational backgrounds. In addition, the North Carolina Division of Aging and Adult Services offers the Family Caregiver Support Program and many hospital systems in North Carolina also provide support groups for families of patients with various medical conditions.[22]

The Task Force acknowledged the value of family caregivers, and recommended strategies to facilitate their partnership with the health care team.

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:

a) The health care team should document the primary (family) caregiver, when applicable, in the medical record and ensure that designated family caregivers have access to the medical record in accordance with applicable (HIPPA) law.

b) The health care team should recognize the role of the caregiver and include them as a member of the health care team.

c) The health care team should treat patients with multiple chronic conditions and their family caregivers as a unit.

d) The health care team should encourage caregiver self-care, and provide assistance with identifying support resources and respite care.

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