Patient and Family-Centered Health Care

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Objectives

- Review basic concepts and reasons for the move to patient-centered care.
- Understand the difference between patient-centered care and patient satisfaction.
- Recognize elements that differentiate patient-centered from provider-centered care.
- Understand applications for behavioral health.
Outline

- Brief history
- Defining patient/family-centered care
- Recognizing and moving from provider-centered care to patient/family-centered care
- Existing examples of patient/family-centered care
- Bringing patient/family-centered care to Care Management
A Little History

[Image of book cover: Crossing the Quality Chasm]

INSTITUTE OF MEDICINE

CROSSING THE QUALITY CHASM
A New Health System for the 21st Century
History

- First modern mention of “patient-centered medicine” in 1970
- Research into elements that contribute to patient centeredness started in late 1980’s
- Institute of Medicine’s 2001 report, Crossing The Quality Chasm: A New Health System for the 21st Century, pushed it to prominence and listed patient-centered care as one of its 6 aims for reforming the U.S. health care system.
What is Patient/Family Centered Care?

- Institute of Medicine definition: “providing care that is respectful of and representative to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions”
- American College of Physicians: “providing the care that the patient needs in a manner that the patient desires at the time the patient desires”
What is Patient/Family Centered Care?

- Donald Berwick, MD: “The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”

- “Nothing About Me Without Me”
Elements of Patient/Family Centered Care?

- Picker Institute/Harvard Medical School

8 Dimensions of Patient-Centered Care

- Patients’ Preferences
- Emotional Support
- Physical Comfort
- Information & Education
- Continuity & Transition
- Coordination of Care
- Access to Care
- Family & Friends
Elements of Patient/Family-Centered Care

- Health care through the eyes of the patient
- Patient/family are the 'drivers’ of team based health care
- Increased health literacy: becoming more informed by having health care explained in an understandable way and having access to health information
  - Includes “Health 2.0”: use of social software to improve collaboration between patients, providers and other health care stakeholders
Patient and Family involved in all treatment planning and decisions

- Includes access to comparative data about providers, tests and treatments that allows for more informed decision making.
- Comparative Effectiveness Research for providers also translated into patient decision supports
Elements of Patient/Family Centered Care

- Access to quality care (the right care) that is timely (the right time) and delivered in a safe, clean, hospitable setting of the patient’s preference whenever possible (the right way).
- Respect for patient preference for involving family, friends, other supports and for culturally competent care.
- Patient involvement also extends to health care education, reform and process improvement.
Why Patient/Family-Centered Care?

- **Improved outcomes**
  - Improved health outcomes, shorter lengths of hospital stay, improved patient experience, reduced anxiety/stress
  - Recent study in Annals of Internal Medicine of patients given electronic access to their whole medical record for 1 year, found high percent felt more in control of their health care and also more adherent with medication and follow-up

- **Centers for Medicare and Medicaid insist**
  - One of the measures in Hospital Compare that will be linked to reimbursement

- **People are ready.**
  - Consumer access to information through digital technology has made each generation more consumer savvy. No reason why anyone should have more information available to choose an automobile than their health care.
Patient satisfaction, the health care equivalent of the marketing concept, is a measure of how well the services or products meet or exceed customer (patient) expectations.

- expectations met – satisfied
- expectations exceeded – high satisfaction
- expectations not met – low satisfaction

Hospitals and providers have started measuring and setting goals increasing patient satisfaction, mostly by improving comfort, appearance, customer service, timeliness, etc.
Patient Satisfaction

- Patient satisfaction has not been found to correlate with health outcomes.
  - Patients can be highly satisfied and at the same time have worse health outcomes. In the MTA community study of ADHD treatment, parents were more satisfied with therapy than medication, but medication was far more effective.
Patient satisfaction in health care differs from other markets for two main reasons:

- **Cost** is usually not included in the calculation of satisfaction by the patient because of third party payment. In the non-health care arena, a consumer would be more satisfied with a service that exceeds expectation the less it costs and expect more with rising cost leading to lower satisfaction with same result at a higher cost. Example: getting drugs in Canada or dental care in Mexico, same quality but lower cost = more patient satisfaction

- **Health outcomes and health measures have different value and meaning to patients compared to providers.** e.g. provider very satisfied with a reduction of hemoglobin A1C, patient may not recognize the value of this and be less satisfied that their diet is more restricted and they have to take more medication
Patient satisfaction is only one aspect of patient/family centered care, with good clinical outcomes, functional outcomes and patient safety being equally important goals. Giving patients everything they want to increase satisfaction may at times be contrary to outcomes and safety.

– Improving patient satisfaction by ordering more tests, more expensive medications or treatments that results in no better or worse outcomes and more risk to safety is not consistent with good patient/family centered care.
On the other hand, patient satisfaction can be aligned with patient/family-centered care by forming a true health care team that recognizes the needs and wants of patients first. The value and appreciation of health care outcomes such as a low HB1C (or PHQ9) can be equal among patients and professionals.
Where We Have Been: Provider-Centered Care
Patients are passive recipients of health care: decisions are made by providers, passed on to patients as recommendations or prescriptions

Health care is delivered at times and in places convenient to providers

Health information is guarded, unintelligible and geared to providers

Goals and outcomes of care are set by providers

Costs are mysterious, controlled by payers and providers.
Common Examples of Provider-Centered Hospital Care

- Hospital has pre-set orders for lab tests, imaging studies, or consultations done for every admission.
- Surgery scheduled for the convenience of the surgeon instead of normal queuing model to reduce waiting time.
- Visiting hours and restrictions on family and friends
- Doctors and nurses round on the patient outside of the patient’s room and make entries in a medical record that is not shared with the patient
Common Examples of Provider-Centered Mental Health Care

- Psychiatric hospital sets up family therapy only during weekday 9-5 hours when the therapist is working.
- Physician visits on the weekend by a ‘covering doctor’ who is not part of the regular treatment team and generally makes no treatment decisions.
- Medication started using samples of the latest detailed brand name medication that will not be on the formulary or have the highest co-pay.
Common Examples of Provider-Centered Substance Abuse Treatment

- Fixed length stay programs (28-day, 90-day)
- Relapse while attending program results in discharge or request for a higher level of care
- Rigid policies regarding medication, e.g. no Suboxone
- Patient placement evaluation done after admission to the program
Moving From Provider-Centered to Patient/Family Centered Care
Moving From Provider-Centered to Patient/Family Centered Care

- Adopting new models of care: Accountable Care Organizations, Patient-Centered Medical Home, team-based care.
- Acceptance and advocacy by Medical Leadership: American College of Physicians, American Academy of Family Physicians, etc.
- Research support from Institute of Medicine (IOM), Institute for Healthcare Improvement (IHI), Agency for Healthcare Research and Quality (AHRQ) and the newly created Patient Centered Outcomes Research Institute (PCORI)
Existing Models

- Patient-Centered Medical Home
- Recovery-based treatment for persons with chronic mental illness
- Planetree hospital units
- Child and Family Teams in wraparound care
The concept of a Medical Home materialized in the mid 2000’s, and in 2007, four primary care organizations jointly issued the “Principles of the Patient-Centered Medical Home” which included team-based care.

The NCQA issued standards for Medical Homes, updated in 2011, which include requirements for patient self management, access and communications.
Team Based Care Includes Patients/Families

- Patients and families are partners in shared decision making with health care providers.
- Differences in opinion between health care providers (different specialists, primary vs. specialist) are shared with the patient.
- The values, preferences and needs of the patient take precedence over those of the provider or health care organization.
Health care providers, especially physicians, rarely have experience with working in teams and receive little to no training.

Health care providers have been trained and acculturated to being the drivers of health care decision making.

Teams and shared decision making take more time and effort; providers may regard this as a needless delay.
Provider led organizations that are accountable for the full spectrum of care and ultimately assume full risk. One of the primary models being promoted for reducing health care costs.

Success depends on collaboration between primary care, specialists, hospitals, labs, pharmacies and other ancillary health and this heavily depends on ability to collect data through technology.

The Patient-Centered Medical Home is the building block for patient contact with the ACO.
Challenges for Integrated Systems

- Prevention and population-based care (immunization vaccines, screening, etc.) fall outside of an immediate patient/family-centered health care model and still need to be implemented and monitored by the larger health care system.

- Privacy preferences of the patient/family may conflict with data sharing, team based health and integration.
Recovery-Oriented Mental Health Care

- Developed in response to the low levels of engagement and improvement of persons with chronic serious mental illnesses in the traditional practice setting.
- Focus shift from symptom reduction to increasing hope, independence, self reliance and collaboration, recognition of patient strengths and preferences.
- Adopted as policy in the 2003 President’s New Freedom Commission on Mental Health
Recovery-Oriented Mental Health Care

- (Definition adapted from CT-DMHAS)
- Focus shift from services and programs to people
- Progress is measured based on outcomes rather than performance
- Emphasis on strengths rather than deficits and dysfunction
- Foster collaboration to replace coercion
- Promote autonomy and decrease reliance on professionals
Planetree

- Introduced at Griffin Hospital, Derby, CT in 1992, now in hospitals worldwide.
- Medical hospital unit modified to include more patient-centered features and amenities
- Planetree Inc. is now a consumer healthcare organization with a mission of humanizing health care
- Open medical record – patient and family access to the record 24 hours a day, documentation for patient as well as provider.
- Patient and family education resources easily at hand and encouraged.
- Flexibility and patient choice in diet and meals.
- Architectural and design away from institutional toward home-like environment.
- Arts, music and entertainment integrated into the environment.
- Patient’s spiritual needs also addressed and integrated into the unit.
Planetree-Influenced NICU, Danbury Hospital
John VanDenBerg, PhD. created the wraparound treatment concept for the Alaska Youth Initiative in 1986 and has helped other places around the country implement the process.

Wraparound is a process for developing individualized treatment for persons with complex needs that is family-centered; it is not a service or treatment but a vehicle for matching the family’s needs and strengths with appropriate services and supports. The family is the driver.
Child and Family Teams are the cornerstone of wraparound: the child and parent/caregiver are paired with a clinical leader and other team members of their choosing. The team must be at least 50% non-professionals.

After a determination of the child and family’s needs and strengths, services and resources are accessed and developed by the team. The plan is needs based rather than the traditional services based plan.

- Services are matched to needs instead of matching patients to available services.
Child and Family Teams

- All decisions at every level include the family.
- The clinical leader also helps the parent or another non-clinician team member gradually assume leadership of the team by helping them develop the skills needed to maintain the process.
- Outcomes are measured along the way. Data drives the plan.
Other Challenges to Becoming Patient/Family Centered

- Health care quality improves with more integration, yet patient-centeredness depends on patients having more choices, which can conflict with attempts to integrate.

- Evidence-based practices need to include evidence for patient centeredness in addition to straight health outcomes.
Other Challenges to Becoming Patient/Family Centered

- Free market health care means that services and providers of lesser quality can compete for patient preference through effective marketing. Health 2.0 also means that unreliable sources of information compete with reliable ones.
Patient/Family Centered Care Management
Patient/Family-Centered Care Management

- Use elements of Motivational Interviewing – start with where the patient/member is and work with them from there.
- Case management skills and processes and outreach employed *before* the usual triggers for case management.
- Questions for providers:
  - What does the member want and need?
  - Has there been a care conference involving the member and family?
  - Are you directing the member toward peer supports?
- In contacts with members, ask if they understand what services they are getting, why they are getting them, and if the services meet their needs.
Always consider the question: Is the care the member is getting provider-centered or patient/family-centered?

Try putting yourself in the shoes of the member and viewing through their eyes.
  – Something you consider stressful or undesirable may not be considered so by the member, and vice versa.

Most health care customs and traditions are the result of provider-centered bias – always question and challenge when appropriate.
Questions and Comments?