Patient Centered Care Movement: Best Practice Models for Stroke Programs

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Objectives

• Review the forces influencing the patient-centered care movement
• Analyze new patient-centered models of healthcare and their implications for stroke programs
• Discuss the future of stroke care through the lens of patient-centered care
“The best interest of the patient is the only interest”

- Dr. William Mayo

“Nothing about me without me”

- Diane Plamping

“Every Patient is the only Patient”

- Arthur Berducci
The Claim: Power Struggle

- Healthcare is more physician and nurse-centered than patient centered (Topol, 2015)
- Patients are not in control of their healthcare (Topol, 2015)
- Patients/families and clinicians often have different goals
  - Interviews of adult hospitalized patients, nurses and physicians: poor to slight concordance regarding goals of care (Figeroa et al., 2016)
The Knee and the Pneumonia: Our Healthcare Year
• History:
  – Active and healthy guy, persistent and debilitating knee pain results in orthopedic visit
  – Dx: likely meniscus tear, hope to avoid surgery, effusion aspirated and steroids injected
  – Plan: MRI of knee, follow up in 2 weeks
  – Follow up visit scheduled
• Follow up visit post MRI
  – Surgery indicated
  – “Simple”, “on your feet in no time”
  – Surgical center is the preferred place for surgery
  – See your PCP to get an H/P, fax it to the surgical center
  – See you at 530am the morning of surgery
From the patient & family perspective

- Significant miscommunication regarding H&P
- Spouse not allowed in room during intake and initial discussions
- Poor communication between team

- Post op course
  - Fundamental misunderstanding of post-op course
  - Significant pain x 1.5 weeks
  - Post-op nurse call 4 days after surgery useless
  - Billed $10,000 out of pocket when we expected $2,000
• Quality outcomes?
  – Meniscus tear removed cleanly, full recovery expected
  – No surgical infection
  – Post-op quality of life more/less
  – Room turned around in timely fashion
• Patient centered?
  – Family not incorporated in care plan
  – Short and long-term post-operative expectations poorly communicated
  – Pain control plan insufficient and poorly addressed
  – Post-procedure nursing phone call poorly timed and useless
  – Poor patient satisfaction scores
  – Established mistrust; “I don’t ever want to get sick again”
• 2am wake up call:
  – Productive cough
    • Brown phlegm
  – Respiratory distress,
  – Respiratory rate 35-40 bpm
  – Out of the crate, into bed
  – Overnight call to the vet
• Urgent vet visit arranged
  – Morning appointment arranged
  – Taken immediately to room due to infectious risk, never separated
  – Entire exam and discussion on the floor with dog in my lap
  – 60 minute visit
To CXR or not to CXR

- $200 investment
- Decide between single coverage and double coverage antibiotics
- Particularly in a puppy
- Establish a baseline in case of hospitalization
The Care Plan

• Single antibiotic with plan to escalate by day 2 if improvement isn't significant
• Puppy Robitussin DM
• Puppy codeine cough syrup
• Puppy probiotics to prevent diarrhea
• Puppy is to sleep near us for monitoring
• BID steam showers with chest percussion
• Phone call day 1 and 2, follow up visit at 10 days
Outcome

• High quality?
  – Pneumonia resolved without complication or hospitalization
  – Antibiotic without side effects

• Patient Centered?
  – Family fully incorporated and involved
  – Care plan enacted as agreed upon
  – Patient loyalty and trust
  – High consumer scores
    • Yelp review
THE PATIENT CENTERED CARE MOVEMENT
• Concept introduced by Picker and Commonwealth Program on Patient Centered Care in 1987

• 6 Dimensions
  – Respect for patient’s values, preferences & expressed needs
  – Coordination and integration of care
  – Information, communication & education
  – Physical comfort
  – Emotional Support
  – Involvement of family & friends

Millenson, 2015, Urban Institute Health Policy Center
PCC: The Concept Evolves

• PCC evolves to Patient and Family Centered Care
  – Dignity and respect of patients & families
  – Patient care plans reflect knowledge, values, beliefs & cultural backgrounds
  – Information sharing is complete & unbiased
  – Participation is encouraged at whatever level the patient and/or family choose
  – Patients and families invited to collaborate with hospital on initiatives, programs and policy

Plane Tree Guide to PFCC
How Did We Get Here in the First Place?

• Paternalism in medicine (and nursing)
  – Hippocrates father of medicine, and father of paternalism
    • “physicians should conceal most things from the patient”
    • “the gods are the real physicians”
  – Plato
    • Acceptable for physicians to lie for “good and noble purposes”
  – Following centuries
    • Patients must honor doctors, and pledge obedience

Epstein & Street, 2011
• As centuries pass, less overt, but persistent
• Nursing line between advocacy and paternalism is thinner than we like to believe (Zomorodi & Foley, 2009)
• Who has the power?
  – Physicians, nurses, hospitals and clinics have/own
    • Data
    • Knowledge
    • Treatment information
    • Treatments
  – “Doctor’s orders”
  – “Patient”
• A history of patient and family marginalization
• Distrust of the system, particularly by minorities
  – Nazi medical experiments
  – Tuskegee syphilis study
  – The Immortal Life of Henrietta Lacks
• Evidence shows:
  – Patients with in-depth knowledge of their disease are poorly received by their provider
  
  Topol, 2015
Fundamental shift of power and control (Berwick)

- The healthcare system often exerts power over reason, respect and even logic in order to serve its own needs, not the patient’s
- Violence lies in the forced separation of an adult loved one from a loved companion
- Patients are not hosted by the healthcare system. The healthcare system is a guest in their lives
- As patients gain more knowledge and control over their healthcare, the power shifts in the system

Berwick, 2009, Topol, 2015
Contributing Factors: The Knowledge Revolution

- The cell phone: the second major revolution
  - Industrial revolution
- Fundamentally reorganizing the patient’s relationship with the healthcare system
- Social networks
- Access to knowledge
- Does your Facebook or Instagram page say more about you than your electronic health record?

Topol, 2015
## The Knowledge Revolution

### Table: Attributes and Their Impact

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Gutenberg’s Press</th>
<th>Smartphone</th>
<th>Topol, 2015</th>
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</thead>
<tbody>
<tr>
<td>Explosion of knowledge</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Spur innovation</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Promote individualism</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Promote revolution, wars</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Basis of social networks</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Reduce interpersonal interaction</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Spread ideas, creativity</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Promote do-it-yourself</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Flatten the earth</td>
<td>✓</td>
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<tr>
<td>Marked reduction in cost</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Archive</td>
<td>✓</td>
<td>✓</td>
<td></td>
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<tr>
<td>Relieve boredom</td>
<td>✓</td>
<td>✓</td>
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Cell phones can now be used to:

- Run an ECG
- Analyze breath for variety of chemical compounds
- Track lung function (FEV)
- Analyze vocal quality to detect early changes of Parkinson's, Schizophrenia
- Point of care labs
- Monitor medication compliance through computer chip embedded in medication coating
- Facilitate physician and nursing visits
2001 Crossing the Quality Chasm

Healthcare must be:

- Safe
- Effective
- Patient (Controlled) Centered
- Efficient
- Equitable

Berwick, 2009, Topol, 2015
Aligning Incentives

• The outcome of a system of care is reflective of its values and engineering

• Financial incentives not historically aligned with PFCC initiatives
PFCC in The Affordable Care Act

- Appears 40 times
- Development of Accountable Care Organizations (ACOs)
  - Key component includes how patients and families are engaged
  - 7 measures and 25% of quality measures directly relate to PFCC
- Included a call to develop a national strategy with an aim to ensure PFCC and engagement

Millenson, 2015, Urban Institute Health Policy Center
Alignment with Public Policy

• Meaningful use provision of the HITCH Act
  – Adoption of electronic health record
  – 3 phases
    • Phase 3: patient engagement is cornerstone
    • Electronic communication with patients highly valued
    • Must report progress in 2017 or suffer payment penalty in 2018
• Medicare Access and CHIP Reauthorization (MACRA)
  – Pay for performance measures
  – Includes patient-reported outcomes and satisfaction measures

• Patient-centered Outcomes Research Institute
  – Initiative approved in the ACA
  – Research priorities central to the patient
  – Patient involvement in research agenda development critical to funding
Intersection with Patient Satisfaction

• Overlap but not the same
• Consumer Assessment of Healthcare Providers and Systems (CAHPS) launched in early 1990s – Hospital HCAHPS followed
• Patient Activation Measure (PAM)
• Health Confidence Measure
• Patient Reported Outcome Measures (PROM)
PFCC – The System Evolves

Beacons of PFCC

• Pediatrics in all disciplines
  – Parent(s) and child as one family unit

• Obstetrics
  – Father outside the room evolved to father presence during birth to catching baby and cutting umbilical cord
PFCC BEST PRACTICES & APPLICATION TO STROKE PROGRAMS
PFCC Best Practices: System (Macro) Level

• Leader rounding on all patients on all shifts
• Fireside chats, breakfasts with senior leaders
  – Staff focused
  – Patient and family focused
• Patient & family focus groups, advisory councils
• Units and clinic design welcoming of visitors
• Patient involvement on hospital committees
• All team members regardless of role in the hospital considered a caregiver
Patient & Family Involvement in Healthcare System

• Patient/family representation:
  – On all hospital committees
    • Eg. Stroke, neuroscience service lines
  – Involvement in strategic planning initiatives
  – Program-based patient advisory councils
    • Eg. Stroke program, ALS program
    • Help to set program goals

• Selection is important
• Collecting real-time patient satisfaction and suggestion feedback during leadership rounding
  – Please tell us 1-2 things we did well today
  – Please tell us 1-2 things we could improve

• May be helpful for program-level evaluation of satisfaction without interfering with CHAPS or HCHAPS
Clinic & Unit Design

• Physical layout of hospital and clinic rooms often poses significant barriers to PFCC
  – If the nurse isn't comfortable, he/she tends to discourage family presence
  – Clinician-centered care prioritizes patient privacy and clinician safety and comfort
  – Growing evidence that hospital layout impacts length of stay
  – Design with PFCC in mind improves communication and collaboration

(Rippin, 2016)
Clinic & Unit Design, cont.

• Examples of design modifications to emphasize PFCC
  – Bigger rooms, wider berth around hospital bed
  – Private meeting spaces
  – Sleep quarters for family, often adjoined to hospital room
  – Comfortable seating

• Clinician challenges
  – Interruptions
  – Relinquishing private work space

(Rippin, 2016)
PFCC Best Practices: Unit or clinic (Meso) level

- Flexible times for hospital or outpatient procedures
- Open visitation on hospital units, invitation to family to participate in clinic visits
- Family presence on interdisciplinary rounds
- Family presence for nursing bedside handoff
- Family presence during resuscitation
- Structured documentation of patient and/or family meetings
Open Visitation: ICU & Beyond

- Movement away from restrictive policies
  - Neuroscience slower to adapt
- Clear evidence that open visitation policies associated with increased patient and family satisfaction, decreased anxiety, improved communication between caregivers & team
- Associated with lower length of stay, fewer medication errors & decreased return ED visits

South & Adair, 2014
• Open does not mean free-for-all, guidelines still apply
• Cue comes from the patient & family
• Nurse workflow challenges must be addressed
• Family exhaustion challenging
• Nurses perception of patient & family needs and reported needs differ

South & Adair, 2014, Hinkle et al., 2009
Structured Family Discussions

- Structured time
- Structured discussion
  - Physician and nursing training often needed
- Structured documentation
  - Thorough documentation is a crucial
  - May require templates, organized program of care
Family Presence During Resuscitation

- Family Facilitator (FF) Model:
  - Team informed family is present and ready for discussion
  - Family assessment
    - Exclusion for combativeness, agitation, extreme emotional instability, altered mental status, Intoxication
- FF prepares family for presence
  - Describe setting, circumstance
  - Explains ground-rules of presence
- FF announces family presence to team
  - Stays with patient
  - Provides comfort measures
  - Description of critical events
  - Allow family to touch patient when feasible
- After care including allowing family to process what they witnessed
- FF documents in the medical record

Weaver et al., 2012
• When patients & families are involved in in-hospital bedside rounds:
  – Report higher level of perceived compassion from the healthcare team (Ramirez et al., 2016, Cypress 2012)
  – Significantly improves patient & family satisfaction (Cypress, 2012)
  – Improves nurse satisfaction
  – Improves communication, perceived by both patients and clinicians
  – No significant difference in teaching on rounds
  – Trainees less satisfied
Family Presence on Rounds

- Setting expectations for both the team and families
  - “We are happy you are here, in the next few minutes we will be discussing XXX’s care and develop a plan of care for the day using medical language, much of which you will understand, some you may not”
  - ”While we want to answer all of your questions because this is very important to you and to us, we are on a schedule to see all of our patents this morning. We will have time for 1-2 questions at the end of our discussion. If we don’t answer all of your concerns, we will agree on a time later today to continue the discussion”
  - “Is this ok with you?”

Westley et al., 2014
• Setting expectations for both the team and families
  – “I would like to introduce you to oncoming nurse. He/she will be your nurse when I leave. We will be exchanging very important information about your care. We ask that you save your questions until after our hand-off report. If you hear anything that concerns you, please let us know”

Westley et al., 2014
• Full access to EHR and test results
• Medical record belongs
• Ability to edit and/or add comments to EHR notes by healthcare providers
• Food available 24 hours a day with the ability to schedule meals according to patient preference
• Support for self care including mutually agreed upon goals for care and modification of risk factors
• Improved coordination of care during transitions such as hospital discharge
• Who owns the information?
  – Organization based or patient based?
• What if we had to ask patient’s permission to access and document in their medical record?
• Should patients be allowed or even expected to document after each patient encounter
  – Edit for errors or misconceptions
  – Document their understanding of discussion and plan of care
• OpenNotes project (2012)
  – 100 primary care physicians, 22,000 patients
  – Unexpected results
    • Few physicians reported adverse impact on their workflow
    • Patient feedback on offensive or upsetting medical talk (e.g. SOB)
    • No increase in time required by physician providers
    • 99% of patient participants wanted access in the future
    • 90% of patients reported they would choose their provider based on open notes
    • 65% of patients improved their adherence to medication
    • 60% of patients felt they should be able to amend their notes

Topol 2015,
• Access to test results
• Study of 1546 patients viewing results online
  – No indication of worry, confusion, fear or anger
  – 98% of patients reported access to results was helpful

Topol 2015, The New Yorker

“It’s a simple stress test—I do your bloodwork, send it to the lab, and never get back to you with the results.”
What PFCC Is Not

• Presence of EHR alone
  – Unless EHR improves communication and documentation of communication between caregiver and patient or family

• Boutique Hotel Experience
  – Greeters, greenery and gadgetry is not alone PFCC

• Renaming of processes without addressing process deficits, eg. Clinic medical assistant now called flow master, patient now called client or partner

• Fundamental infrastructure & culture changes required

Epstein & Street, 2011; Howard et al., 2016
THE FUTURE OF PFCC IN STROKE PROGRAMS
Further Shift of Control & Information

Technology will continue to change our world:
Issues on the Horizon

• Transitions in Care
• Evidence of patient and family engagement
  – Care plan
  – Stroke program planning and evaluation
• Continued shift of power
  – Embrace and innovate or fight and frustrate?
• Education must adjust to teach skills and core competencies
• Understand and define appropriate boundaries in new environment
Conclusions

• Multiple forces are converging to change the nature of healthcare to be patient and family centered

• To be truly patient centered, our systems must adjust to compensate for the needs and values of our patients as they articulate them to be, not only as we perceive

• These forces are impacting stroke programs today and will continue to demand change in the future