Barriers to Care

Healthcare from the Patient's Point of View

copyright Linda Golley 2017

Concept of Barriers to Care

- You can look at healthcare from one of two points of view:
  - Business perspective: What product is sold, how many people are paid to provide the product, how many visits are completed, what goods are used up.

  OR
  - Essential service perspective: What is needed for people to be healthy, what are people actually getting in terms of health outcomes.

Essential Service Perspective

- How are we doing?
  - We know that our outcomes in the United States are not very good, particularly in light of how many dollars and percentage of GNP we collectively spend on healthcare.
  - We know that as individuals we run into barriers at every step of our attempt to get value from the healthcare system, be it in our interactions with our primary care setting, our hospital, or our insurance plan. It is hard work to get healthy.

Essential Service: Let's Fix the Problems One by One

- Healthcare is not one monolithic thing. It is lots of little chunks which patients encounter one by one as they seek medical care.
- We will look at each step of the patient journey.
- We will see where patients encounter barriers at each interface. Once we understand the concept of barriers, we can verbalize the patients' comments more clearly.

Who Can Eliminate the Barriers?

- Two groups of people, working together, can eliminate the barriers to care:
  - Patients and their families
  - Healthcare workers, which includes interpreters
- Support can push progress and prevent backsliding
  - Government programs paying for care, looking at outcomes
  - Regulatory bodies
  - Community organizations which recommend care providers.

Value of Conceptualizing Barriers

- Healthcare workers should be committed to improving health outcomes of patients, not just to doing their job function and going home.
- Committed to improving health outcomes for patients, it is essential to have an analytical tool which identifies what needs to be fixed and how these problems can be fixed.

Interfaces in the Healthcare System

- We will look at the healthcare system as a series of interfaces where the patient tries to achieve a specific goal. The patient has a “job” at each of these interfaces.
- For example, the patient is told to:
  - Call the doctor back later if his stomach still hurts
  - Get copies of his medical records from his previous providers
  - Take his 6 medications correctly
  - Fill out the 3-page intake questionnaire completely and accurately in 10 minutes

Patient Care Map in detail

- Refer to the Patient Care Map poster, which contains a pictorial representation of about 50 barriers commonly encountered by patients.

- The Patient Care Map is also available in Excel spreadsheet format, listing each barrier and the elements related to it.

Map: Each Interface Described

- The Barriers to Care Map identifies the following aspects of each goal or interface:
  - Patients most vulnerable to hitting barriers here
  - What barriers commonly crop up for patients trying to achieve this goal
  - What are the consequences to patients of hitting barriers at this interface
  - What can be done to prevent patients from hitting barriers at this interface, to eliminate the problem

Invitation and Challenge to Amplify the Inventory of Barriers and Bridges

- As we move through the list of patient interfaces on the Map, all are invited and encouraged to think about additional barriers, additional solutions, additional vulnerable patient groups.

Key

- The blue octagon is the patient goal or interface, what the patient tries to accomplish
- the red spiky blob is the set of barriers
- the orange triangle is the consequences of hitting the barriers
- the heart is the set of vulnerable patients
- the green bridge is a set of proposed fixes

Scope and Source of Map Items

- There are about 50 care interfaces listed on this poster of the Barriers to Care Map.
- These barriers have been reported to the author from thousands of patients in many care settings. Some barriers have been reported by non-English-speaking patients, but the majority of barriers are common to both native-born and immigrant patients.

Broad Categories of Patient Interfaces

- Access to new providers/ programs, access to own medical record
- Intake process, setting good foundation
- Communication with own care team
- Negotiating care that meets pt's needs
- Managing information about own condition
- Navigating the care system and coordination of care

Another Way of Slicing: Type of Interface

- Phone: get in touch or be reachable
- Reading/writing
- Go there
- Get that done
- Carry out self-care
- Build trust with team, feel comfortable with team, build partnership

Details

- Phone: reach who? accountability to pt?
- Read/write: literacy? eyesight? learning style? time?
- Go there: mobility? transportation? wayfinding? time?
- Get that done: system knowledge? assertiveness? persistence? time?
- Self-care: skills? knowledge? mental state? commitment to treatment plan?

Individual Interfaces

Initial Access to Services, Record

- Interfaces the patient must navigate:
  - Know the service exists, what it is
  - Contact service for first time
  - Negotiate realistic appt. time
  - Get an appt. rather than resort to ER care
  - Get copy of medical record from each POS
  - Find support group that fits logistics
  - Move referral forward when stalled
  - Be invited into research protocols

Getting Established

- Interfaces the patient must navigate
  - Successfully transition in on a referral
  - Be assigned to appropriate provider/ program
  - Come to first appt. prepared
  - Complete intake documents accurately
  - Set up financial records/Reg accurately: ID
  - Understand financial relationship, scope of coverage

Communicating with Own Care Team

- Interfaces the Patient must Navigate
  - Reach care team during working hours
  - Make appt or change appt from home/work
  - Receive lab results or instructions by phone
  - Reach care team after hours
  - Deal with automated reminder calls
  - NEW: Sign up for and use the patient portal to interact with care team on: appts, results, need for advice, Rx refills, referrals, medical records, patient education

Interacting with own care team, cont.

- As inpatient, be kept in the loop
- Speak with members of care team to get needs met: receptionist, biller, phlebotomist, etc.
- Make a complaint or get a problem addressed
- Understand messages left on answering machine by care team
- Understand medication directions and refill process and how to solve meds problems

Appropriate Care Plan, Dignity

- Interfaces the Patient must Navigate:
  - Receive treatment plan aligned with goals, prefs
  - Have privacy or family support as desired
  - Use mental health system safely, with dignity
  - Direct end-of-life decisions as desired
  - Make decisions about reproductive health
  - Understand expectation that patient participate in care
  - Understand medical decision-making process

Information about own Condition

- Interfaces the Patient must Navigate
  - Literacy: Receive info in usable form: oral, visual, written
  - Health literacy: Receive info that pt can understand and use
  - Understand self-care instructions
  - Understand instructions on how to prepare for procedures

Information about own condition, cont.

- Maintain logs to monitor own health: B/P, blood glucose, fertility, food allergy…
- Benefit from group classes: birth class, transplant class, parenting class, diabetic ed class
- Make informed consent for care decisions
- Understand and make decisions around genetic counseling
- Absorb detailed self-management teaching: ostomy care, insulin dosing, catheter care, etc.
- Understand letters, reports, instructions sent to pt's home

Navigating the system across multiple points of service

- Interfaces the Patient must Navigate
  - Use wayfinding materials successfully
  - Get into the queue successfully at lab or pharmacy
  - Follow instructions of care team to have labs or studies done
  - Follow instructions of care team to contact own insurance to verify coverage

Navigating, cont.

- Understand role of primary care versus specialty care with respect to benefit and cost
- Interact with agencies regarding care: birth registry, assistance programs, organ registry…
- Understand treatment facility options: hospice, SNF, mental health continuum, rehab continuum, detox continuum…

Summary

- Health care is full of barriers for patients.
- Care team members can work with patients to identify and fix the barriers common to each interface in the system.
- Interpreters can help by recognizing when a patient mentions a barrier and clearly articulating this to the care team.
- Interpreters can help by learning as much as possible about how health care systems function.

Contact Info

Slides and supporting materials from this presentation are available from:

- Linda Golley
  - lgolley@u.washington.edu

  University of Washington Medical Center
  - linda_golley@yahoo.com

  independent health activist