Delivering outstanding outcomes: Why PCC must be at the center of the strategy

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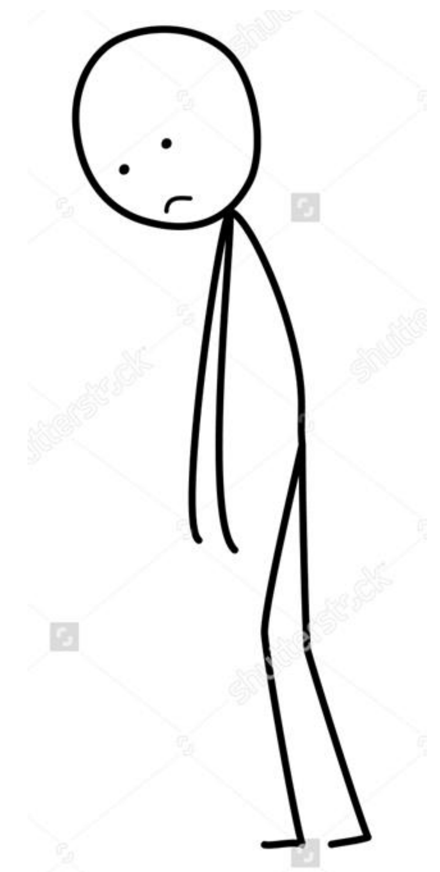
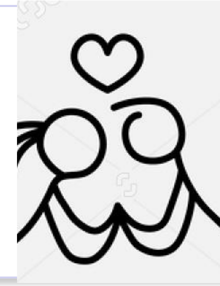
Herman and Eva – A true story

- Herman has COPD
- Admitted to hospital three times in past year after Eva called 911 because he could not breathe
- Loosing weight , chair- to- bed life
- Breathing is hard, getting to the restroom is hard, changing clothes is hard …Even eating is a chore now
- Eva stays with Herman often now to help him out. She has been skipping work often and fears she could lose her job.



Herman and Eva – A true story



- Eva loves Herman
- She hates that they often fight now
- She has heard how “awful” COPD can get and she is frustrated with Herman because he still smokes and won’t eat enough like the doctor advised him to
- She dreads the idea of him stopping breathing and constantly checks his breathing when he is asleep

Herman and Eva – A true story

- Eva and Herman participated in a self management support program
- They realized COPD is not a death sentence
- Herman learned to use his inhaler correctly
- Eva learned how she can help him manage his COPD
- Herman stopped smoking, completed acute pulmonary rehab and exercises daily now (uses oxygen when exercising)
- Life is much better now !

Unmet needs of patients with COPD

- Patients report needing information about their disease and how to manage it "at an intellectual, emotional, and social level".[1-4]
- More than half lack the skills for proper inhaler use.[5,6]
- Patients lack the skills for managing 'breathlessness episodes' and detecting signs of acute exacerbations.[7]

1. Jones R. Chron Respir Dis. 2007;4(4):189 2. Rodgers S, Dyas J, Molyneux AW, Ward MJ, Revill SM. Chron Respir Dis. 2007;4(4):195-203. 3. Lynch T, Brown T, Naqibuddin M, Chung S, Aboumatar H. Abstract presentation at ICCH. New Orleans. Oct 2015 4. Michael Stellefson, Bethany Tennant, and J. Don Chaney. Public Health Volume 2012, Article ID 152047 5. Press et al. JGIM 2012; 27(10):1317–25 6. Melani et al. Respiratory Medicine 2011;(105): 930-938
7. Kessler R, Stahl E, Vogelmeier C et al. Chest 2006; 130(1):133–142

MDI with Spacer

MDI

Diskus

Handihaler

Twisthaler

Autohaler

Aerolizer

Flexhaler

Neohaler

Respimat

Pressair

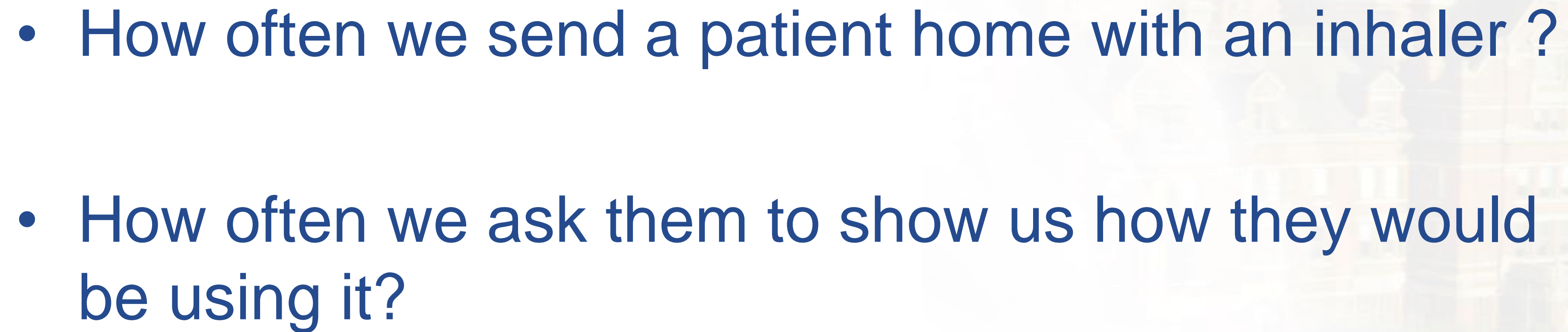
Turbuhaler

Ellipta

“ …I was doing it wrong, the disk breathing. You have to do it [take a breath] backward fast. I wasn't doing that. I was like, [takes a breath] like that and it made my tongue real sore around the edges and it was swelling up…

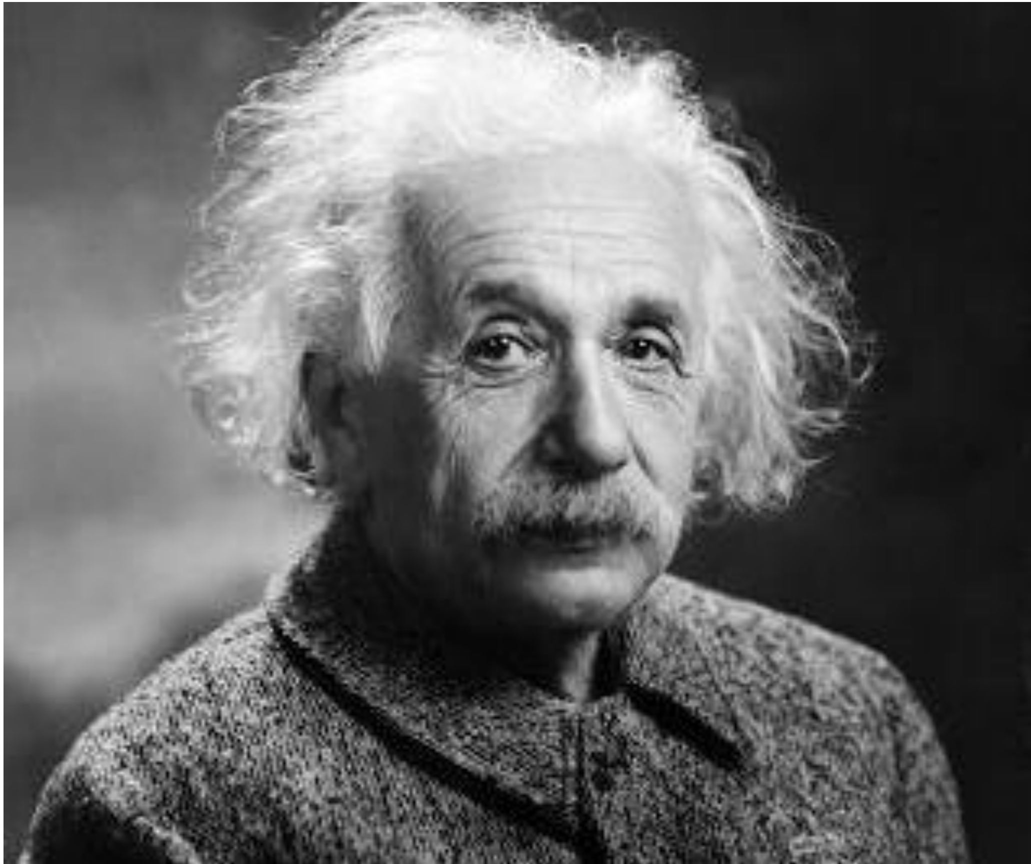
I got it now. I had a lady come up from the pharmacy and taught me how…and that was just recently. All this time I was like [takes a breath] and [medicine] laying on my tongue and I was rinsing my mouth. I was telling them about it the whole time, but then they actually come up and saw me do it and then they seen that… “

Ed, 66 yr old



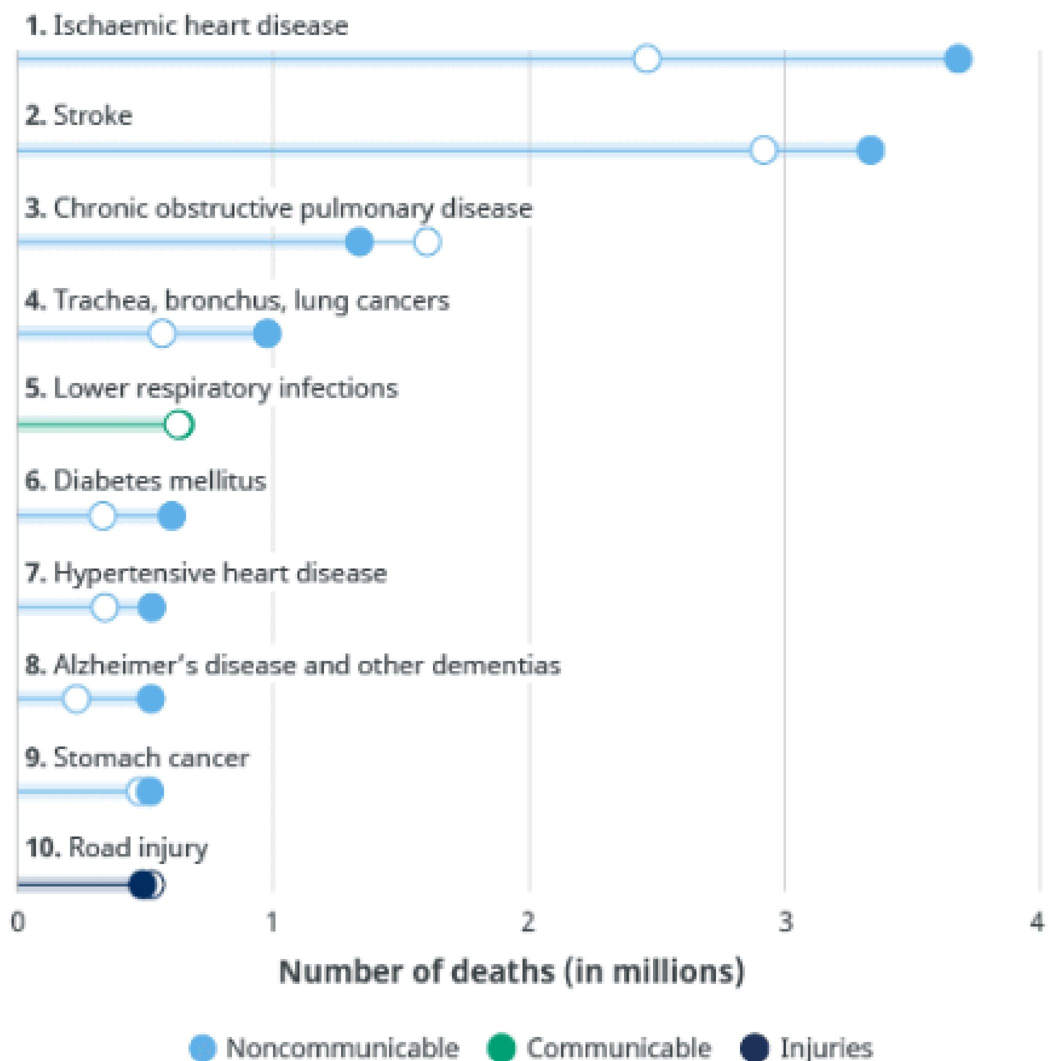
- How often we send a patient home with an inhaler ?
- How often we ask them to show us how they would be using it?

To improve outcomes we must do things differently



“ Insanity is doing the same thing over and over and expecting different results.”

Albert Einstein



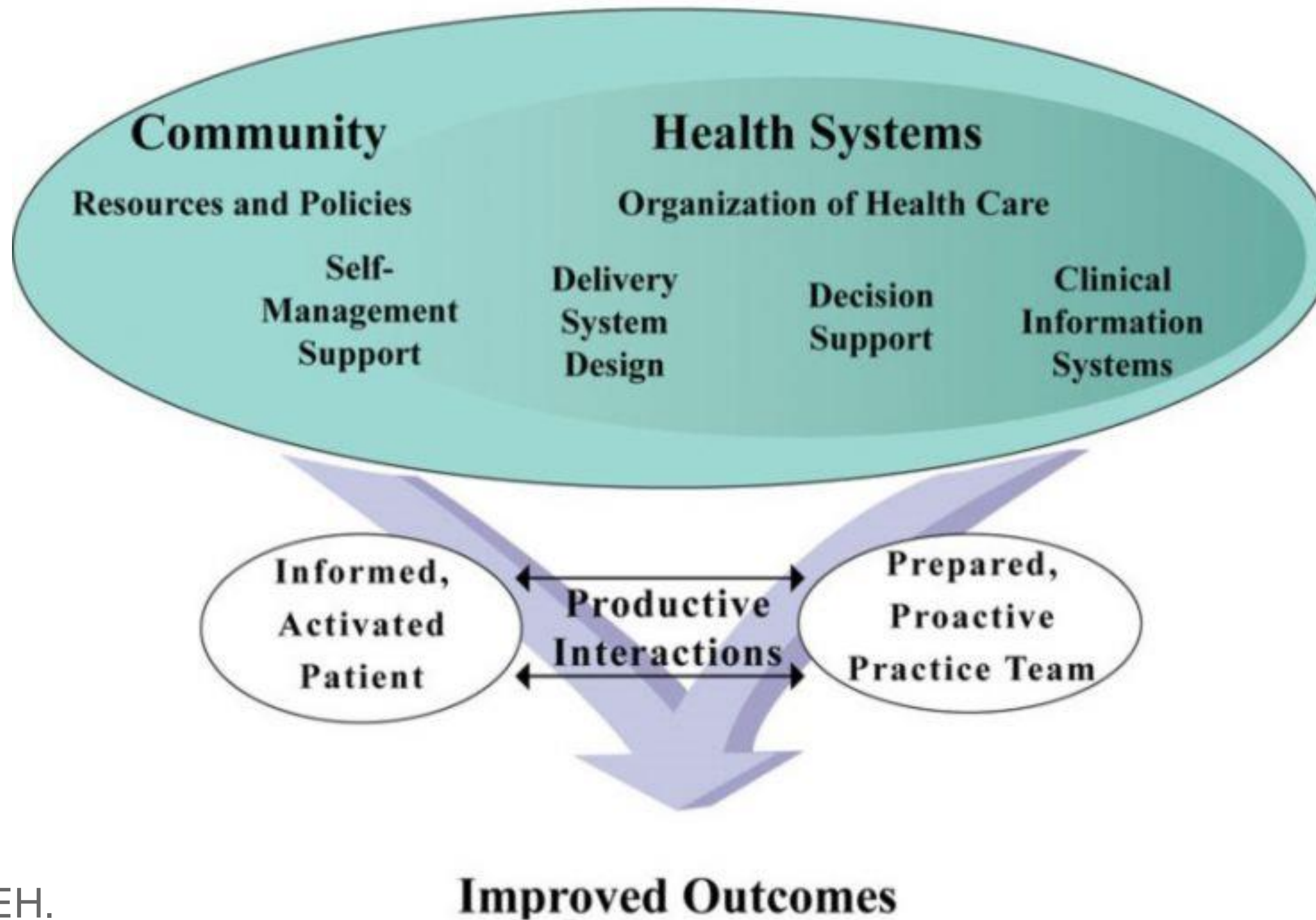
Leading causes of death in lower-middle-income countries

2000 2019

1. Ischaemic heart disease
2. Stroke
3. Neonatal conditions
4. Chronic obstructive pulmonary disease
5. Lower respiratory infections
6. Diarrhoeal diseases
7. Tuberculosis
8. Cirrhosis of the liver
9. Diabetes mellitus
10. Road injury

0 1 2 3 4

Number of deaths (in millions)



Source: Wagner EH. https://www.act-center.org/our-work/primary-care-transformation/chronic-illness-care/improving-chronic-illness-care

Patient-centered care (PCC)

- Early conceptualization in 1969 by Balint as "understanding the patient as a unique human being"
- The concept has evolved to become multidimensional and include what is needed for individual providers and health systems to become patient-centered. For example, partnership rather than a paternalistic approach , sharing information, coordinating care, etc.
- Lately, Scholl et al conducted a concept analysis of the various published PCC models

Principles
Essential characteristics of the clinician
Clinician-patient relationship
Patient as a unique person
Biopsychosocial perspective
Enablers
Clinician-patient communication
Integration of medical and non-medical care
Teamwork and teambuilding
Access to care
Coordination and continuity of care
Activities
Patient information
Patient involvement in care
Involvement of family and friends
Patient empowerment
Emotional support

Dimension	Brief description
Principles	
Essential characteristics of the clinician	Attitudes towards the patient (e.g. empathy, respect, honesty) and oneself (self-reflectiveness) as well as medical competency
Clinician-patient relationship	A partnership with the patient that is characterized by trust and caring
Patient as a unique person	Recognition of each patient's uniqueness (needs, preferences, values, beliefs, expectations)
Biopsychosocial perspective	Recognition of the patient as a whole person (biological, psychological, and social context)

Source: Scholl, 2014

Dimension	Brief description
Enablers	
Clinician-patient communication	verbal and nonverbal communication skills
Integration of medical and non-medical care	Integration of non-medical aspects of care (e.g. patient support services) into health care services
Teamwork and teambuilding	Recognition of the importance of effective teams characterized by a set of qualities (e.g. respect, trust, shared responsibilities, values, and visions) and facilitation of development of such teams
Access to care	Facilitation of timely access to healthcare that is tailored to the patient
Coordination and continuity of care	Facilitation of healthcare that is well coordinated and allows continuity

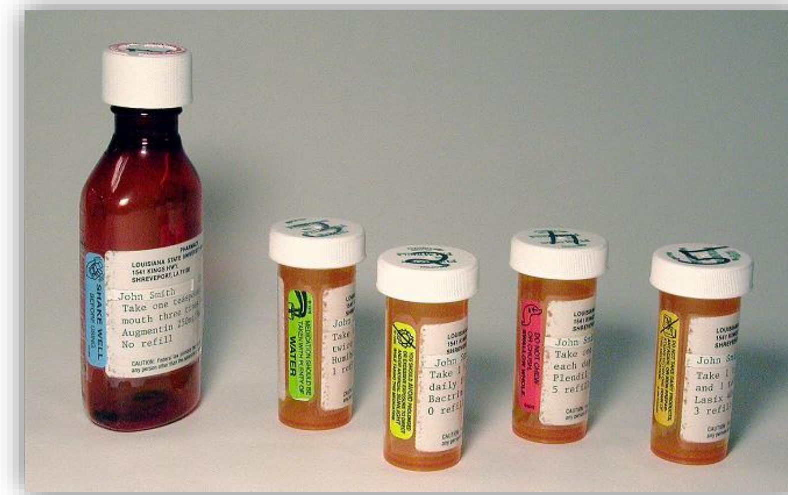
Dimension	Brief description
Activities	
Patient information	Tailored to patient's information needs and preferences
Patient involvement in care	Collaboration with the patient regarding health considering their preference for involvement
Involvement of family and friends	Active involvement and support for the family and friends to the degree that the patient prefers
Patient empowerment	Recognition and active support of the patient's ability and responsibility to self-manage
	Physical support for the patient (e.g. pain management, assistance with daily living needs)
Emotional support	Recognition of the patient's emotional state and a set of behavior that ensures emotional support for the patient

Source: Scholl, 2014

Communication about medications

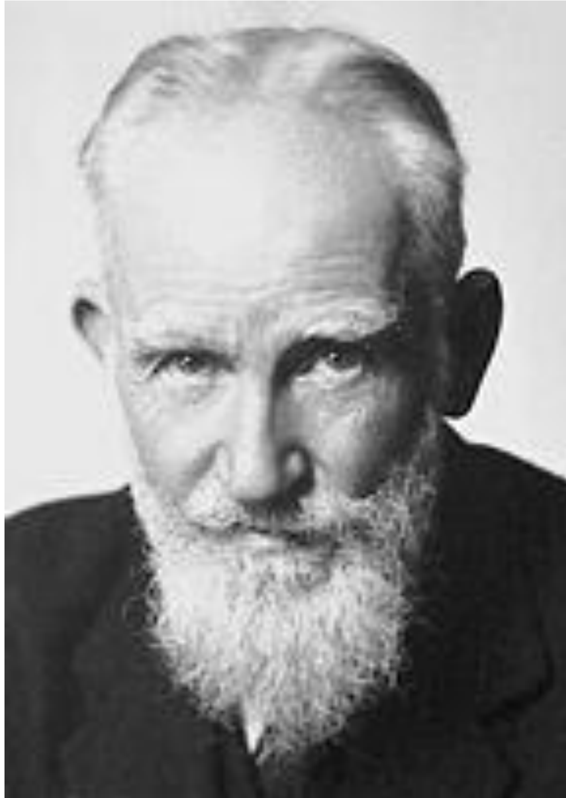
“How would you take this medicine?”

395 primary care patients in 3 states



- **46%** did not understand instructions ≥ 1 labels
- **38%** with adequate literacy missed at least 1 label

Davis TC , et al. Annals Int Med 2006



The single biggest problem in communication is the illusion that it has taken place.

George Bernard Shaw

Why focus on patient-centered communication ?

- Medical providers frequently use complex language.[1]

- Many patients have low health literacy and are embarrassed to ask any questions.[2] More than half of US adults experience difficulties in understanding medical information.
- Improved patient-provider communication is associated with improved medication adherence, satisfaction, and health care outcomes.[3-5]

1. Castro, 2007 ; 2. IOM : A Prescription to End Confusion. 2004; 3. Improving medical education, 2004; Rao et al, 2007; Cegala et al, 2002

The American Medical Association's 6 steps for communication

1. Slow down, slow down, slow down
2. Create a shame-free environment, encouraging questions
3. Limit the amount of information provided (keep it action-oriented- ”this is what you need to do”)
4. Use plain, nonmedical language
5. Show or draw pictures
6. Use the teach-back method or show-me technique

Weiss, B.D., 2007.

Teach-back

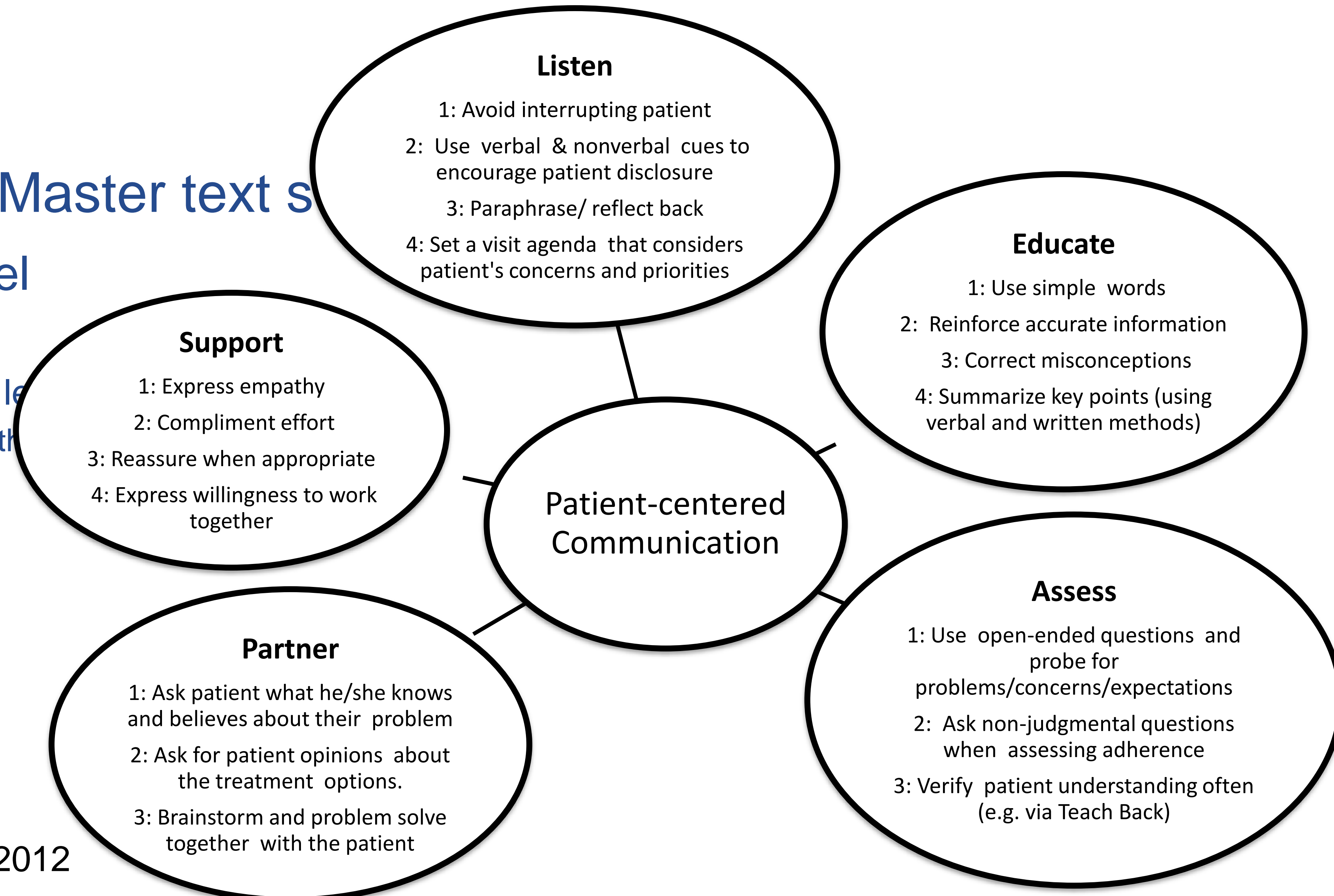
Schillinger, et al. 2003.

Teach back practice

- One approach to encourage patients to state what they understood without feeling embarrassed if they did not get it
- “ We have covered a lot of information. I would like to make sure that I have explained things clearly. Could you tell me how you're going to take the new medicine?”

LEAPS Communication Framework

- Click to edit Master text s
  - Second level
    - Third level
      - Fourth le
        - Fifth



Roter et al. Patient Educ Couns. 2012

You can learn specific patient centered communication skills for interviewing and partnering with patients, assess your own skills, or view brief (2-3 sec) demos at Time toTalk Cardio :

[Time to Talk Cardio Network]

Communication Pointers

JOHNS HOPKINS MEDICINE

- **Use simple terms.** Avoid medical jargon
- **Ask open-ended questions** eliciting the patient's knowledge of their medical condition, their opinions about treatment options, and any concerns they have.
- **Deliver information in 'chunks' and focus on key messages**
- **Use Teach Back often to verify patient understanding.**

- **Avoid questions like "Do you understand? "or "do you have any questions".** Most patients would reply "No" to both. Instead say : "What questions do you have for me?".

Medical Jargon vs. Plain Language

JOHNS HOPKINS MEDICINE

Medical term	Translation into plain language
Analgesic	Pain killer
Anti-inflammatory	Lessens swelling and irritation
Benign	Not cancer
Carcinoma	Cancer
Cardiac problem	Heart problem
Cellulitis	Skin infection
Contraception	Birth control
Enlarge	Get bigger
Heart failure	Heart isn't pumping well
Hypertension	High blood pressure
Oral	By Mouth
Toxic	Poisonous

Self-management support for chronic conditions (1)

JOHNS HOPKINS MEDICINE

- Mostly tested within multi-component interventions
- Interventions included

  - education on condition and treatment options

  - helping patients with goal-setting/ monitoring/symptom management

  - using reminders and alerts, remote monitoring, and decision support to facilitate patient-provider communication and adherence

  - providing psychosocial support including health care navigation assistance, connection to social services and peers, counseling and cognitive behavioral therapy.

Self-management support for chronic conditions (2)

JOHNS HOPKINS MEDICINE

- Positive effects on adherence to medication or self-management tasks, chronic disease control measures (e.g glycemic control), quality of life, patient satisfaction, and health care utilization.[1]
- Community-based health worker interventions among low-income, underserved, and minority patients were cost-effectives in self-management of hypertension, diabetes, and other conditions. [1,2]

1. Aboumatar H et al. Patient engagement strategies for adults with chronic conditions: an evidence map. Syst Rev. 2022 Mar 5;11(1):39 2. Kim K et al. Effects of community-based health worker interventions to improve chronic disease management and care among vulnerable populations: a systematic review. *Am J Public Health.* 2016;**106**(4):e3–e28)

Patients leaving the hospital are at high risk

- 20% of patients discharged home have an adverse event within 3 weeks
  - 66% were drug-related adverse events
- 12% of patients have a preventable or ameliorable adverse event immediately following discharge
- Of 2644 patients, 40% had pending test results at discharge
  - 10% of these required some action
- Drug discrepancies result in more readmissions

Beck D, Budnitz T, et al. Transitions of Care Consensus Policy Statement: American College Of Physicians, Society of General Internal Medicine, Society of Hospital Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society for Academic Emergency Medicine. *J Hosp Med.* May 28 2009.

Patient-centered transitions of care
Hospital discharge

Includes two major components:

1. Transition of care to outpatient physicians

2. Preparation of patient and family for self management

Discharge Education & Counseling Key points

- Understanding Health Condition
- Warning Signs and Symptoms
- Purpose for each Medication
- How to take Medications
- Medication Side Effects
- Pending tests and follow up appointments
- Confirm Understanding
- Allow for Questions

Improving transitions from hospital to home

- Education on self-management
- Discharge planning with structured follow-up and coordination of care
- Team changes may be needed. E.g, transition coaches, case managers, CHWs, social work as needed.)

Transition support for older adults with chronic conditions reduces mortality, ED visits , and readmissions post-discharge (Le Berre, 2017)

From an ethical standpoint healthcare must be patient-centered

- PCC is about respect for a person seeking healthcare , as someone who has worth and dignity , and the right to make their own decisions (autonomy)
- "Using consequentialist reasoning, patient-centered care is morally required, on account of the empirical evidence that it leads to improved outcomes for patients".

Duggan et al. The moral nature of patient-centeredness: Is it "just the right thing to do"?, Patient Education and Counseling. 2006

Treatment with Respect and Dignity

- Treatment with respect and dignity is a patient right and a foundational aspect of patient -centered care.
- What does it really mean?
- We sought to better understand what it encompasses (via mixed methods study in ICU)

Aboumatar, et. al. Understanding treatment with respect and dignity in the intensive care unit. Narrative Inquiry in Bioethics, 2015. 5(1A), 55–67.

Treatment as a human being	Treatment as a unique individual	Treatment as someone entitled to professional patient care	Treatment with sensitivity to the patient's vulnerability
Offering introductions and greetings	Treating patient as an important and valuable person	Responsiveness and rapport	Orienting patients and families to the environ-ment (machines, alarms)
Attending to basic bodily concerns (modesty, toileting, pain and comfort)	Facilitating ability to control aspects of care and make choices	Caring/positive attitude, demeanor, body language	Updating patients on their status and care plan
Treating patient as an equal	Recognizing individual preferences	Information Exchange a. Orientation/telling b. Explaining / Educating d. Listening e. Inviting questions and feedback	Interacting properly with professionals and patients and families during rounds
		Refraining from judgmental remarks and labeling	Interacting considerately with critically ill patients
		Professional Interactions with colleagues	

Story of 81 years old man diagnosed with advanced lung cancer as told by daughter in law:

" My father- in- law sat on a stretcher in a multibedded outpatient room. My mother-in-law had a chair, but I did not. The physician's first words spoken to my father-in-law were, "Turn up your hearing aid; I talk softly." He never spoke to my mother-in-law or to me. He then proceeded to tell my father-in-law that he had a type of cancer that was very aggressive and not responsive to any available therapies.
He offered no hope or help. I watched my father-in-law be devastated by this news, delivered without empathy or compassion."

" My father-in-law
sat in a chair with arms; he could put his feet on the floor. My mother-in-law and I each had a chair. The doctor entered the room, introduced himself and spoke to each one of us. He shared the same terrible news with us, but he then said, "I want to know your questions and concerns. We will develop a plan and work through this together." We did not feel abandoned; there was a connection with each of us, we were a team. "

Acad Med. 2016 Mar;91(3):297-300.. Promoting Patient- and Family-Centered Care Through Personal Stories. Johnson BH.

"I have learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

Maya Angelou

Thank you !

- Any questions?

Donabedian Model for Healthcare Quality, 1980

PFE – an evolving concept

- Actions that **patients must take** to "obtain the greatest benefit from the health care services available to them"[1]

- Patients, families, and health care providers "working in active partnership at various levels", including direct care, organizational design and governance, and policy-making to help improve health care outcomes [2]

1. Gruman J, Rovner MH, French ME, Jeffress D, Sofaer S, Shaller D, et al. From patient education to patient engagement: implications for the field of patient education. *Patient Educ Couns.* 2010;**78**(3):350–356
2. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff.* 2013;**32**(2):223–231