

Improving Health Literacy

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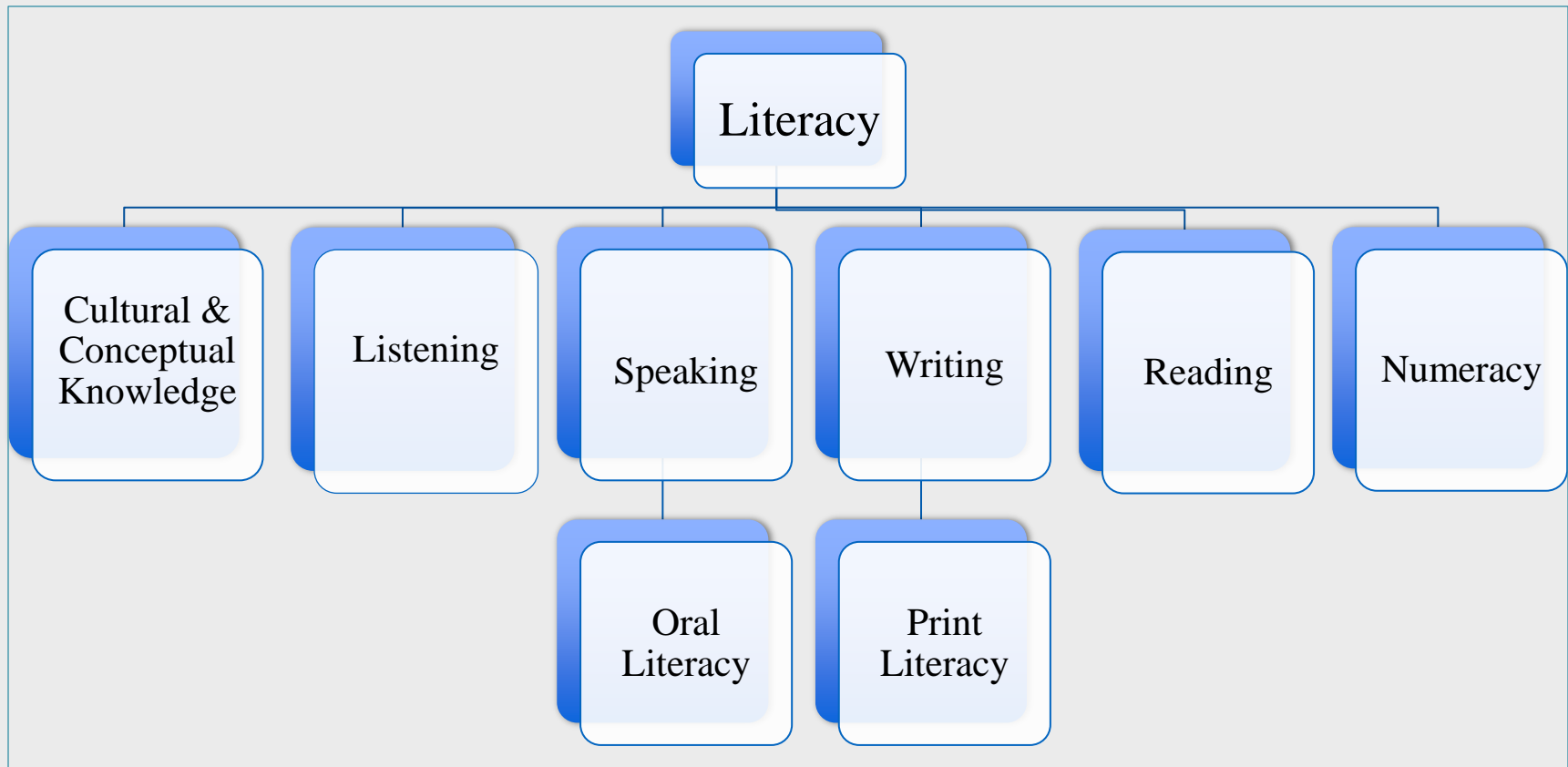
Objectives

- Define health literacy and describe factors that contribute to low health literacy
- Describe the role of the social worker in addressing health literacy challenges among patients and families
- Identify tools and techniques to improve health literacy and assist patients to better understand complex concepts to help them manage their healthcare needs

What is Health Literacy?

- Definition: The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions
- According to the Department of Education, **only 12%** of Americans are proficient in Health Literacy

Components of Literacy



Dageford & Cavanaugh, 2013

“It is a troubling paradox. In the midst of rapid expansion of medical knowledge intended to benefit many, too few actually understand medical information well enough to improve their health...**The paradox is that people are awash in knowledge they may be unable to use.**”

-Koh & Rudd, 2015

Factors Impacting Health Literacy

- Culture, language, diversity
 - In the NY metropolitan area, there are over **190 languages** spoken in households
 - **30.5%** of New Jersey residents speak a language other than English at home
- Patient demographics, educational attainment
- Communication skills and context
- Complexity of healthcare system, demands on healthcare systems, new technology, advances in scientific discoveries

Consequences of Poor Health Literacy

- Limited health literacy in kidney patients is associated with:
 - Low kidney health knowledge
 - Hospitalizations
 - Poor adherence to medications
 - Poor adherence to treatment
 - Death

Kidney Disease is Complex!

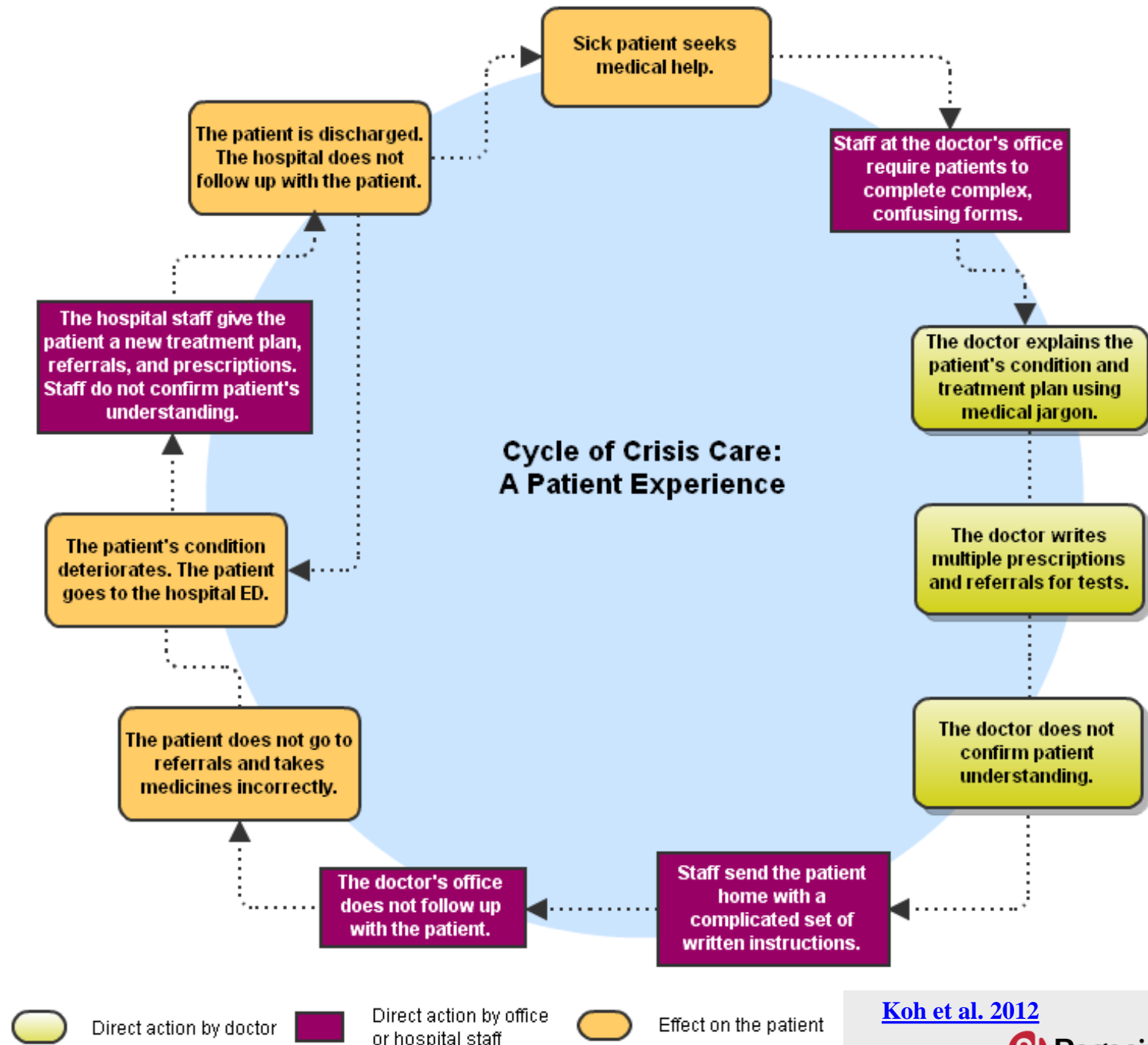
- Kidney
- Renal
- Nephrologist
- CKD
- ESRD
- GFR
- Creatinine
- Hemodialysis
- Peritoneal Dialysis
- Dialyzer
- Dialysate
- Potassium
- Phosphorous
- Sodium
- PTH
- Urea
- EPO

➡ How can we describe these terms in plain language?

Patient Stories



Cycle of Crisis Care: A Patient Experience



[Koh et al. 2012](#)

Goal: More Health Literate Organizations



This graphic reflects the views of the authors of the Discussion Paper "Ten Attributes of Health Literate Health Care Organizations" and not necessarily of the authors' organizations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.

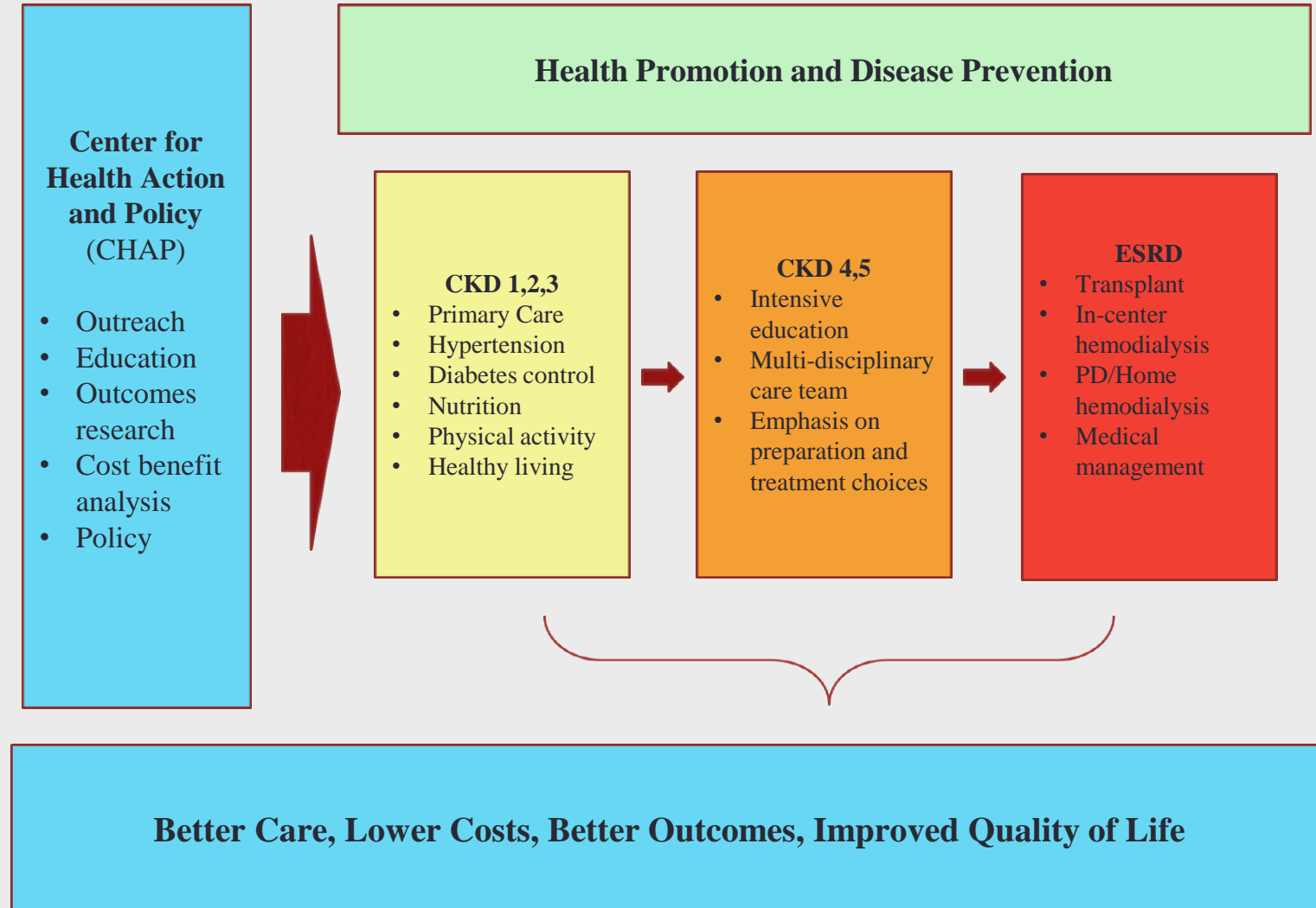
 **INSTITUTE OF MEDICINE**
OF THE NATIONAL ACADEMIES
Advising the nation • Improving health

The Rogosin Institute: 550 people serving NYC



- 8 dialysis units in Brooklyn, Manhattan, and Queens (1600 ESRD patients)
- CKD clinic
- Clinical research
- Kidney transplant program
- Center for Health Action and Policy

The Rogosin Kidney Care Model



Center for Health Action and Policy

Goal: To be a premier center for the discussion of key issues in health and health care with an emphasis on chronic illness and renal disease and its multiple co-morbidities;

Policy Formation and COLLECTIVE ACTION!

- Symposia
- Roundtables (Health Literacy, Mental Health, Nutrition, Transplant)
- Kidney Health Trainings (for patients, caregivers, and community leaders)
- Problem Solving for Better Health® (PSBH®)
- Collaborative CKD project with Shanghai PSBH/N colleagues
- Patient interviews and focus groups
- Cultivating strong partnerships with our patients, local communities, and critically important organizations and peoples



Together we can prevent and/or slow the progression of chronic kidney disease and improve the healthcare delivery system

Chronic Illness is on the Rise and so are Healthcare Costs

- End-Stage Renal Disease (ESRD) patients make up 1% of the total Medicare population, but their care uses 7.2% of the Medicare budget (\$32.8 billion annually)
- The annual medical cost associated with Chronic Kidney Disease (CKD) and ESRD is \$99 billion in Medicare spending, and is predicted to continue to increase
- Individuals with CKD on Medicare incur approximately double the cost for prescription medications than beneficiaries without CKD

Kidney Disease is Costly in Economic Terms

Cost of CKD by Comorbidity

- Patient with CKD: \$21,909
- Patient with CKD, CHF: \$34,715
- Patient with CKD, DM, CHF: \$38,230

(Average cost of CKD patient on Medicare: \$10,854)

Source: 2015 USRDS ADR, vol. 1, table 6.1

Cost of CKD by Stage

- CKD 3: \$23,680 per year
- CKD 4: \$33,374 per year
- CKD 5: \$36,147 per year
- CKD 5 on Dialysis: \$84,645 per year

Source: 2013, 5% Medicare Claims data set

The Human Cost is Enormous!!

- Kidney Disease is costly in mortality, morbidity, quality of life
- Diabetes, hypertension as root causes
- Co-Morbidities – renal, CV, neuropathy, stroke, dementia, bone disease
- Early disability/death from above co-morbidities
- Renal replacement therapy – dialysis, transplantation

Dialysis as a Full-Time “Job” (Non-Paying)



- Four hours, 3x/week
- Plus transportation
- Other physician, ER visits
- Hospitalizations
- Anxiety/depression
- Isolation from family, friends
- Fatigue

What can we do
about this situation?

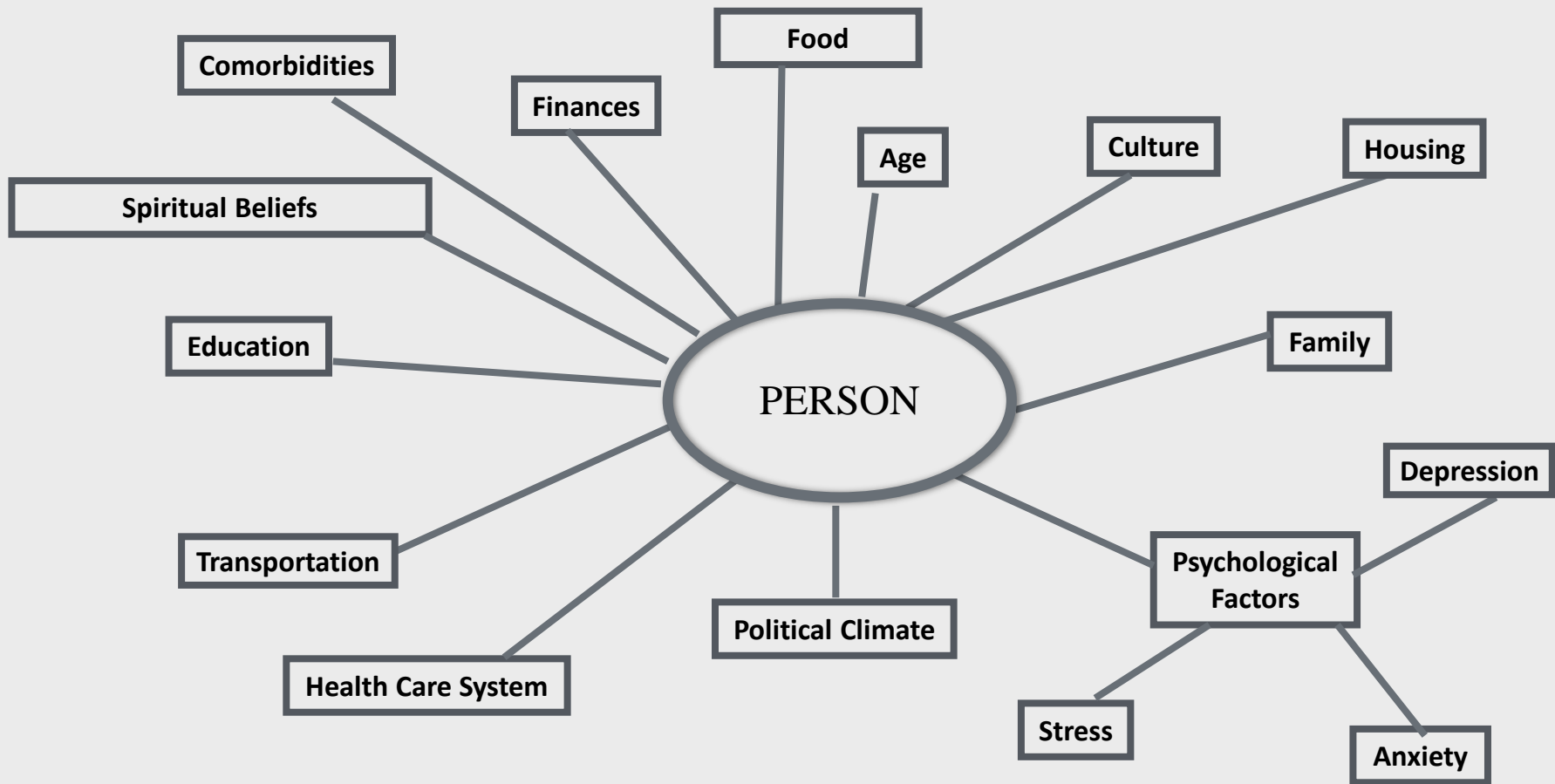
We Need to Equip Patients with the Right Tools!

The people with the problems are not the problem; they are the solution when equipped with the right tools!

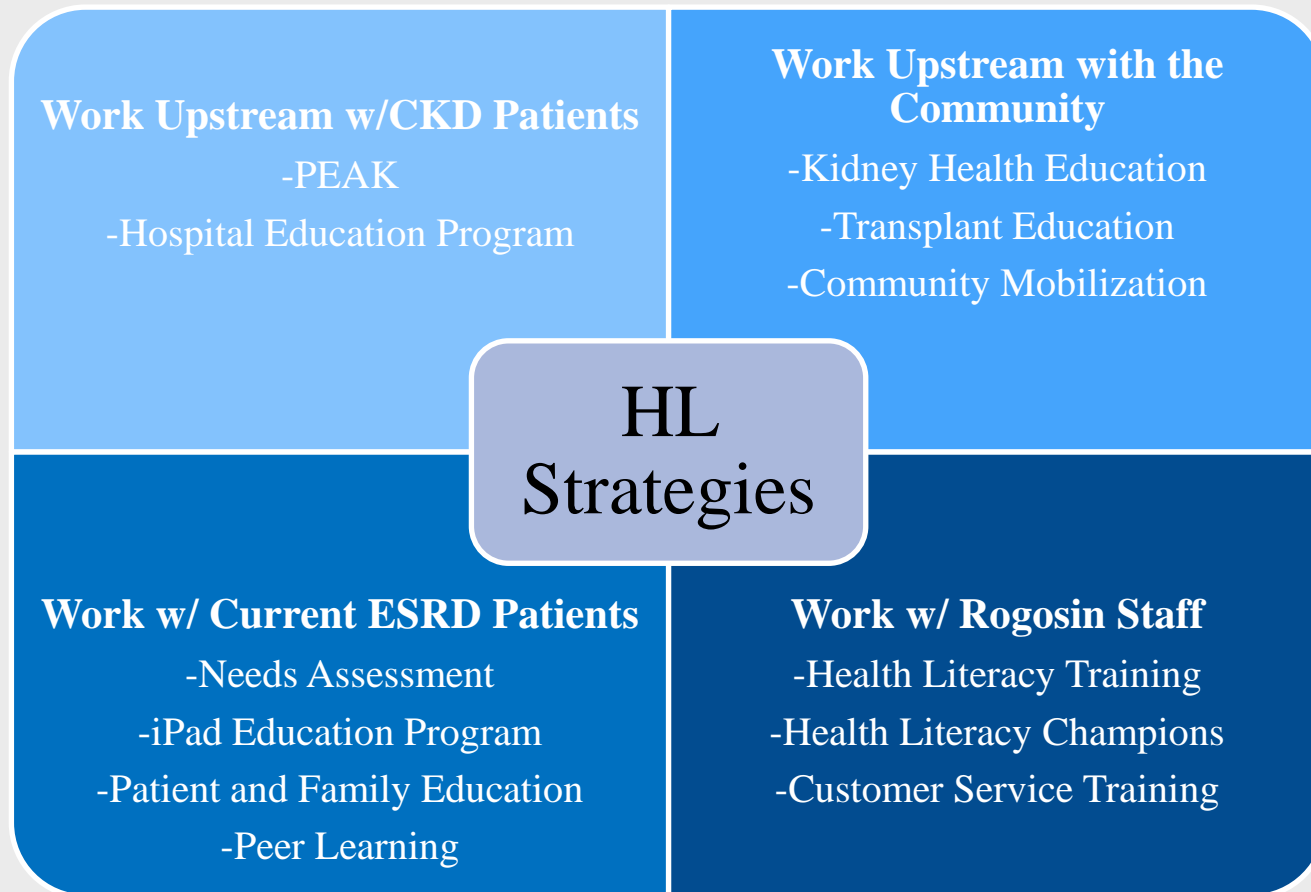


Releasing Human Potential!!!

Factors Influencing Health: Health as a Product of Society



Rogosin's Strategies to Become a Health Literate Organization



Working Upstream: CKD

- PEAK (Program for Education on Advanced Kidney Disease): CKD Stage 4 and 5
 - Establish relationships between kidney disease patients and patient care team early in their treatment
 - Facilitate informed decision making on renal replacement options with emphasis on transplant and home dialysis
 - Enforce standard of care application of vascular access; i.e. <10% vascular catheter policy
 - Rigorously apply Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines to slow progression of CKD
 - Interdisciplinary care team (nurse practitioner, nurse educator, nutritionist, social worker, collaborating physician)

Work Upstream: Community





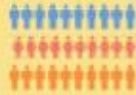
ROGOSIN INSTITUTE

ORGAN DONATION

22 PEOPLE DIE EACH DAY WAITING FOR A TRANSPLANT

120,000 PEOPLE

are on the wait list for organs nationwide



NEW YORKERS 8,400

are waiting for a kidney transplant



27% ORGAN DONORS

New Yorkers are signed up to be organ donors compared with the national average of 50%



1 DONATION CAN SAVE 8 LIVES



GIVE THE GIFT OF LIFE TODAY

Sign up today at <http://www.liveonny.org>



ROGOSIN INSTITUTE

LIVING DONOR

WHEN A LIVING PERSON DONATES A KIDNEY

WHO CAN BE A LIVING DONOR?

Anyone in good mental and physical health over the age of 18



HOW DO I BECOME A LIVING DONOR?

Contact your local transplant center which can be found at:

<https://optn.transplant.hrsa.gov/members/member-directory/>



ADVANTAGES OF A LIVING DONATION

A kidney from a living donor usually functions immediately

The recipient can find a more compatible donor and schedule the surgery at the convenience of both the donor and recipient

QUICK FACTS

Living donors are covered under the recipient's health insurance

You can delay or end the donation at any time

Join Rogosin as we work to increase the number of living donor transplants

EDUCATE YOURSELF

www.kidney.org



ROGOSIN INSTITUTE

DECEASED DONOR

23 PEOPLE DIE EACH DAY WAITING FOR A KIDNEY TRANSPLANT

DECEASED KIDNEY DONATIONS

Occurs at the time of the donor's death, where an organ is given to someone in need of a transplant

101,000 PEOPLE

are on the wait list for a kidney nationwide



NEW YORKERS 8,400

are waiting for a kidney transplant



3-5 YEARS FOR A KIDNEY

is the average waiting time to receive a deceased donor kidney



GIVE THE GIFT OF LIFE TODAY

Sign up today at <http://www.liveonny.org>



Confidential

Work with Current ESRD Patients

- Conducted Needs Assessment
 - 41 Interviews conducted at seven sites
 - 54% female, 46% male
 - Ages ranged from 24 to 88 with average age of 66
 - Race/Ethnicity* - White (37.5%), Black (40.0%), Hispanic/Latino (12.5%), Asian Indian (5.0%), American Indian (2.5%), Chinese (2.5%)
 - Languages spoken at home – English (85%), Spanish (15%), French (5%), Chinese (2.5%), Arabic (2.5%)

ESRD Patient Needs Assessment

- Reasons for kidney failure:
 - Diabetes, Hypertension, Polycystic Kidney Disease, Cancer, “Don’t know”
- Length of time on dialysis
 - Range – 2 months to 15 years
 - Average – 3.5 years
- Kidney disease hopes:
 - 51% hope to get transplant
 - Survival – hope to last a long time on dialysis
 - Hope kidneys start working again

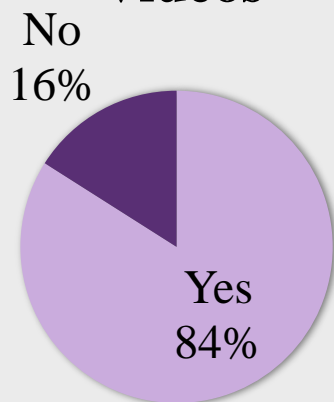
ESRD Patient Needs Assessment

- 58% want to learn more about their kidney health
- Where patients get information about their health*:
 - Asking a Rogosin staff member – 65%
 - Brochures/pamphlets – 20%
 - Books – 5%
 - Internet – 15%
 - Progress reports – 10%
 - Conversations with other patients – 2.5%

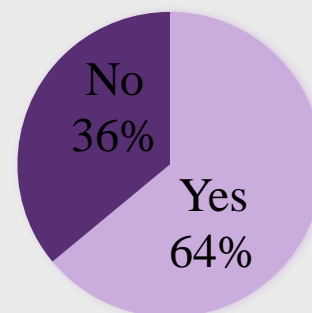
* Percentages are greater than 100 because some people had more than one response

ESRD Patients Needs Assessment: Would the following be helpful?

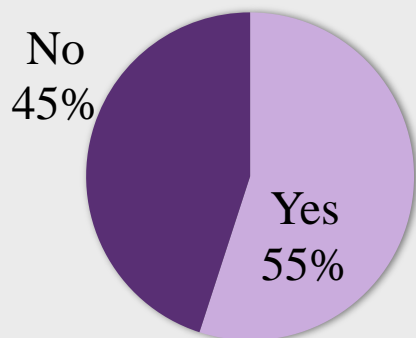
Videos



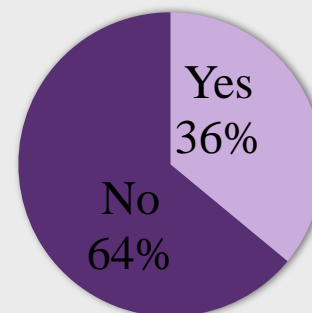
More brochures



Group classes



More time with doctor or nurse



ESRD Patient Needs Assessment: Technology Use

- 51% of respondents do research on the internet about their health
- 53% own a smartphone or tablet
- 41% connect to internet during treatment
- 50% were aware of wifi at units
- 71% would use an iPad during treatment, if supplied
- 64% would be comfortable filling out KDQOL surveys on an iPad
- 88% would watch videos or engage in interactive educational materials available online (either in centers or at home)

ESRD Patient Needs Assessment: What's Missing

- More information at time of ESRD diagnosis
 - Structured classes leading up to the start of dialysis and in early days of dialysis about what to expect
- Information about the dialysis machines – what is actually happening
- Fistula vs. catheter
- Ways to engage families/caregivers
- More information about transplant processes
- Education materials in different languages
- Rogosin specific videos and materials on the website

Work with Current ESRD Patients

- iPad Education Program
 - Interactive educational e-books
 - Link to National Kidney Registry sign-up
 - Kidney Disease Quality Of Life (KDQOL) survey completion
 - Apps for therapeutic purposes (including meditation apps, coloring apps, games)
- Peer to peer learning
 - Videos with patients discussing their experiences
 - Support groups

Work with Rogosin Staff

- Health Literacy training
 - New staff orientation unit on health literacy
- Health Literacy Champions at each facility
 - Full day, in-depth training on health literacy techniques with two representatives from each facility
 - Participating staff brought lessons learned back to their facilities
 - Champions help review health education materials

Social Workers and Health Literacy

- Social workers can and should play a key role in assessing and promoting health literacy
- Social workers know the importance of meeting people where they are, listening, culturally sensitive interactions
- Social workers as advocates for patients and families
- Role of stress/anxiety/fear on health literacy

Table 2. NSW Survey Results

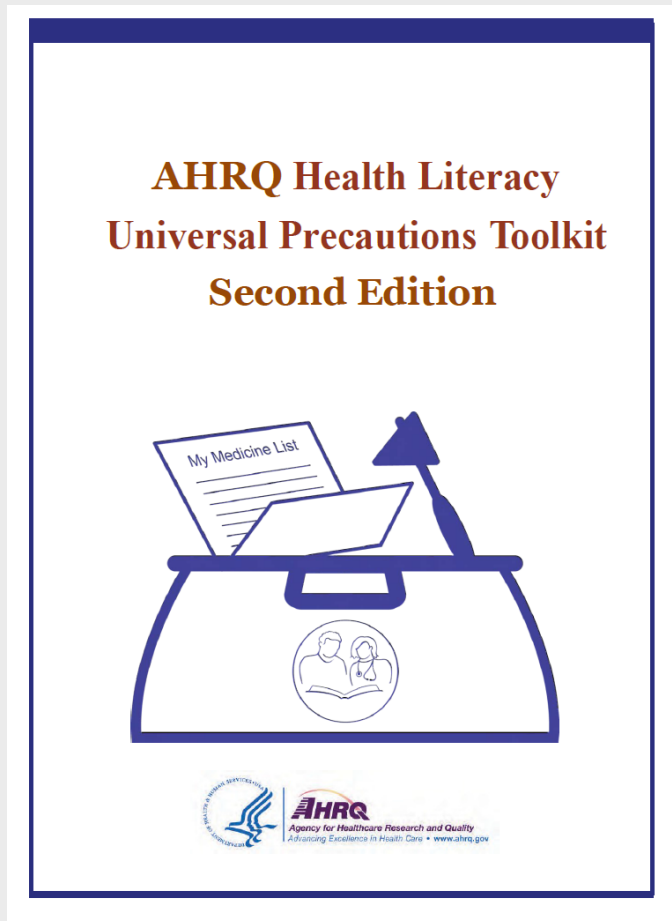
Question:	Answer	Percentage
Health Literacy is assessed at my clinic.	No	70
	Yes	30
If HL is assessed, which staff member does it?	Facility MSW	36
	Facility RN	20
	Nephrologist	17
	Dietitian	15
	CKD Educator	5
	Primary Care Provider	4
	CKD (pre-dialysis) MSW	3
Is HL assessed during the psychosocial evaluation?	Yes, all of the time	32
	None of the time	26
	Only when indicated (i.e., if low education level or non-English speaking)	20
	Most of the time	12
	Sometimes	7
	Rarely	3
A patient's education level is a good indication of HL.	No, but is commonly used	58
	No	27
	Yes	15
I am comfortable with my skills to provide good communication in a HL manner.	Yes	73
	Would like more guidance	24
	No response	3
I use techniques such as "teach back" or asking patients to repeat instructions in their own words to ensure that patients and families understand.	Most of the time	44
	Sometimes	39
	Rarely	11
	Never	6
HL is an important issue that: (Respondent could check multiple responses.)	Needs to be addressed	70
	Will require a systematic, interdisciplinary change within my clinic	47
	Not a focus at my clinic	27
	Needs to be addressed, but not a priority for me	9
What tool is used to assess HL?	Open-ended questions (no validated tool)	96
	Single Item Literacy Screener	2
	Short Assessment of HL (SAHL)	1
	Rapid Estimate of Adult Literacy in Medicine	1

Health Literacy Tips

- Always ask about patients' preferred language at initial meeting
- Identify where the patient is in their acceptance and understanding of their chronic disease
- Use universal precautions, plain language
- Teach-back techniques
- Slow down, review, and reinforce information in different ways
- Deliver information in manageable pieces
- Summarize action steps and end with “What questions do you have for me?”

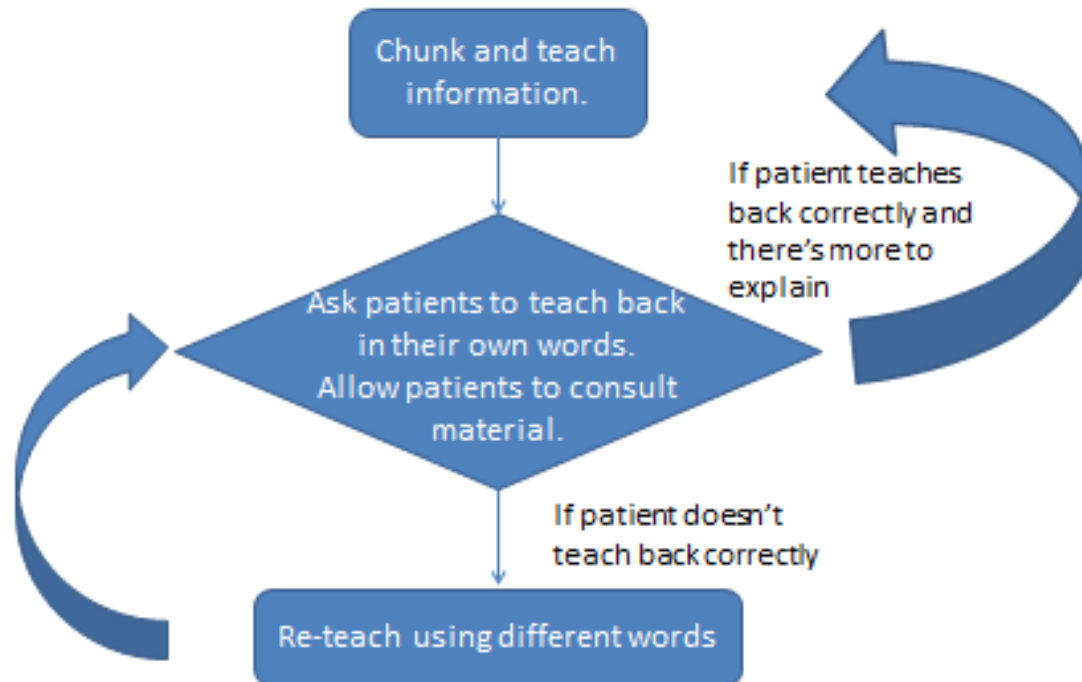
Universal Precautions

- Assume that everyone has limited health literacy
 - Everyone benefits from clear communication
 - Higher literacy, education level does not necessarily mean higher understanding
 - Emotions, fear, stress, all factor in to understanding



Teach Back

The Teach-Back Method



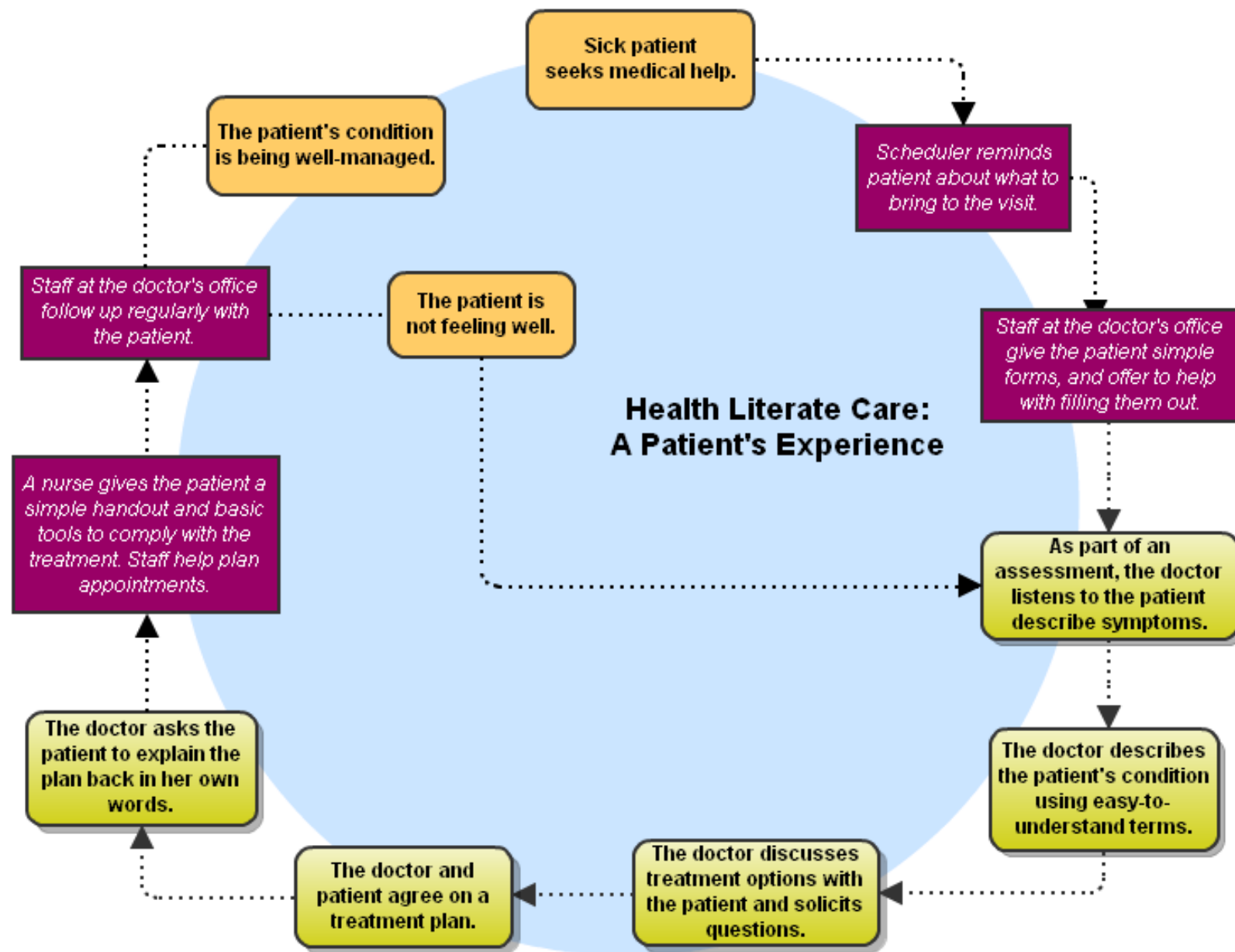
Teach Back

- “We went over a lot of complicated content today. To make sure that I explained things in a clear way, can you tell me in your own words how you’ll take care of your fistula?”
- “I know your wife helps you with your medications at home. Can you tell me how you will explain your medication instructions to her?”

Action Steps

- Create action plan with steps for follow up
- Help patient break goals into manageable steps
- Create opportunities for patient feedback
- Create environment where patients feel comfortable asking question
- Informed, empowered patients perform better!

Health Literate Care: A Patient's Experience



Direct action by doctor



Direct action by office or hospital staff



Effect on the patient

[Koh et al. 2012](#)

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