

Children's Mercy Kansas City

SHARE @ Children's Mercy

Health Literacy Events

Health Literacy Challenges and Opportunities:
Bringing Children's Mercy and Kansas City
Together

Apr 18th, 3:20 PM - 4:40 PM

Roundtable Discussions

Children's Mercy Hospital

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Overview

Using a World Café model, an interactive set of 8 roundtable brainstorming sessions were conducted.

Participants received randomized orders of rotation among the 8 tables to foster interaction with a greater number of attendees and to inspire more varied dialogue.

Planning committee members developed facilitation guides ahead of time to lead discussions. Each table included large sheets of paper and markers, and participants were encouraged to write down thoughts, ideas, and questions. The same sheets of paper were used throughout all rounds to encourage discussants to build on previous groups' brainstorming. Summarized results are included herein.

Directions

- There will be 8 tables, each with a different discussion topic.
- You will spend 7-10 minutes at each table brainstorming and writing down thoughts and ideas.
- Look in your welcome packet to find the order you will rotate in.
- The timekeeper has a copy of all table assignments – look for her if you have a question about where to go next!
- There will be a brief discussion of results at the end. A full summary will be distributed post-workshop.

Sample Roundtables Assignment Card

World Café Roundtables							
You will spend 7-10 minutes at each table. Please rotate through the tables in the following order:							
Round 1	Round 2	Round 3	Round 4	Round 5	Round 6	Round 7	Round 8
Table 4	Table 8	Table 7	Table 6	Table 5	Table 3	Table 1	Table 2
Notes							

Numeracy

Facilitator Guide

Topic Intro:

Patient centered care engages patients to be partners in their health care decisions. This model has been shown to improve control of chronic diseases, improve adherence to treatment, and increase satisfaction. However, for a patient to be able to effectively engage in their own care they need certain skills and our discussion topic today health numeracy is a vital one.

Is anyone familiar with health numeracy and can share with the group what it is?

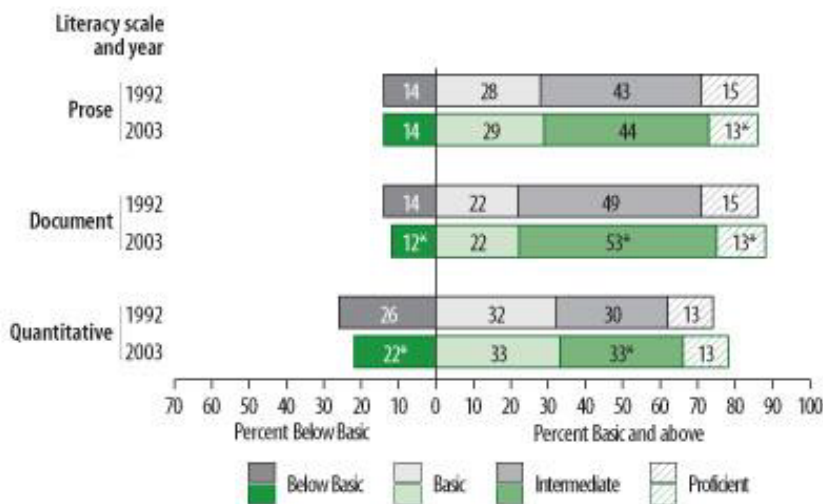
- Numeracy is the ability to access, use, interpret, and communicate mathematical information and ideas, to engage in and manage mathematical demands of a range of situations in adult life. (US Department of Education.)
- "being numerate," as possessing an at-homeness with numbers and an ability to use mathematical skills to cope confidently with the practical demands of everyday life. (Cockcroft, 1982).
- Numeracy is a critical awareness which builds bridges between mathematics and the real world, with all its diversity. (Johnston, 1994)

Patients are required to use numeracy skills all throughout the healthcare system. Can everyone take 60 seconds to write down ways patients use health numeracy and then we can go around and share:

- Medications “dose, frequency, duration”
- Understanding lab results
- Diabetes
- Insurance plans
- Deciding on treatment options (RR vs AR)

American adult numeracy competency from the national assessment of adult literacy

(<https://nces.ed.gov/naal/>):



These numbers may be a best case scenario because the people studied were not involved in making health care decisions. What factors in a health care setting could cause additional stress to make numeracy skills more challenging?

- Time pressure of a decision
- Anxiety from being at a hospital or doctor's office
- Being sick or stressed
- Being overwhelmed with too much information

Has anyone had an experience where a patient didn't have the required health numeracy skills? If so what solution was come up with to help them?

What are ways to make health numeracy information easier to understand?

- Provide numeric information as opposed to not providing it.
 - Numbers inform, educate, and give meaning to information. In short, numbers matter.
- Reduce the cognitive effort that is required.
 - Individuals who are less numerate are less comfortable dealing with numbers. Giving careful attention to the ways in which numeric information is presented is critical among this population. A variety of techniques can help those who are less numerate to better understand and use important health information.
- Provide evaluative meaning for numeric information.
 - This can occur through the use of symbols or interpretive labels. This is particularly helpful when the numeric information is unfamiliar.
- Draw attention to important information.
 - People who are less numerate are less likely to attend to numeric information, even when it is provided. There are techniques that can be used to draw attention to important numeric information.
- Set up appropriate systems to assist consumers and patients.
 - One of the most important parts of these appropriate systems is to determine the goal of the communication. Once a goal has been identified, then the provider or health educator can use the evidence base to find the best way to communicate to the less numerate population to meet that goal.

HIGH CHOLESTEROL

When there is too much cholesterol—a fat-like substance—in your blood, it builds up in the walls of your arteries and increases your risk of developing heart disease. Know your total cholesterol, your LDL (bad) cholesterol, and your HDL (good) cholesterol, and triglycerides. Make an appointment to get tested.

20s 21% **30s** 29%

HIGH CHOLESTEROL BY AGE (GREATER THAN OR EQUAL TO 200 MG/DL)

40s 46% **50s** 59%

High Cholesterol

• National Center for Health Statistics, [2011-2014], *National Health and Nutrition Examination Survey*.
• National Center for Health Statistics, [2007-2010], *National Health and Nutrition Examination Survey*.
• National Center for Health Statistics, [2005-2008], *National Health and Nutrition Examination Survey*.
• National Heart, Lung, and Blood Institute, *National Cholesterol Education Program (2002), Third Report of the National Cholesterol Education Program (NCEP) Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults (Adult Treatment Panel III) final report*.

TOTAL CHOLESTEROL NUMBERS

NOTE: CHOLESTEROL IS MEASURED IN MILLIGRAMS PER DECILITER (MG/DL).



NEARLY 1 IN EVERY 2
AMERICAN WOMEN HAS HIGH OR
BORDERLINE HIGH CHOLESTEROL.



HeartTruth.gov



Source: National heart lung and blood institute (<https://www.nhlbi.nih.gov/health/educational/hearttruth/downloads/html/infographic-riskfactors/infographic-5.htm>)

Discussion Summary

Ways Patients Use Numeracy Skills:

- Vital Signs
- Medications
- Appointment Dates
- Metric Conversions
- Costs
- Treatment Options
- Mixing Formula
- Counting Carbs
- IV Rates
- Administer Formula to NG Tube
- Lab Results & Vales
- Medication Concentration
- Pump Rates
- Daily Supply Meds
- Frequency of Dosing
- Follow-up Times
- Travel Times
- Pre / Post Procedure Instructions
- Diabetes

Ways to Make Health Numeracy Information Easier to Understand:

- Charts – Color Coding
- Interactive Charts – Shading
- Sticker
- Scheduling Tools
- Pill Boxes
- Teach Back
- Educate more than one person
- Specificity on Medication Label (dosing)
- Pictures / Examples (i.e.: showing measuring cup)
- Picture held with language barriers
- Star Chart for Doses
- Pictures of medication, clock and dose
- Writing name on medication and marking dose
- Prevent information overload

Developing Written Materials

Facilitator Guide

Applications in Healthcare: as we all know, written information is an inevitable part of health care—pre-appointment information, discharge instructions, medication usage explanations, etc.

Take 60 seconds: think about all the different written documents that patients and families receive when navigating health care. **Please share.**

What are some ways to make written documents more understandable and usable for patients and families?

Prompts:

- How do you provide written info?
- What methods can families use to obtain written documents?
- How do you organize a document?
- How can you lower the literacy level on a document?
- What options are there for translation of documents into other languages?
- How does a written document get published in your organization?

Discussion Summary

Written documents that patients and families receive when navigating health care:

- Advance Directives
- Admission paperwork
- Applications
- Appointment Instructions/reminders
- Bills
- Care Cards
- Check-in screen/papers
- Consents
- Diagnosis Info
- Discharge Instructions
- Electronic notes
- Explanation of Benefits
- Forms
- Handouts
- Healthy Kids Education
- HIPPA info
- Imaging/Radiology reports
- Immunization info
- Insurance
- Lab Results
- Mailings
- Maps
- Medication logs

- Menus
- Name badges
- Paperwork
- Patient Portal
- Prescriptions and Rx labels
- Resources
- Rights and responsibilities
- Room/hospital info
- School forms
- Signage
- Surveys
- Teaching Instructions
- Treatment Plans
- Webpages

Ways to make written documents more understandable and usable for patients and families:

- Aim for 4th Grade reading level, check level in Microsoft Word
- Bullets
- "Chunking" info
- Color coding
- Computer programs to translate notes, etc.
- Consistency
- Define Terms
- Educating families about LEAN
- Ensuring up-to-date resources
- Escorting pts to help them find their way
- Highlighting (or bold) important info & reviewing with family
- How to access additional help
- Including patients and families (i.e. focus groups, FAB, individual families)
- Large print/fonts
- Maps on phone app
- Most Important point first
- No acronyms
- No words over two syllables
- Non-medical words/terms
- Patient portal
- Personalization
- Pictures/Visuals/Charts/picture menus
- Pictures with diverse populations
- Plain Language
- Plain Language thesaurus (cdc.gov)
- Pre-read before providing
- Redundancy
- Return demonstration
- Simplify
- Standardized treatment plans and pictures

- Steps
- System of review/updating
- Taking time to identify needs
- Teach Back
- Technology
- Translation into multiple languages
- Use/refer to credible, appropriate resources
- Verbal directions/supplementation
- Videos

Challenges

- Translations – not enough resources or documents in other languages
- Patient Portal access and response time
- Medical staff language/terms
- Access to resources
- Contradictory info across systems/areas

Consumer Health

Facilitator Guide

Definition: The focus of Consumer Health is to enable patients, families, caregivers, and the general public to find current, reliable, and accessible health information. Access to this information allows participation and choice in health care decision making.

Consumer health is intended to be evidence-based and purely informational in simple, plain language that the general public can easily understand. It is not intended to offer diagnoses or specific treatment recommendations.

People used to rely solely on their medical providers for information. Why or how has this changed?

- Rise of the internet
- Google culture

What are some scenarios where a patient or their family member might look for information?

- Googling symptoms before (or when deciding whether or not to make) an appointment
- Googling a new diagnosis
- Helping with prevention or treatment decisions (e.g., vaccines, chemotherapy)
- Public health
 - safety (e.g., are the chemicals in this household cleaner safe?)
 - prevention (e.g., recommendations for washing hands, covering your mouth, etc.)
 - monitoring (e.g., strains and spread of flu, etc.)

What, if any, are some of the benefits to people seeking out additional information?

- Patient/family empowerment, especially for care decisions
- Being more proactive about embarrassing questions (e.g., sexual symptoms)
- Getting information in plain language they can understand
- Discovering resources for support, accommodations, etc.
- Not feeling like they are burdening busy physicians with too many questions

What are some risks or negative effects?

- Lots of incorrect or misleading information available online

How can providers or support professionals encourage the benefits while minimizing the risks?

- Be open to discussing outside information – don't shame or get angry at patient for Googling
- Be aware of and recommend high quality websites
- Be aware of and refer to hospital or community resources (e.g., librarians)

What would make a resource “good” or “high-quality”?

- Accurate
- Easy to read
- Impartial, fact- and evidence-based

What are some helpful/high-quality resources you are aware of?

- Can be within your organization, the community, nationally, online, etc.
- May also be specific people, websites, etc.

Discussion Summary

Why look up online:

- Find information on a new diagnosis
 - Including treatments/options
- Look up symptoms
 - Especially if no provider or insurance
- Figure out what questions to ask providers
- Figure out what type of provider to see (e.g., who do I go to for a rash? What about bad headaches?)

Benefits:

- Patient empowerment; active participants in care
- Free
- Encourages seeking healthcare
- Less embarrassing to ask a computer than a person
- Find support groups and resources
- Lessen anxiety (e.g., my symptoms are not an emergency)
- Additional language/pictures to help understand a concept

Negatives/Risks:

- Misdiagnosis/incorrect self-diagnosis
- Misinformation
- False/ineffective/non evidence-based treatments
- Increased fear/anxiety (e.g., this website says my minor headache could be a fatal brain tumor)
- Overwhelming
- "Knowing" too much, not listening to providers
- False hope

Do:

- Recommend and/or help identify high-quality, reliable resources
 - Professional, government, disease websites
- Consider accessibility when developing resources
- Provide direct access to resources through the patient portal
- Provide handouts
- Don't discourage them from seeking the information – encourage informed empowerment
- Encourage searching, but teach how (see guidance below)

Guidance:

- Make sure the source is authoritative – question who is authoring
- Determine the purpose of the site – informative/impartial? Personal stories? Trying to sell something?
 - Remember anecdotal resources (e.g., blogs) are just one person's experience/opinions and should not be considered treatment recommendations
- Consider how often the site is updated/date last updated

Good Sources:

- National Foundations (e.g., NIAID, American Heart Association)
- NIH
- CDC
- Kids Health
- MedlinePlus
- Google scholar
- Mayo Clinic
- Children's Mercy links/resources
- Patient portal
- Kremer Resource Center

Health in the Mass Media

Facilitator Guide

Topic Intro:

Most people receive their first knowledge of health and medical topics through the mass media: television, radio, newspapers, magazines and social media. But how accurate is that information? Back in the early 2000's, as the human genome was being completed, there was a lot of mass media coverage of how this would change the practice of medicine, such as personalizing the choice of drug by testing someone's genome. A doctor I worked with at the time came into a meeting complaining that a patient had just asked him to test her DNA to figure out which drug she should take. He said "we're a decade or more from being able to do that!" Yet, the patient had read it in a news magazine so she wanted it right then.

Take a 30-second look at <https://www.healthnewsreview.org/> or <https://www.acsh.org/> if you have a connected phone or tablet. Then think, discuss, and write about medical/health news reporting, focusing on the 3 important groups: journalists, consumers, and physicians.

Journalists:

- How much do journalists know and understand about the stories they are reporting?
- How much is 'sensationalized' to gain viewers/readers and ad dollars?
 - Do you think they read and analyze the actual published studies?
 - What kind of training do most journalists receive in medical and scientific fields?
 - When they conduct interviews with people who happen to have the right credentials after their name (MD, PhD, etc.), how much checking of those credentials and personal biases/conflicts of interest are considered and/or questioned?
- What is the effect of misleading or exaggerated press releases or reports from publishing scientists?
 - How many people still believe that vaccines cause autism, even though that study was debunked? <http://time.com/5175704/andrew-wakefield-vaccine-autism/>

Consumers:

- How often do you think they critically consider the information they are receiving?
- What do consumers see as authoritative sources?
 - Can they differentiate commercially-purposed or biased sources from others?
 - Could they track down, read and understand the primary study data?
 - Do they bring it to their doctors or just act on it?

Healthcare Providers:

- How much of that information is brought to care providers by consumers with questions?
- How many care providers are aware of what their patients are reading and viewing?
- How can care providers prepare themselves to answer those questions?

Resources:

<https://www.acsh.org/news/2017/03/05/infographic-best-and-worst-science-news-sites-10948>
<http://www.cfah.org/blog/2013/accuracy-of-health-news-pressure-on-journalists-consequences-for-us>
<https://nccih.nih.gov/health/know-science/facts-health-news-stories>
<https://www.bmj.com/content/349/bmj.g7015>

Discussion Summary

Media:

- Limited knowledge on medicine
 - Spot training, thrown in the field
 - Not specialist
 - Limited time/resources for fact checking
 - Lack of understanding of what they are reporting
 - Difficulty assessing quality of studies
- Problems with sources
 - Opinions sometimes presented as "facts"
 - Hearsay presented with no evidence
 - Clips/paraphrased quotes
 - Expertise of sources (e.g., "Dr. Oz" is a cardiologist by background yet preaches overall health)
- Personal biases (e.g., opinions)
- Motivation
 - Increase readership/ratings
 - Fame/promotions
 - Financial benefits (e.g., ad dollars)
 - Corporate pressure to push story out
 - Rushing, cutting vital info from stories
- Sensationalization
 - Drama
 - "Miracles"
 - Fear-mongering
 - Soundbites
 - "Hype" stories for more readers
 - Keywords to catch consumers' attention, but the story is unrelated or misleading (i.e., clickbait)
- Conflict of interest

Consumers:

- Consumers aren't educating themselves outside of the article
 - "If it's in the media it's real"
 - Do not dig deeper for more information
 - Not able to differentiate commercial sources
 - Social media for information
- People believe what they want to hear
 - Quick fixes
 - Fake News
- Healthcare is confusing
 - People don't reach out to confirm stories they hear in the news with providers
 - Can be confusing when they do reach out and receive different answers

Providers:

- Difficult to remain aware of information patients are seeing/receiving
- MD needs to be cognizant and correct bad info when possible

Teaching Methods

Facilitator Guide

Topic Intro:

The teach-back method is a way of checking understanding by asking patients to state in their own words what they need to know or do about their health. It is a way to confirm that you have explained things in a manner patients understand. (Evidence Based Practice: developed in diabetes research)

Applications in Healthcare: Patients and families receive so much information during health visits, call and emails. Too often we only ask them if they understand, but we do not truly check to see if they understand or if we have provided them the information that they need. Utilizing teach back allows us to:

- verify their understanding by having them actually tell us in their own words what they need to know
- clarify any misunderstood or lack of information
- to ask them open-ended questions to check their understanding and make sure they have the information they need
- decrease errors due to misunderstandings
- confirm necessary follow-up

Prompts:

- Do we create an environment of learning and respect for learning?
- How do you use teach back in your practice or daily work?
- Do you use teach back regularly? How often? With every patient/family?
- What misconceptions are there about using teach back?
- What barriers do you encounter in utilizing teach back? What do you hear from your colleagues?
- How do you document your use of teach back?
- What can improve the use of teach back in your area or throughout your organization?

Tips:

- **Keep in mind this is not a test of the patient's knowledge.** It is a test of how well you explained the concept.
- **Plan your approach.** Think about how you will ask your patients to teach back the information.
- **"Chunk and Check."** Don't wait until the end of the visit to initiate teach-back. Chunk out information into small segments and have your patient teach it back. Repeat several times during a visit.
- **Clarify and check again.** If teach-back uncovers a misunderstanding, explain things again using a different approach. Ask patients to teach-back again until they are able to correctly describe the information in their own words. If they parrot your words back to you, they may not have understood.
- **Start slowly and use consistently.** At first, you may want to try teach-back with the last patient of the day. Once you are comfortable with the technique, use teach-back with everyone, every time!
- **Practice.** It will take a little time, but once it is part of your routine, teach-back can be done without awkwardness and does not lengthen a visit.

- **Use the show-me method.** Have patient say when and how will do what you are asking them to do. Have them demonstrate.
- **Use handouts along with teach-back.** Write down key information to help patients remember instructions at home. Point out important information by reviewing written materials to reinforce your patients' understanding. You can allow patients to refer to handouts when using teach-back, but make sure they use their own words and are not reading the material back verbatim.

<https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool5.html>

Discussion Summary

Organizationally:

- Providers take responsibility for information provided
- Need to make it a habit to do with everyone
- Buy-in from ALL clinical staff
 - Prioritize
 - Ensure coverage/time to teach
 - Practice
- Culture Change

Create a “safe” environment:

- Set the environment
- Remove distractions
- Establish relationship
- Sit down (eye level)
- Slow down
- Close the door
- Talk **with** the patient for understanding
- Check prior knowledge and assumptions
- Ask “Why?”
- Prepare them – explain to the parents that they will have to explain instructions in their own words before starting teaching
- Make pressure seem like it’s on the provider – “I want to know that I did a good job explaining this information to you.”
- Teach them first – “I do, we do, you do”
- Focus on most pertinent information
- Have a plan – Tell them the plan, prepare what will be shared
- Script it out

Barriers:

- Time
- Language
- Overwhelmed
- Anxiety

- Misconceptions – family feel like they’re being tested
- Rudeness
- Fatigue
- Educational level
- Buy-in
- Motivation
- Distractions
- Sick kids
- Attention
- Space
- Intimidation/Deferential
- Staff not comfortable with Teach Back
- Unengaged patients who don’t want to participate
- Overconfident patients
- Age, maturity
- Varying perspectives

Documentation:

- No way in outpatient setting for nurses to document “teach back” was used
- Standardization
- Individualized notes

Culture and Language

Facilitator Guide

Topic Intro:

Effective health communication is as important to health care as clinical skill. To improve individual health and build healthy communities, health care providers need to recognize and address the unique culture, language and health literacy of diverse consumers and communities. Diverse consumer groups might include: racial/ethnic minority groups, gender or sexual orientation minority groups, Generation groups (i.e. Baby Boomers and Millennials), and other special population groups (refugees, asylees, immigrants).

(Source: <https://www.hrsa.gov/cultural-competence/index.html>)

Launching Exercise (3-5 minutes):

Using flip chart paper, ask group to list out all of the things that describe what culture is. Facilitator can put the superficial things on top of the list and the deeper more values based items at the bottom of the list. Allow folks to distill that majority of the values based descriptors of culture are not visible. See image:

VISIBLE AND INVISIBLE DIVERSITY

Children's Mercy HOSPITALS & CLINICS Kansas City

Visible

Food
Dress
Language
Behavior
Etiquette
Religion

10 %

What you see is not what you get

Customs
Assumptions
Attitudes
Beliefs
Values

90 %

Less Visible

THE CROSS CULTURAL HEALTH CARE PROGRAM

2

Questions to Consider:

- **Ask the group to describe what is cultural competency** (Use flip chart)
 - Read off the definition (for today's purposes we will use HRSA's):
 - *A set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.*
 - Ask the group to describe the skills needed to achieve this definition (note on flip chart)
 - How do you gain these skills? (note on flip chart)

- **Given that this is a Health Literacy conference, how important is it to translate documents into written languages other than English?**
 - How do you go about prioritizing these languages? Allow group to discuss
 - What if you only have 3 patients in your whole system that need a rare language...are you obligated by federal guideline to translate everything?
 - What about those patients and families that do not have a written language, but only oral tradition? How do you meet their needs?
 - How do organizations finance the translation work?

Case Scenario #1: A Mixteco Patient

A nurse practitioner is giving very complicated instructions on a medication regimen to a patient. The patient is immigrated from Mexico about four years ago. The patient speaks very little English or Spanish; Their primary language is Mixteco. The nurse opts not to use the telephone interpreter since it can be difficult to find the code number. She makes the false assumption that because the patient is smiling and agreeing to everything, she understands the complex instructions.

When the patient returns in a week for follow up, the nurse discovers that the patient's status has not changed. She opts to utilize the telephone language interpreter and discovers that the patient had not been taking the prescription as instructed.

- What Health Literacy implications are there?
- Does smiling and nodding always indicate understanding?
- Can this be applied to almost any non-Western culture?
- How would you have handled it differently?

(Adapted from Toward Culturally Competent Care: A Toolbox for Teaching Communication Strategies, 2002)

Case Scenario #2: A Hmong Family Decision

A Hmong family has recently been told by the doctor that their 6-year-old daughter has epilepsy. The Doctor has prescribed multiple medications for the child. The family, through the help of a medical interpreter, understands the complex medication regimen for the child. Upon follow up visit in one month, the family reports that they stopped giving the medication to the child, as they report her to have a changed personality, like a "zombie". The family explains that the sickness is actually a blessing from God, and that the child functions as a messenger with her seizures. The family refuses to continue to medicate her.

- What are the Health Literacy implications?
- What are the implications for the family and child? What are the implications for the provider?
- Can they meet in the middle somehow?
- What if there is a possible negative outcome?

(Adapted from Anne Fadiman, "The Spirit Catches You and You Fall Down")

Case Scenario #3: Deaf Culture

A 9-month old infant is being seen by his primary care doctor. The doctor has just completed the hearing exam to find out that the patient has severe sensory-neural hearing loss (nerve deafness), which can be remedied with hearing aids to maximize the likelihood of speech and language development. The parents and the two other older siblings are all profoundly deaf and communicate by using sign language. The Doctor is recommending double hearing aids for the child, yet the parents are refusing, stating that they do not wish to raise their child in the hearing world, since they are all part of the deaf culture.

- What are the Health Literacy implications?
- Can they meet in the middle?
- What are the implications for the child? The parents? The provider?
- How do patient's rights play into this scenario?

(Adapted from Toward Culturally Competent Care: A Toolbox for Teaching Communication Strategies, 2002)

Case Scenario # 4: Old and New Traditions

An 8-year-old girl is diagnosed with a heart defect. The Mom of the child is originally from Cambodia, but immigrated to the US ten years ago. The child was born here, but has grown up in a primarily Cambodian, Buddhist community. The Cardiologist is recommending open heart surgery to repair the defect. The Mom is confused because her family members (Grandma and aunties) are telling her not to have the surgery and that a traditional Cambodian Shaman can heal the child. Their belief is that if the child has a large scar, she will not be able to peacefully pass into the next life, and she will have struggles. The Mom is confused because she is leaning toward surgery, but does not want to disappoint her family members.

- Are there any Health Literacy implications here?
- What should Mom do next? What about Doctor?
- Can they meet in the middle?
- How can you acknowledge the beliefs of a family but offer recommendations that might be contrary?
- Can they explore both options?

(Adapted from Worlds Apart Video Series, Fanlight Productions, 2005)

Discussion Summary

We began this roundtable discussion with a "launching exercise" in which each of the eight group members listed words/phrases that came to mind when think about culture. The facilitator listed the more superficial words/phrases "above the line" and the deeper more values- based words/phrases below the line. The group discussed that diverse consumer groups might include:

- racial/ethnic minority groups
- gender or sexual orientation minority groups
- Generation groups (i.e. Baby Boomers and Millennials)
- other special population groups (refugees, asylees, immigrants)

This exercise allowed the group to appreciate and distill that the majority of the items generated about this topic are values-based descriptors and are not readily visible at the surface, requiring us to dig below the "philosophical surface" in order to study deeply and understand.

The group spent the remainder of the roundtable exploring the health literacy implications for patients and their families as well as for health care providers around three challenging case scenarios.

The roundtable concluded with the dialogue that effective health communication is as important to health care as clinical skill. To improve individual health and build healthy communities, health care providers need to recognize and address the unique culture, language and health literacy of diverse consumers and communities.

Digital Inclusion

Facilitator Guide

Definition: Three main components -

Version 1

- Access to broadband internet
- Access to internet-capable devices
- Training to use both
- [Promoting the value of a connected life – relevance, overcoming resistance to change]

Version 2

- Access: Availability, affordability, design for inclusion, and public access
- Adoption: Relevance, digital literacy, and consumer safety
- Application: Economic and workforce development, education, health care, public safety and emergency services, civic engagement, and social connections [Must also include policies and programs that promote inclusion]

Applications in Healthcare: patient health portals, looking for information on the internet (symptoms, insurance/benefits, providers)

Digital Divide: economic and social inequality with regard to access to, use of, or impact of information and communication technologies (ICT). Many people, especially lower-income, only access the internet through a mobile device.

What are some problems exclusion from internet access can cause?

- Many employers require online job applications
- Social Security information is moving to online-only access
- Accessing the Health Insurance Marketplace requires a device and an Internet connection
- Schools increasingly rely on electronic tools to educate our children - the GED/HiSET tests are only available online [There's even an FAQ on the GED website that says if you don't have an email address, go get one!]
- The Internet keeps people connected to their friends and family

Who is being left out?

- Seniors
- Less Educated
- Lower Income
- Disabled

Why?

- Skills
- Understanding of Relevance
- Intimidation
- Affordability
- Inclusive Design

Digital Literacy: an individual's ability to access both information and methods of communication through technologic tools such as smartphones, tablets, laptops and desktop PCs. Might include everything from how to turn on a computer and use the keyboard and mouse to how to use social media and critically evaluate the websites they visit.

What skills do you need to be able to access and use the internet?

- Basic Computer (double clicking, typing)
- Information Literacy (evaluating the quality of information, think “fake news” or WebMD diagnosing everyone with something fatal)
- Familiarity with Common Programs (Browser, Word, Email)

Even if you have internet, what problems could people run into if they don't have digital literacy skills?

- Clicking on or opening malicious links or attachments
- Believing misinformation
- Feelings of frustration, shame, or embarrassment
- Not being able to take advantage of online programs (GED, Social Security)
- Not understanding the information they need to bring to a doctor's appointment
- Not understanding when the appointment is or how to get there
- Accidentally sending miscommunications (think, all caps)
- Accidentally posting "weird", personal, or inappropriate things on social media
- Having to pay someone to help them with their taxes
- Not being able to apply for jobs that have online only applications

Additional Questions

What initiatives or resources are you aware of at your local organization or in the community?

- Libraries
- Digital Inclusion KC
- Literacy KC

How can you or your organization help with this problem?

- Inclusive design, such as mobile friendly apps and information
- Not making assumptions of access or skill
- Not judging based on access, skill, or preferences (it's okay if someone wants a paper copy)
- Training

Discussion Summary

Benefits of technology in healthcare:

- Better access to timely care and communications, e.g.:
 - Scheduling online
 - Reminder texts, emails
 - Direct messaging through portals
 - Telehealth
 - Fewer handouts to lose

Problems with digital inclusion in healthcare:

- Hospitals push technology initiatives forward but don't inform or train staff well
- Different systems don't communicate well, which leads to redundant efforts
- Funding models for hospital technology incentivize creation of tools but not usability
- Providers move forward with new technology and tools but patients can get left behind (e.g., being required to sign in on a computer/tablet to check-in can be frustrating and embarrassing if the patient/family doesn't know how to use the device)
- Top-down policies discourage paper, even though not all patients/families may be digitally literate or process information well via computer
- Overreliance on technology – lots of problems when it goes down (e.g., residents not knowing how to chart manually)
- Patient portals not mobile friendly
- Legal/procedural barriers to access information (e.g., clinic cannot release old labs to patient – must go through medical records)
- Required to sign-up for the portal in-person

Ways to help:

- Don't make any assumptions about digital literacy levels!! Age, education, etc. are not predictors of ability or preference to use technology
- Provide education/training on how to use the patient portal for both patients **and** employees
- Perform teach back in the clinic where providers can show patients/families how to find and use high quality online resources before they leave
- Be aware of and direct to resources such as community computer classes
- Simplify discharge information

Financial Literacy

Facilitator Guide

Definition: the possession of the set of skills and knowledge that allows an individual to make informed and effective decisions with all of their **financial** resources. (very similar to health literacy)

Applications in Healthcare: if they have insurance – understanding how it works; whether they do or don't – paying out of pocket expenses; all affected by rising costs

Take 60 seconds: write down all the words you associate with money; next, put a plus (+) next to the positive words, and a minus (-) next to the negative words.

- Did anyone put a plus sign next to paying bills? Or making a budget? Emotions vary from person to person and situation to situation; One person's sense of accomplishment can be another's biggest source of stress.

How many of you pay attention to prices when you go grocery shopping? Do we have any coupon experts?

- A common misconception is that "poor" people are not good at managing their money. But who do you think keeps closer track of where every single penny goes – someone who is well off or a single mother without a high school degree?

Difficult trade-offs: are a reality for many families. Think about a mother who sacrifices being able to afford a car so she can pay for cable because she lives in a dangerous neighborhood and entertaining her children inside is the only way she knows how to keep them safe

- What about when the choice is between paying for treatment and paying for food?

Financial Coaching: based on the fundamental belief that the client is competent, and that the relationship should be client-driven and focused on personalizing goals and strategies

- Differs from financial counseling, which assumes the client is flawed and needs someone to fix them, that there's a single right answer or path

Take the rest of the time: jot down any other thoughts, ideas, strategies, or resources. For example:

- What are some other problems or barriers we haven't discussed?
- Does your organization offer financial literacy training? What does it look like?
- Do you know of any community resources for financial literacy?

Discussion Summary

Issues:

- Public Assistance
 - Families are unaware of benefits for which they are eligible
 - many different types are confusing
 - State/Fed eligibility guidelines are always changing and communication is slow
 - Families need to start applications for kids for Medicaid before 18 years old
 - Unique KC issue with state line transitions
 - Families don't understand Go Fund Me-type pages impact taxes and can make you lose benefits

- Billing
 - Bills are confusing!
 - Bills for one visit or procedure can come from lots of different places (physicians, radiology, etc.)
 - People don't know they can get financial assistance and that any effort to pay counts
- Who to Ask
 - Patients not sure who to ask for clarification, and providers don't always have answers
 - People don't know you can call insurance ahead of time for costs
 - Patients not sure how to ask questions about insurance
 - Navigating insurance is a full-time job, difficult to find time to get answers
 - Money conversations can be off-putting and embarrassing
 - Can vary based on if the person who makes money decisions is present
- Lack of Transparency in Costs
 - Costs are opaque in many cases
 - Even providers don't always know what things cost or what exactly ends up being billed
 - Often "coverage" is not consistent even in a hospital, hard to parse
 - Healthcare system does not monitor what is being charged
 - People worry about costs of everything, including dinner trays
- Lack of Clarity in Concepts and Terminology
 - Terminology (co-pay, etc.) is confusing
- Culture and Education
 - People raised to handle money differently
 - Skills not widely taught in schools so people don't know implications in real world
 - Example: knowing to not take out a pay day loan, max credit cards
 - Example: Not knowing how to track balances/accounts
 - Urgent Care or ED may be normal place to go in different cultures
 - Cultural beliefs prohibit participation in public assistance programs
- Banking Situation
 - Often need credit cards or cash upfront to be seen, which not everyone has
 - Online billing can be a barrier if no credit card or bank account

Consequences:

- More trips to the ER, which is more expensive and often compounds financial issues
- Families may forgo treatment and/or medication altogether if they don't think they can afford it

Ways to Help:

- Help patients understand costs and benefits
 - Be a resource for understanding billing and addressing financial concerns or be aware of high-quality resources where patients/families can be directed
- Work with PCP to get costs down