



Beyond the Pharmacy:

Addressing Patient Overwhelm with Patient Advocacy

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Conflict of Interest

- Founder of Stacie Lampkin LLC – Pediatric Patient Advocacy Coaching and Education

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Objectives

- **Pharmacists:**

- Examine the difference between medical advocacy and patient advocacy.
- Describe healthcare encounters, patient expectations, patient needs, patient satisfaction, and healthcare barriers from a patient perspective.
- Evaluate patient advocacy strategies pharmacists can use to engage patients in their healthcare.

- **Technicians:**

- Examine the difference between medical advocacy and patient advocacy.
- Describe healthcare encounters, patient expectations, patient needs, patient satisfaction, and healthcare barriers from a patient perspective.
- Evaluate patient advocacy strategies technicians can use to engage patients in their healthcare.

Self Reflection

- Do you try to do what is best for your patient?
 - All the time
 - Usually
 - Sometimes
 - I could do better
 - Never

Self Reflection

- Do you consider yourself an advocate for your patients?
 - All the time
 - Usually
 - Sometimes
 - I could do better
 - Never



Why we think we
are advocating for
our patients and
why we might not
be.



Introduction to Patient Advocacy

(Examine the difference between medical advocacy & patient advocacy.)



Merriam Webster Definition

Advocate: one who supports or promotes the **interests** of a cause or group

Patient Advocate Definition

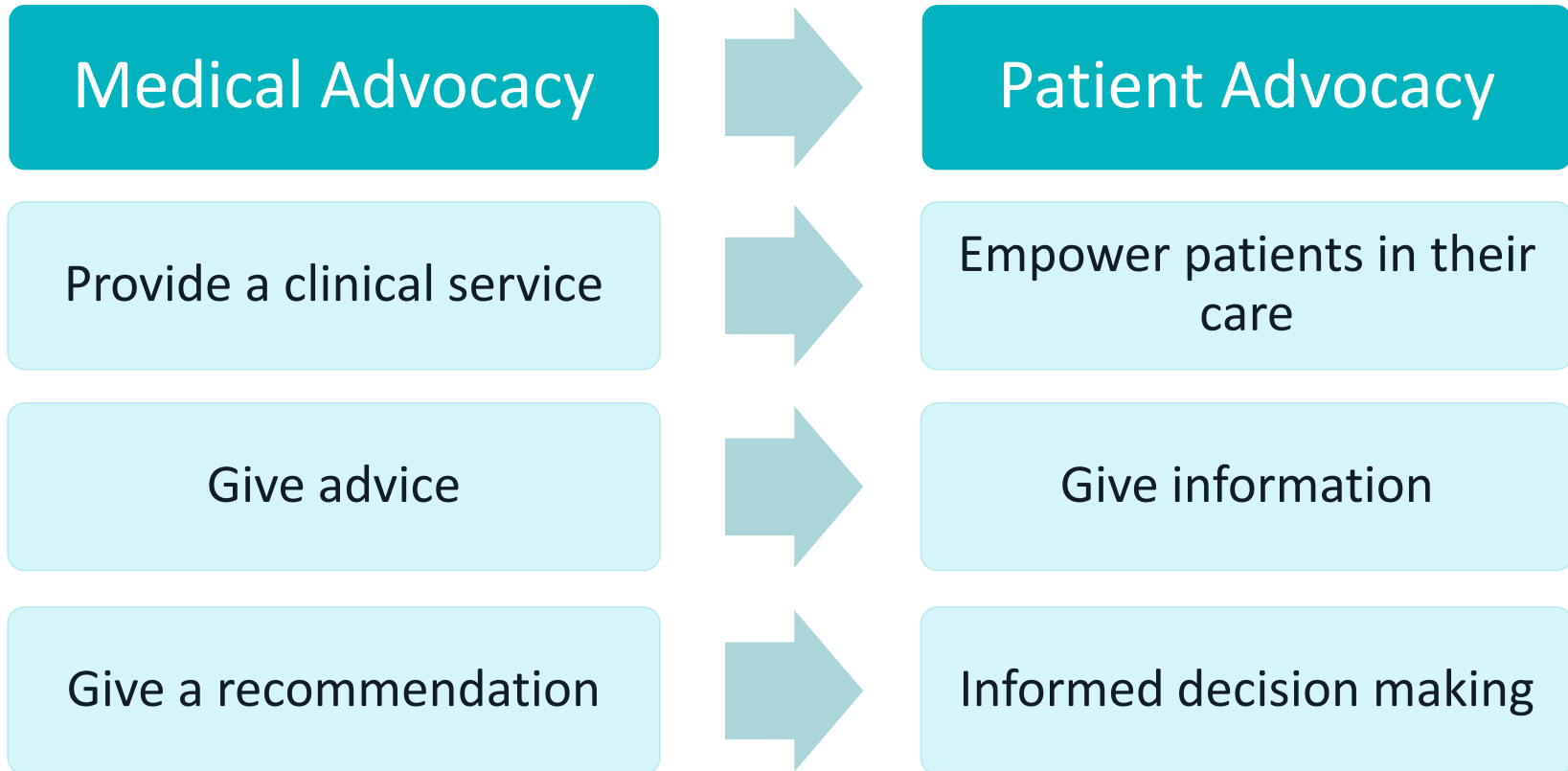
per Patient Advocate Certification Board

- One who helps clients and client communities make informed choices and access resources
- Informational, not medical
 - Advocates shall not recommend specific treatment choices, provide clinical opinions, or perform medical care of any type, even if they possess clinical credentials.

Patient Advocacy Overview

- Working directly with patients to ensure that **they have a voice in their care**
- Working to make sure that **patients have sufficient information** to promote informed decision making
- Ensuring that a **patient's wishes are the guiding force behind decisions** affecting medical care and the withholding of care
- Providing services to patients as they **navigate** the healthcare system

How do we advocate?





But patients...



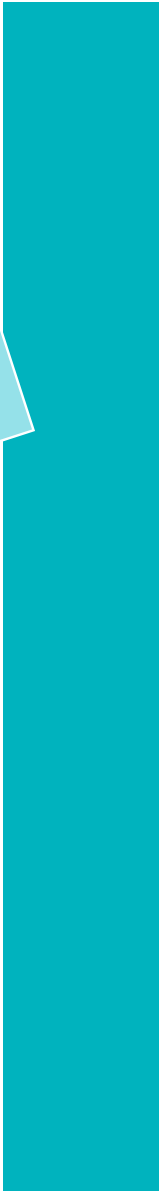
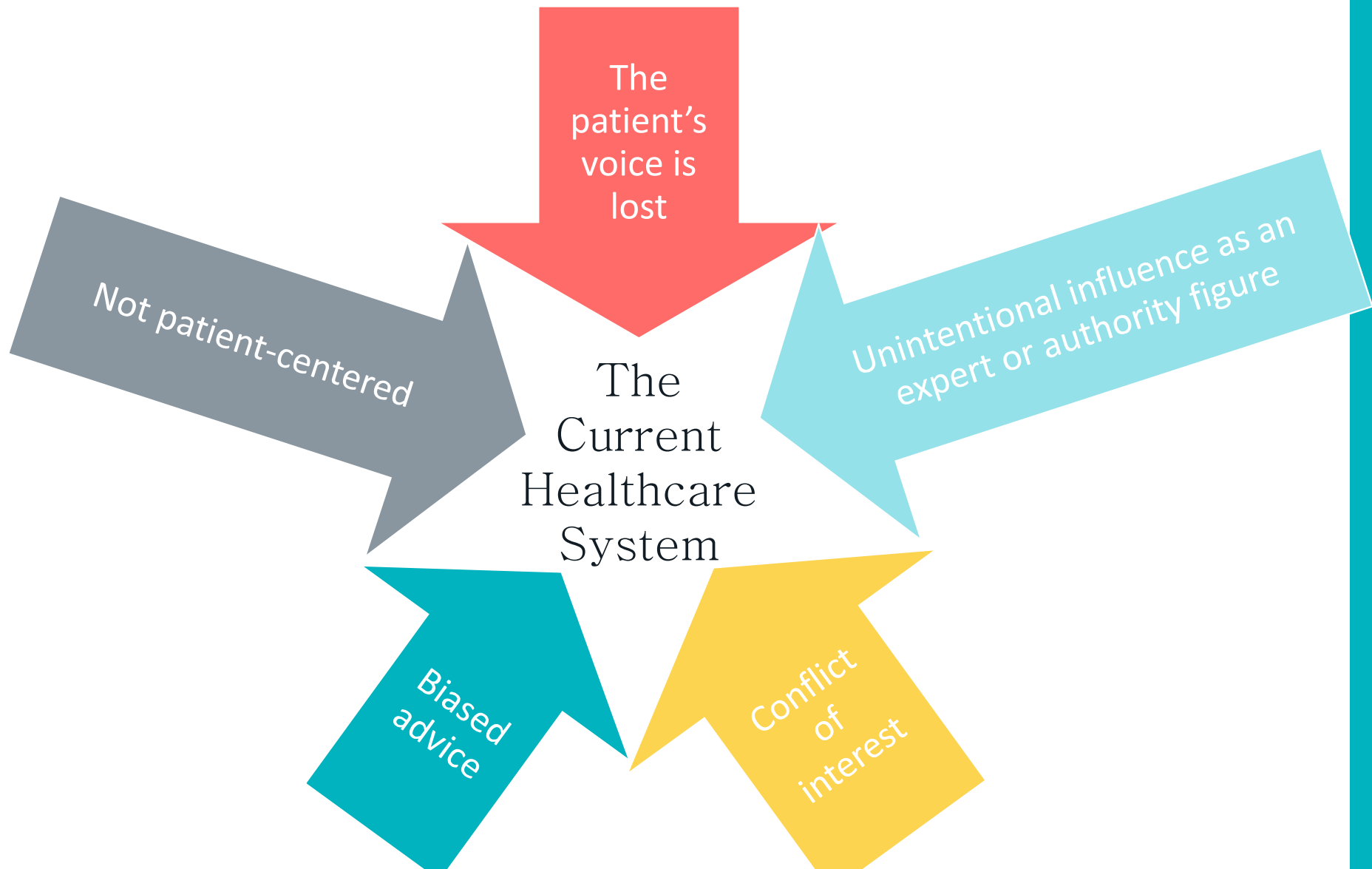
But it'll take too...



But we are...



But, but, but....



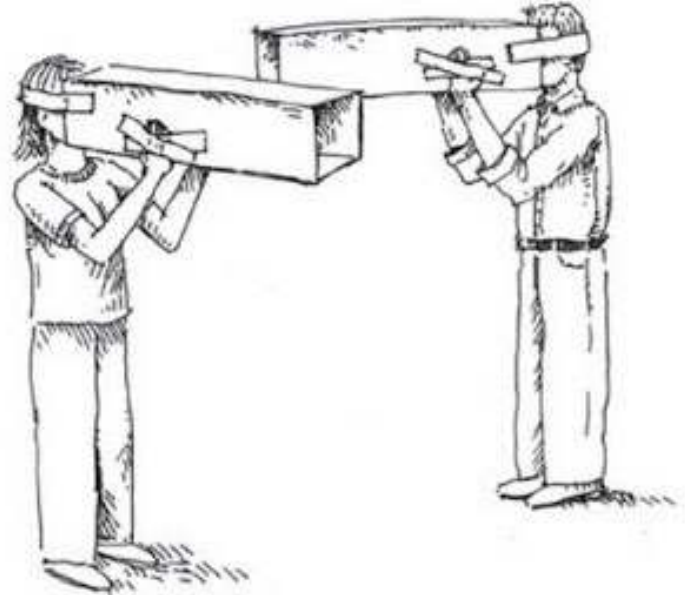


The Patient Experience

(Describe healthcare encounters, patient expectations, patient needs, patient satisfaction, and healthcare barriers from a patient perspective.)

Take off the blinders – We are one healthcare system

- A negative interaction with one pharmacist alters a person's perception about all pharmacists.
- A negative interaction at the doctor or hospital influences trust of the healthcare system.
- How often have you heard patients “complain” about another part of their care?



Healthcare Encounters

Case: 33-year-old female

- Medications
 - Past: Compazine prn
 - Current: Zyrtec, Zofran prn
 - New: Flexeril, Voltaren gel
- Partner comes to pick up the medication and the Voltaren gel isn't ready, because the doctor didn't put the amount per dose on the prescription



The Exchange:

- Irritated Partner: The doctor told me it would be ready.
- Technician: I'm sorry, we are waiting for them to call us back.
- Irritated Partner: My wife really needs it and is in the car. There isn't anything you can do?
- Technician: Let me check with the pharmacist.
- Pharmacist comes over: Sorry, sir. We really need the instructions you'll have to come back.
- Irritated Partner: Sighs, I don't understand. It is a cream, the doctor just said to apply a small amount why do you need to know the exact amount.
- Pharmacist: We really need the exact amount for this medication, there is a measuring strip in the box. For future, you can have your wife call and check if her prescription is ready before you come. Here is the Flexeril.
- Irritated Partner: K. So can someone call me when this is ready?
- Pharmacist: Yes, someone will call the number on file when it is ready.

Case Thoughts

- What do you think about this encounter?
- What emotions run through you?
- Have you ever responded similarly?
- What assumptions are you making about what is going on with this patient?



Question: Who did you empathize with?

- The Pharmacist
- The Irritated Partner

I've been waiting for 20 minutes!

Down the hall. You want "Impatient Registration".



Pirako
7-5-14
w/ GARY COOPER

HOW LONG DOES IT TAKE TO STICK A LABEL ON A BOX?!

ONLY A FEW SECONDS. IT'S THE "MAKING SURE THE MEDICINE DOESN'T KILL YOU" THING THAT TAKES A BIT LONGER



ETH

Patient Needs & Expectations

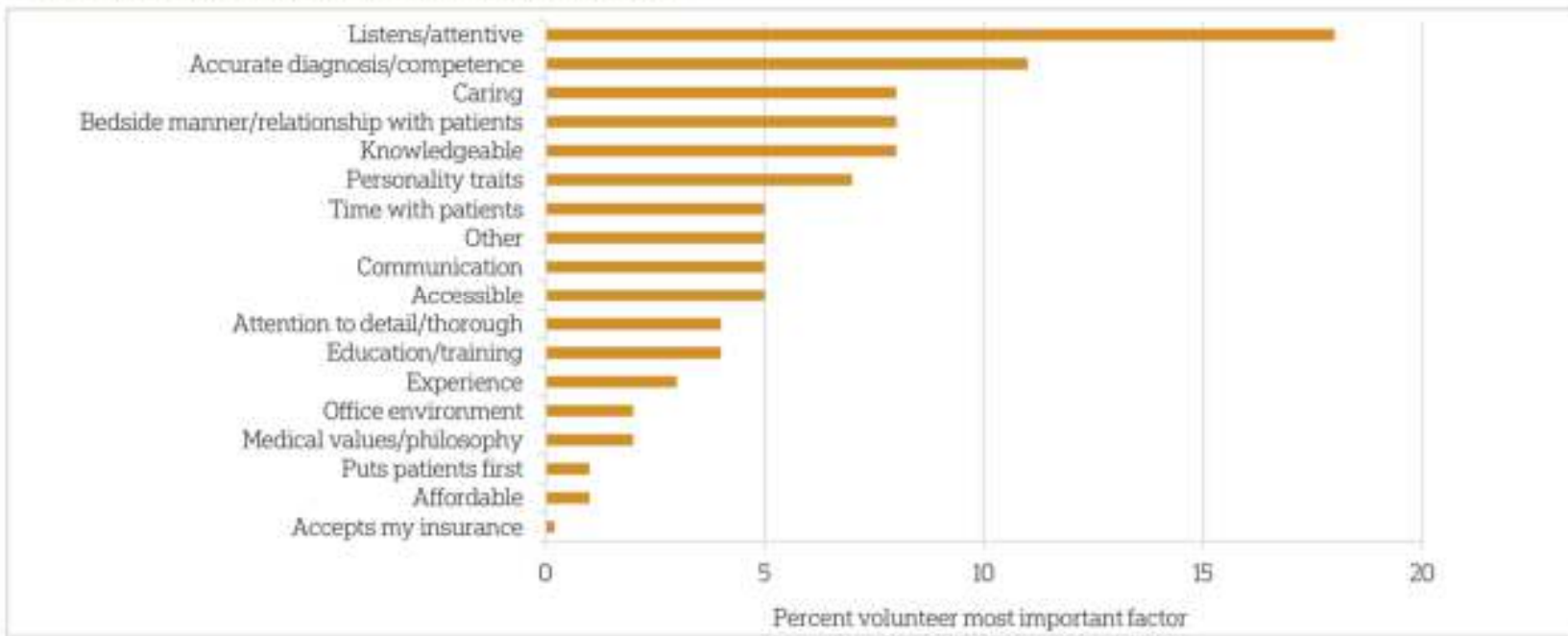
Patient Wants and Expectations:

1. Patient-Centered Care
2. Access
3. Communication and Information
4. Courtesy and Emotional Support
5. Efficiency of Care/Effective Organization
6. Technical Quality
7. Structure and Facilities

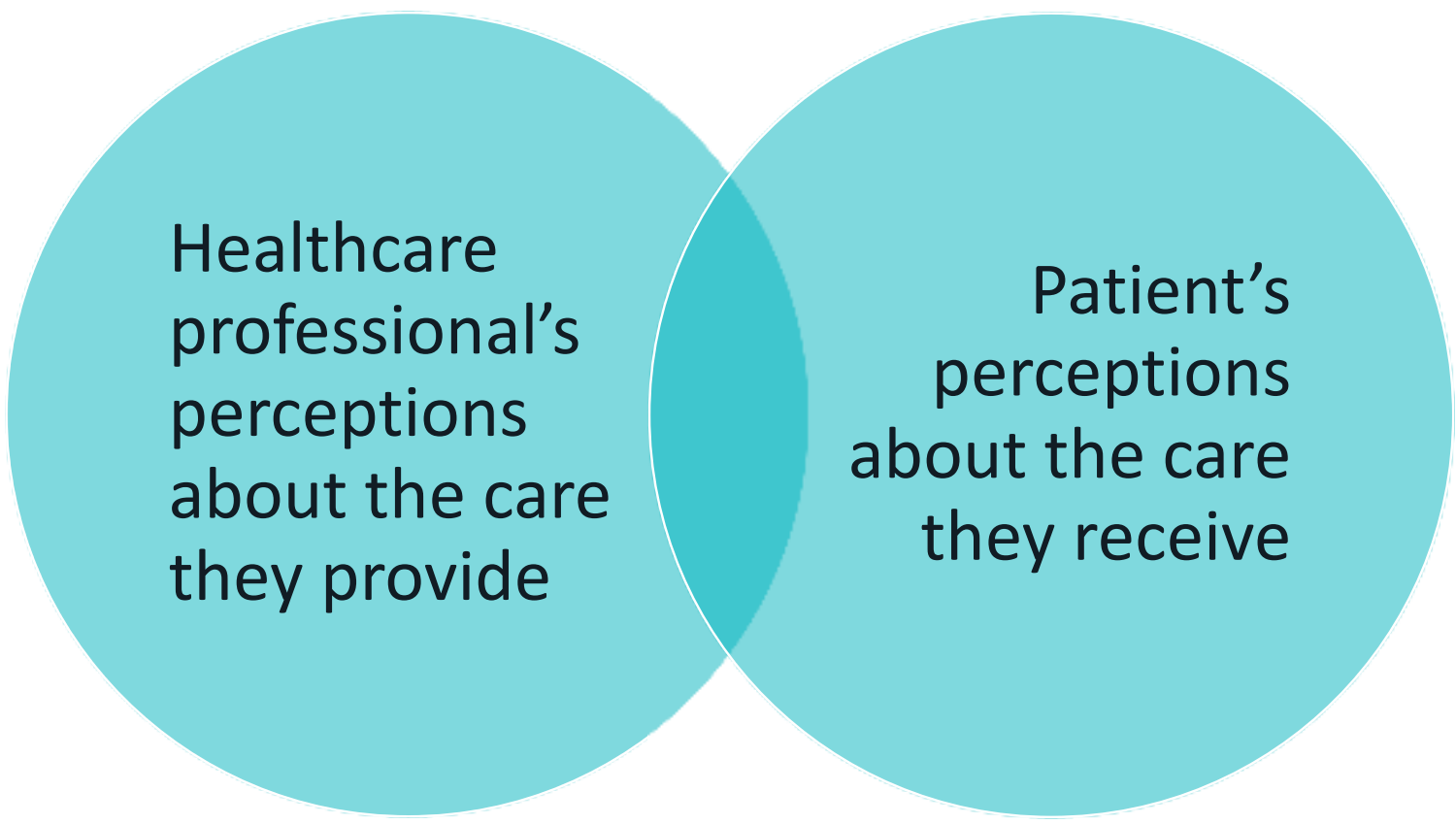


Sofaer S, Firminger K. Patient perceptions of the quality of health services. *Annu Rev Public Health*. 2005;26:513-59.

Most important factor that makes a high-quality doctor



A Disconnect: The Perception Gap



Healthcare professional's perceptions about the care they provide

Patient's perceptions about the care they receive

Patient Satisfaction

Patient Satisfaction \neq Patient Advocacy

“Patients can be very satisfied and dead an hour later. Sometimes hearing bad news is not going to result in a satisfied patient, yet the patient could be a well-informed, prepared patient.” ~The Atlantic

Patient Satisfaction

Copyright 2003 by Randy Glasbergen.
www.glasbergen.com



**"That pill they advertise all the time on TV.
I'm not sure what it is, but I want it!"**

- When satisfaction is tied to financial incentives
 - Providers more likely to give into to patient's requests
 - Telling patients what they want to hear
 - Processes in place to "manipulate" patient responses

Benefits of Satisfied Patients



More adherent to
provider
recommendations



More loyal to
physicians



Lower emergency
department utilization

Risks of Satisfied Patients



Higher inpatient
utilization



Greater total
health care
expenditures

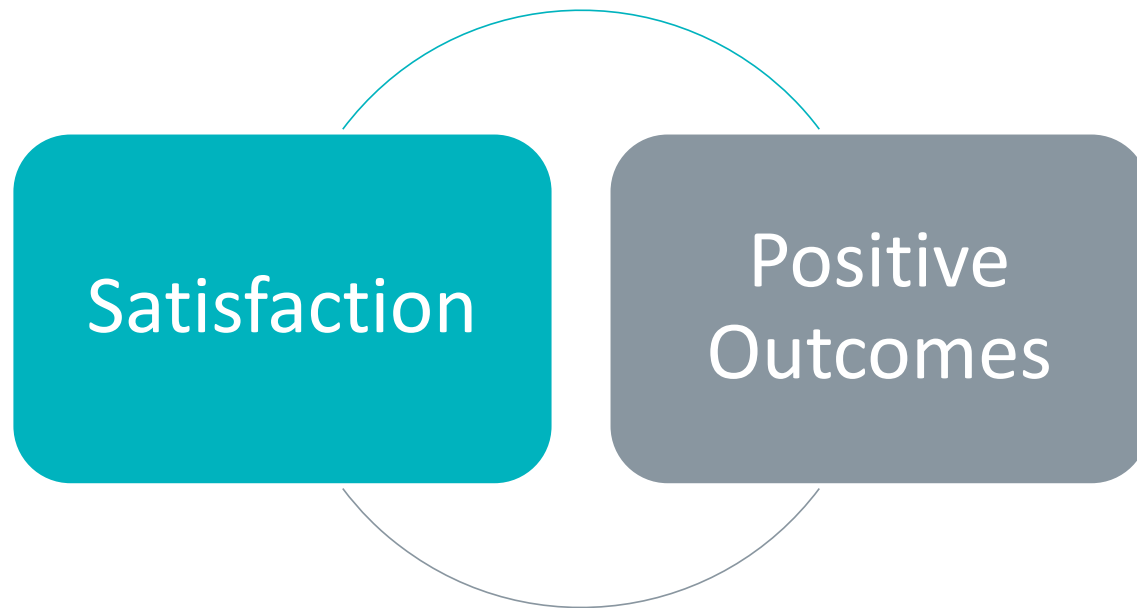


Higher
expenditures on
prescription
drugs



Greater
mortality risk -
26% greater
mortality risk

A Balancing Act





Case Debrief: 33-year-old female

- The interaction:
 - What did the partner want?
 - What did the patient want?
 - Was the patient “satisfied”?

Case Debrief: 33-year-old female

- What the partner really wanted was
 - to not have a sick wife in the car
 - to be able to help her debilitating headaches
 - to not watch the pain inhibit her bouncing back
 - to know what to do next to get the medication
 - to be treated with some empathy
- What the patient really wanted to was
 - to get home and rest
 - to feel better so she could see her three and five-year-old sons

Case Debrief: 33-year-old female

- Patient has breast cancer
 - 3rd round of chemotherapy Adriamycin/Cytoxan
 - Round 1 - The patient was so nauseous she couldn't eat or rest
 - The Compazine gave her tremors
 - The Zofran gave her headaches
 - Round 2 - The addition of Emend to Aloxi and Zofran
 - Had tolerable nausea and could eat
 - Debilitating headaches that radiated down the head and neck. Tylenol & Ibuprofen around the clock didn't help
 - Round 3 – In an attempt to control he headaches, the doctor was trying Flexeril and Voltaren

Case Debrief: 33-year-old female

- Medication Indications
 - Zyrtec – bone pain
 - Compazine – chemo-induced nausea
 - Zofran – chemo-induced nausea
 - Flexeril – chemo-induced pain
 - Voltaren – chemo-induced pain

- Irritated Partner: The doctor told me it would be ready.
- Technician: I'm sorry, we are waiting for them to call us back.

→ Projecting fear

- Irritated Partner: My wife really needs it and is in the car. There isn't anything you can do?

→ Desperation, know how to help

- Technician: Let me check with the pharmacist.

- Pharmacist comes over: Sorry, sir. We really need the instructions you'll have to come back.

→ Miscommunication

- Irritated Partner: Sighs, I don't understand. It is a cream, the doctor just said to apply a small amount why do you need to know the exact amount.

- Pharmacist: We really need the exact amount for this medication, there is a measuring strip in the box. For future, you can have your wife call and check if her prescription is ready before you come. Here is the Flexeril.

→ Lack of empathy

- Irritated Partner: K. So can someone call me when this is ready?

→ Needs support

- Pharmacist: Yes, someone will call the number on file when it is ready.

→ Loss of trust if someone doesn't

My Story



Remember

	Overwhelming
Coping with a new diagnosis	<input checked="" type="checkbox"/>
Living with a health condition and health changes	<input checked="" type="checkbox"/>
Adjusting to a different lifestyle	<input checked="" type="checkbox"/>
Informing family and friends	<input checked="" type="checkbox"/>
The complex healthcare system	<input checked="" type="checkbox"/>

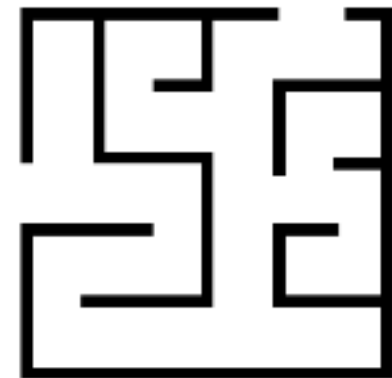
Healthcare Barriers

Healthcare Barriers: Patients Know About

- Financial
- Access
- Race and ethnicity
- Gender or gender identity
- Sex or sexual orientation
- Intellectual and physical disability
- Location
- Age
- Language
- National origin and immigration status
- Incarceration status
- Religion and cultural beliefs
- Socioeconomic status
- Health literacy and ability to access information

Healthcare Barriers: Patients don't Realize Exist

- Fragmented care and Poor coordination:
 - Unnecessary treatment
 - Duplicate testing
 - Wasted time
 - Laboratory results not reaching the clinician
 - Not sending reminders to patients
 - Not using nonphysician staff to coordinate care
 - Not spending enough time with the patient

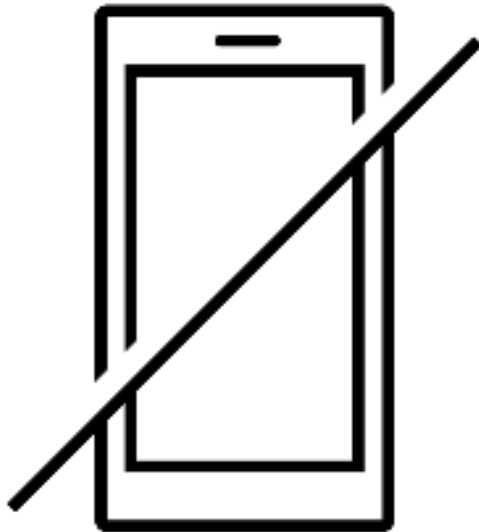


Healthcare Barriers: Patients don't Realize Exist

- Inadequate information technology
 - Lack of electronic medical records and linkage between systems
 - Inability to access test results, prescribe medications, enter clinical notes, electronically order laboratory tests, receive drug alerts
 - Inability to track laboratory abnormalities, overdue tests or vaccines, or medications



Healthcare Barriers: Patients don't Realize Exist



- Miscommunication
 - Healthcare professionals not sharing important medical information with each other
 - Specialist recommendations
 - Test results
 - Medical records
 - Reasons for referral before appointments
 - Lack of response or follow-up from healthcare professionals

Healthcare Barriers: Patients don't Realize Exist

- Medical errors
 - Medical mistakes
 - Incorrect medication or dosage
 - Incorrect results on diagnostic tests
 - Delays in being notified of abnormal results





The Spirit of Patient Advocacy

- One method to:
 - Help patients by providing risks and benefits, so they can make informed choices
 - Get to know patients by learning about their interests, beliefs, and cultures
 - Decrease the burden on healthcare professionals to make the “right or wrong” recommendation
 - Improve patient satisfaction by including patients in decision making
 - Empower and engage patients in their care

Patient Engagement can

1

Lead to better
health outcomes

2

Contribute to
improvements in
quality and
patient safety

3

Control health
care costs

US Health Outcomes

- The United States compared to
 - Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom

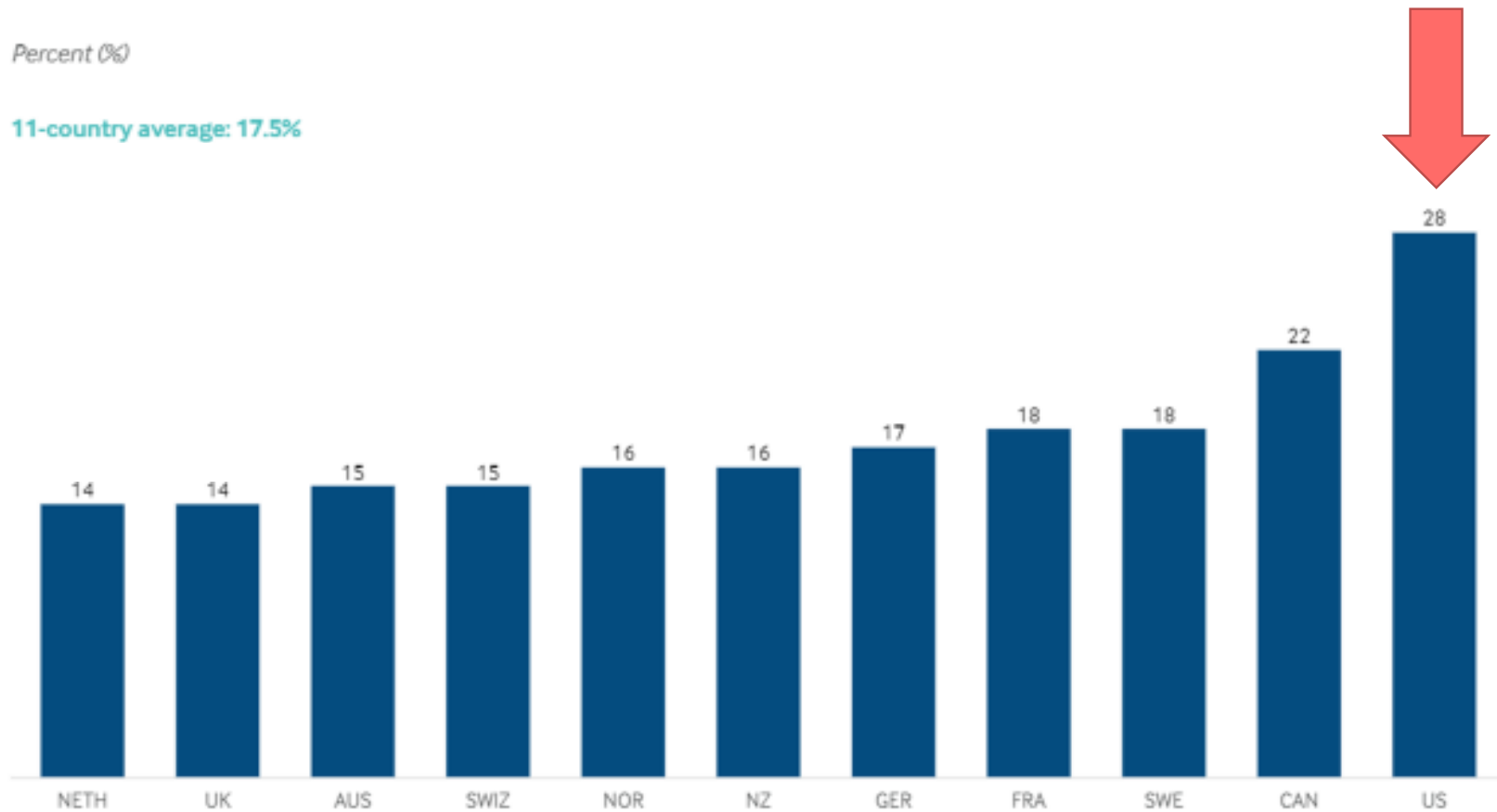


POPULATION HEALTH

U.S. Adults Have the Highest Chronic Disease Burden

Percent (%)

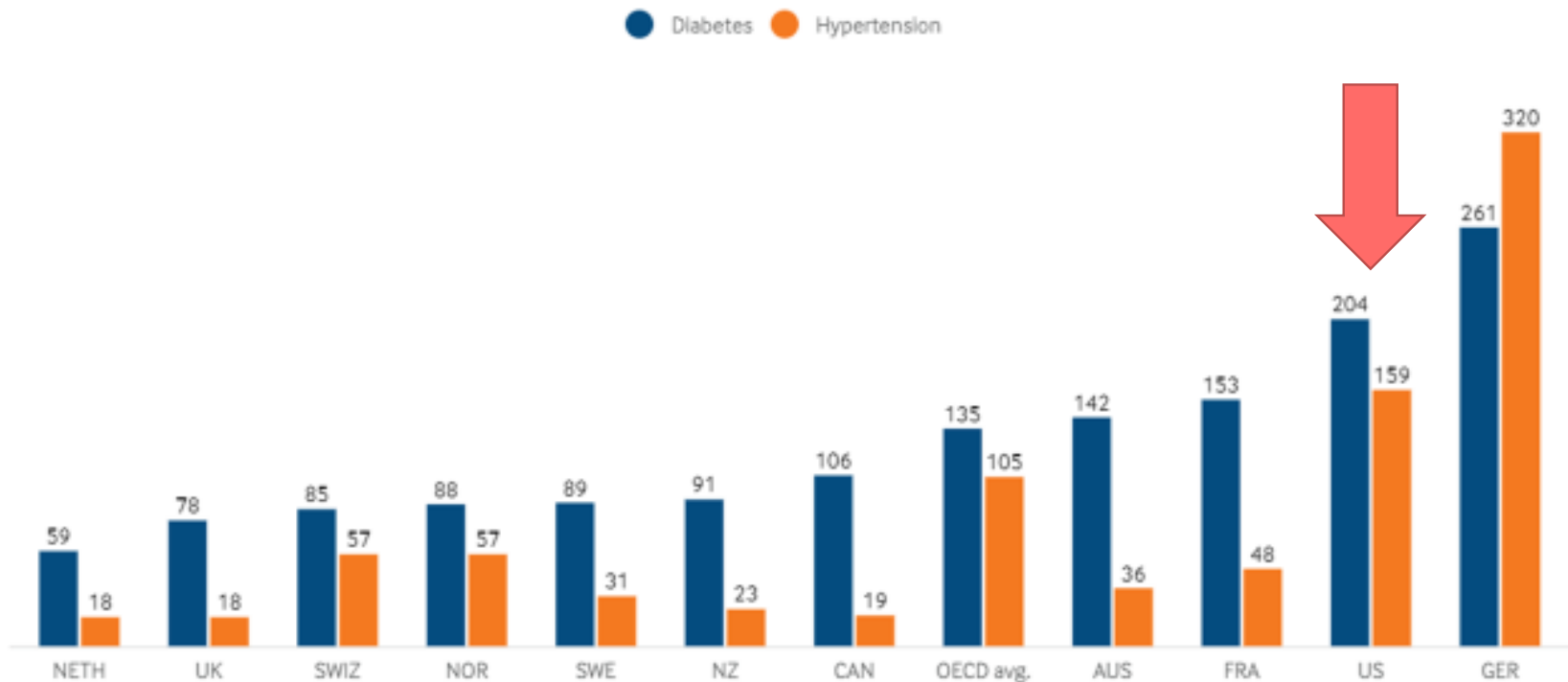
11-country average: 17.5%



QUALITY AND CARE OUTCOMES

The U.S. Has Among the Highest Rates of Hospitalizations from Preventable Causes Like Diabetes and Hypertension

Discharges per 100,000 population

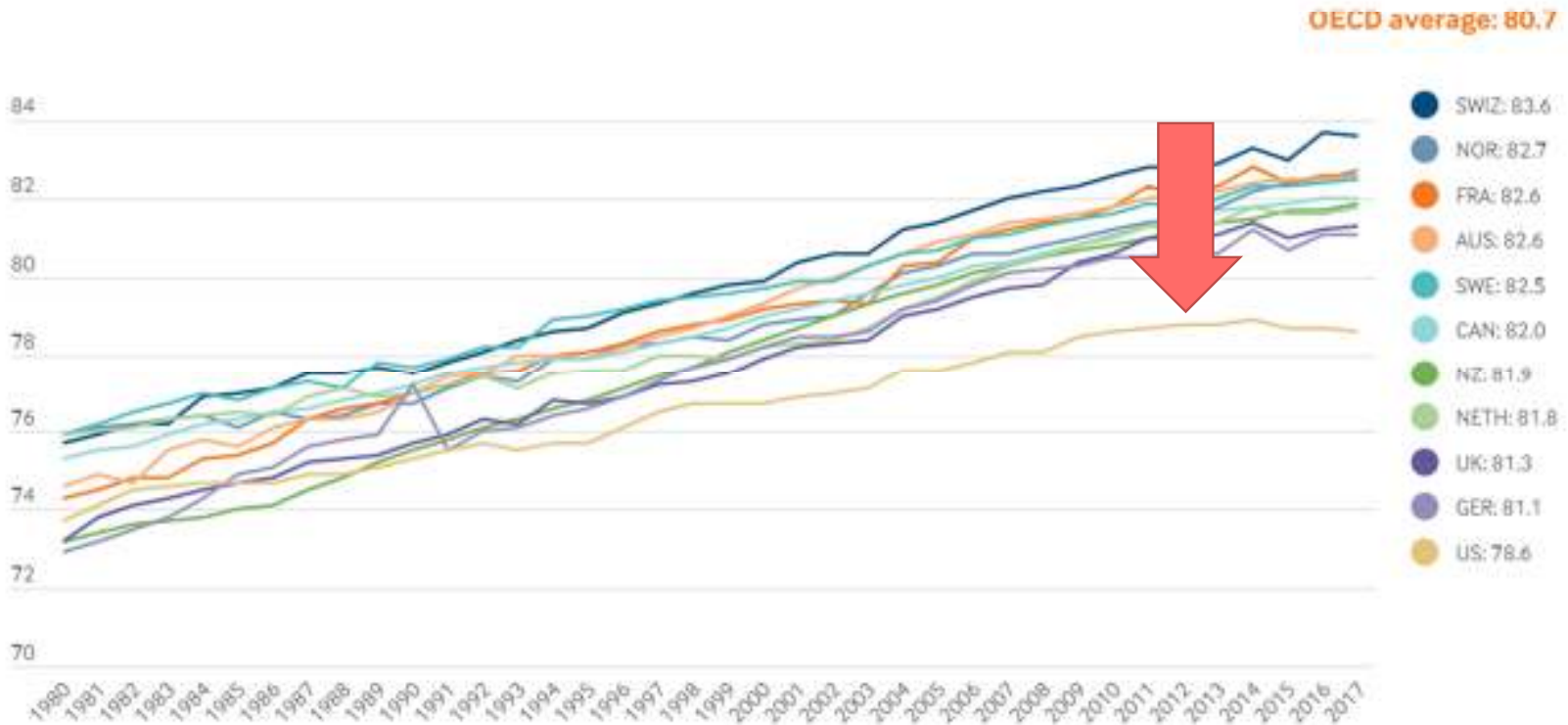


HEALTH OUTCOMES

The U.S. Has the Lowest Life Expectancy

Years

Legend shows 2017 data

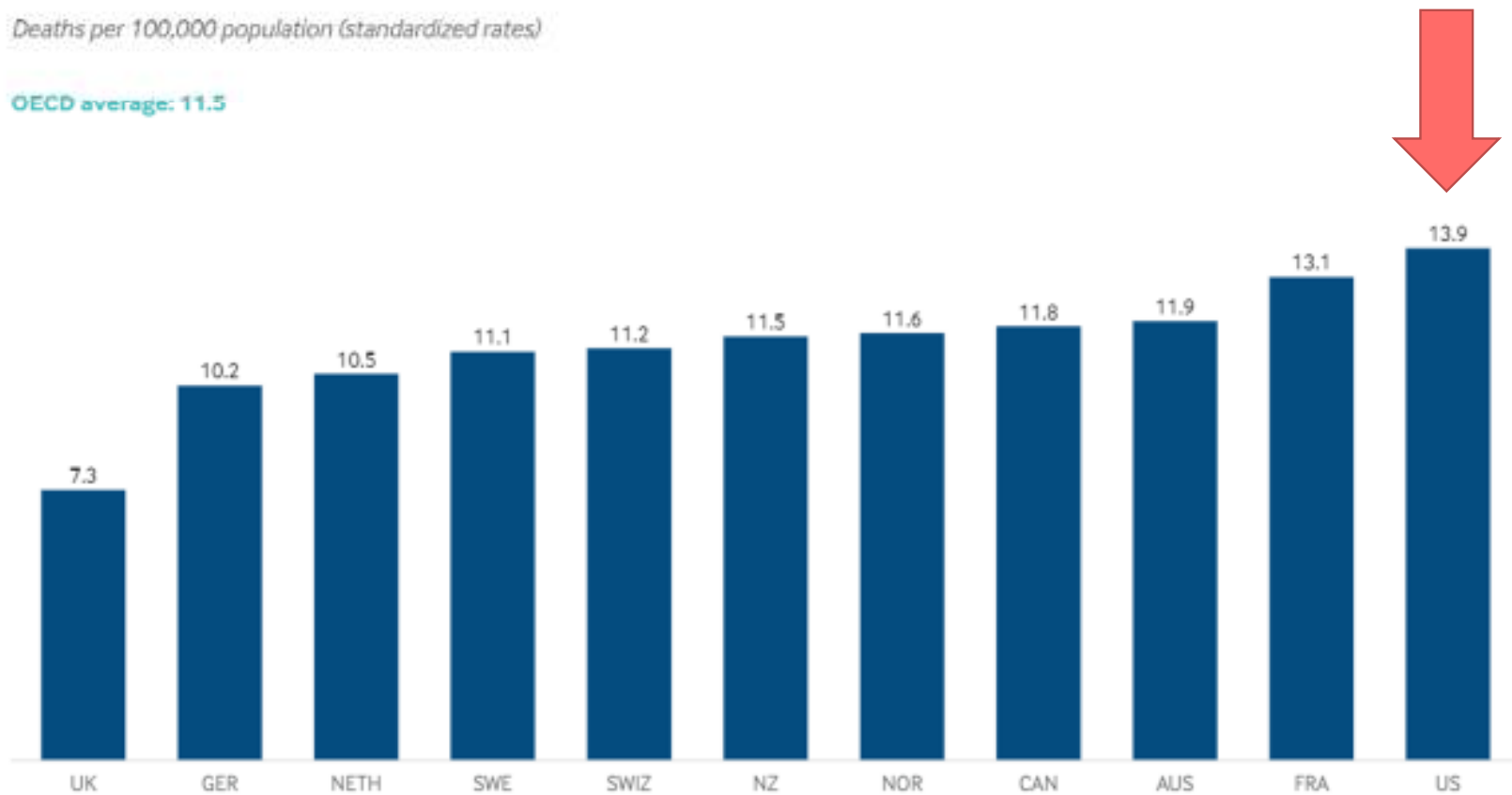


HEALTH OUTCOMES

Suicide Rates Are the Highest in the U.S.

Deaths per 100,000 population (standardized rates)

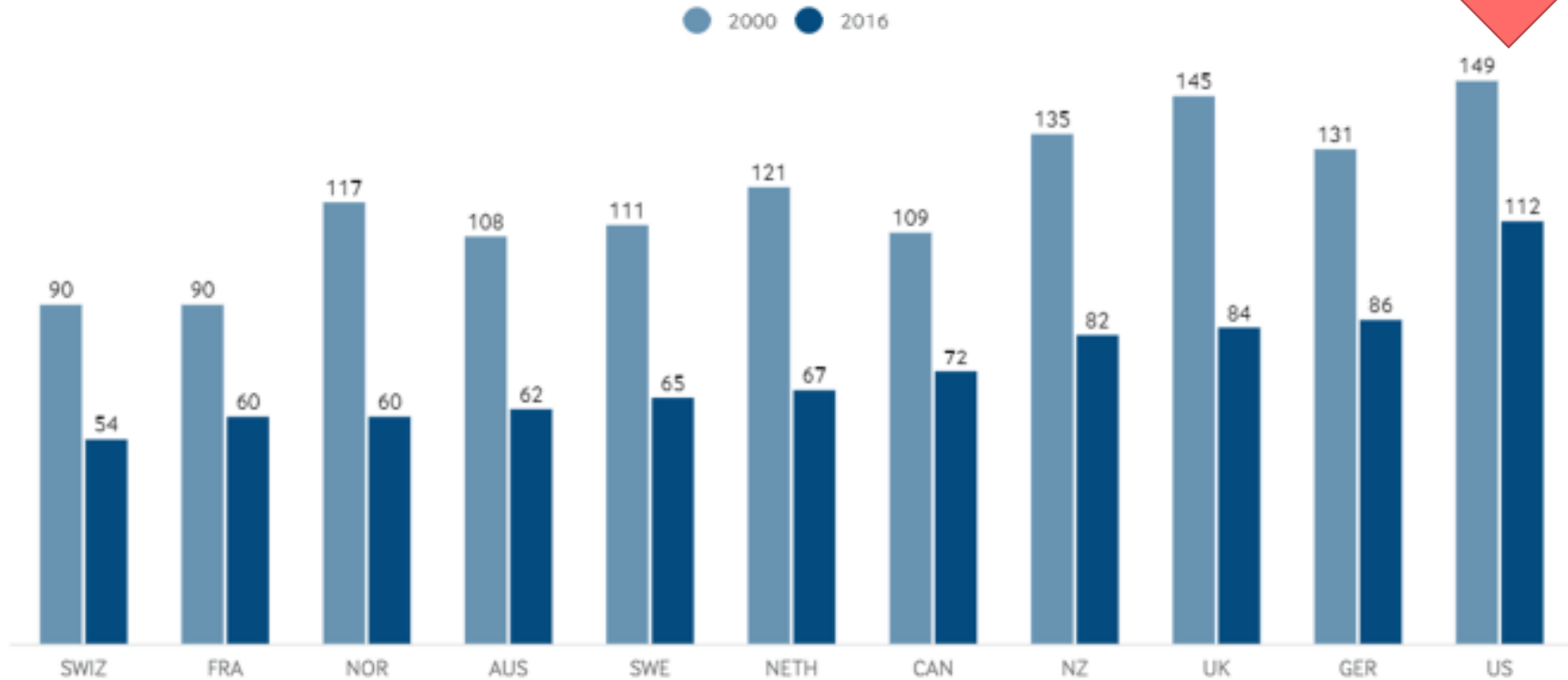
OECD average: 11.5



QUALITY AND CARE OUTCOMES

The U.S. Has the Highest Rate of Avoidable Deaths

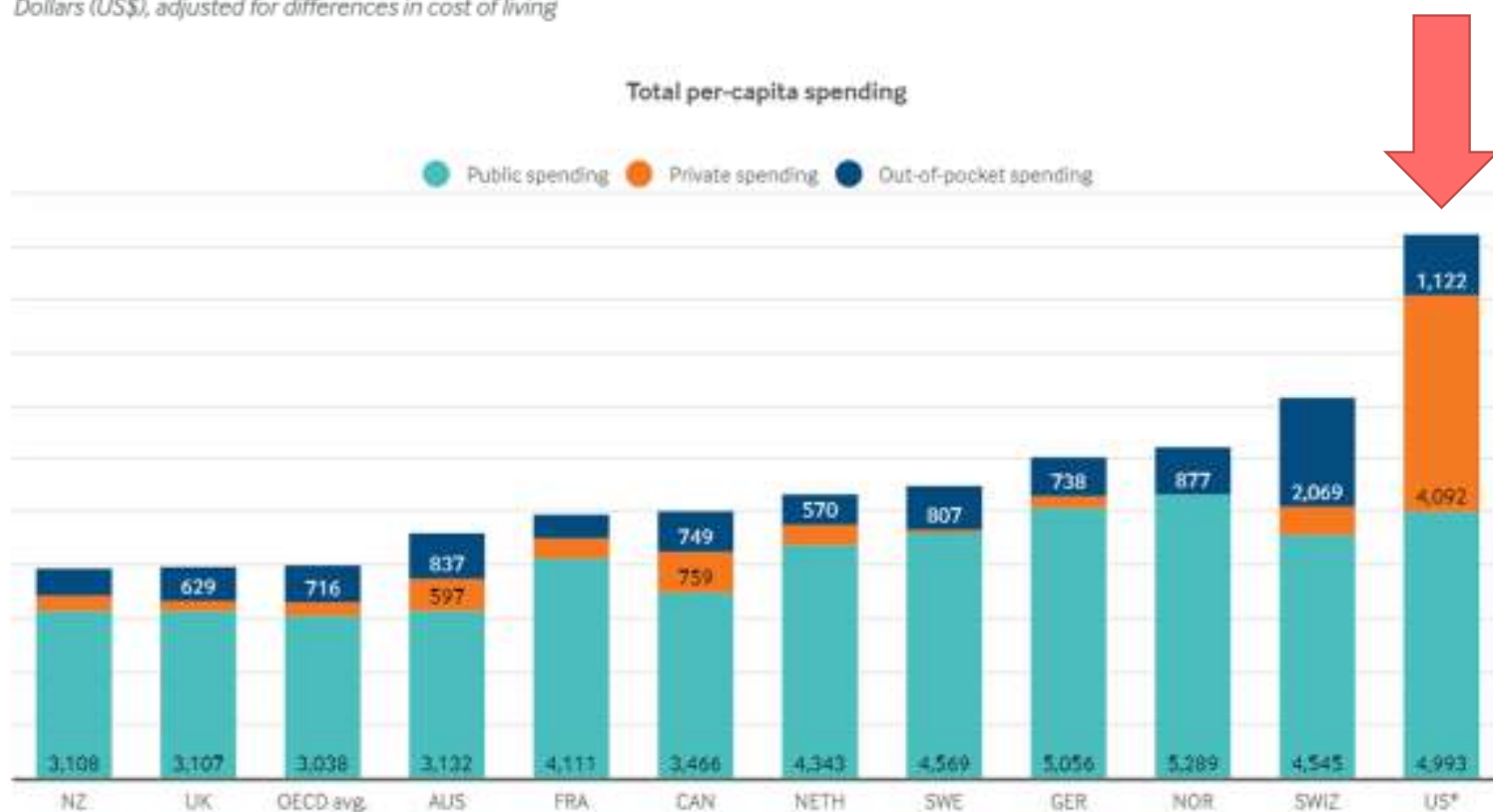
Deaths per 100,000 population



SPENDING

U.S. Public Spending Is Similar to Other Countries; Out-of-Pocket and Private Spending Are Higher Than Most

Dollars (US\$), adjusted for differences in cost of living



Self Reflection

- Do you consider yourself a true advocate for your patients?
 - Yes, all the time
 - Usually
 - Sometimes
 - Not anymore, I could do better
 - Never
 - I don't know what to think anymore

Can't let our fight for a voice on the healthcare team compromise the patient voice.

- Pharmacists have been fighting for their voice on the care team too.
 - 1915 Abraham Flexner Speech
 - Pharmacy was not a profession – a physician “thinks, decides, and orders; the pharmacist obeys—obeys of course with discretion, intelligence, and skill-yet in the end obeys and does not originate.”



Strategies & Action Items

(Evaluate patient advocacy strategies pharmacists can use to engage patients in their healthcare.)

What can I do?



Patient Advocacy

- How do I ensure that **patients have a voice in their care?**
- How do I make sure that **patients have sufficient information** to promote informed decision making?
- How do I ensure that a **patient's wishes are the guiding force behind decisions** affecting medical care and the withholding of care?
- How do I help patients **navigate** the healthcare system?

The Advocacy Spectrum

Medical Advocacy

Patient Advocacy

Provide a clinical
service

Empower patients in their
care

Give advice

Give information

Give a recommendation

Informed decision making



**LITTLE
BY LITTLE,
A LITTLE
BECOMES
A LOT**

Personal Projects

Behappy.me



Strategy 1:

Give patients a **voice** in their care.

Action Items



Be Aware of and Control Biases and Stereotypes



Listen to Understand Patients



Encourage Active Communication from Patients

Be Aware of and Control Biases and Stereotypes



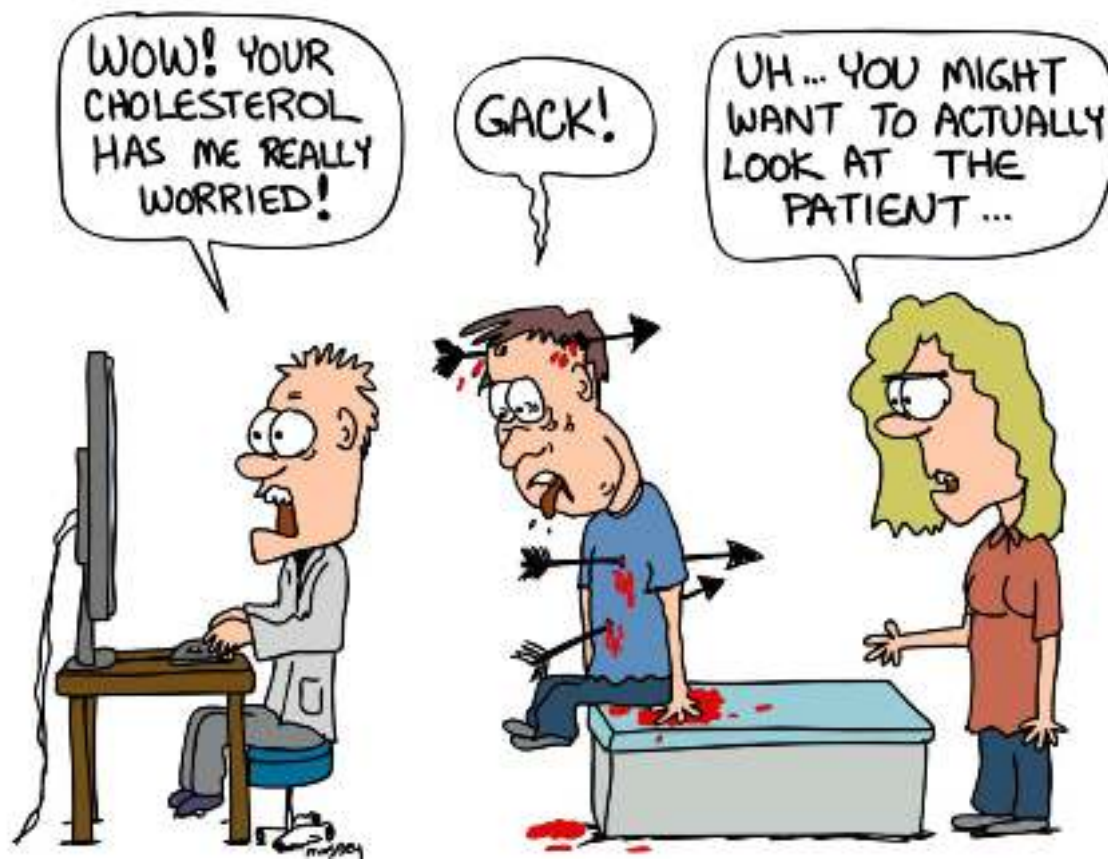
- **Be Aware**

- Attend cultural humility trainings from people of diverse backgrounds
- Engage in opportunities to have positive interactions with people of other groups
- Reflect on your own positive and negative stereotypes
- Take implicit biases tests



- **Control**

- Use self-awareness skills to recognize and prevent biases in personal and healthcare interactions



Listen to
Understand
Patients

Encourage
Active
Communication
from Patients





Strategy 2:

Make sure that patients have **sufficient information** to promote informed decision making.

Action Items



Assess Understanding



Accept and Adapt to Patients using the Internet



Refer to Someone with Expertise



Provide Questions to Ask



Assess Understanding

- Upon discharge from a hospital:
 - 58% of patients thought that physicians always explained things in a comprehensible way
 - 57% of patients knew their diagnosis
 - 77% of providers believed patients knew their diagnosis
 - 10% of patients reported being told of adverse effects for new medications
 - 81% of providers stated they discuss adverse effects with patients

THE PATIENTS KNOW MORE ABOUT
THEIR DISEASES THAN ME. I MUST
GET FASTER MODEM, HIGHER
SPEED INTERNET ACCESS THAN
THEM



© Мозгосна .

Accept and Adapt to Patients using the Internet

- 80% of Internet users in the US have searched for a health-related topic online
 - 63% Specific disease or medical problem
 - 47% Medical treatment or procedure
 - 44% Diet, nutrition, and vitamins
 - 36% Exercise or fitness information
 - 34% Prescription or over-the-counter drugs
 - 28% Alternative treatments
 - 25% Health insurance
 - 21% Depression, anxiety or stress
 - 21% Particular doctor or hospital
- Help patients filter and understand



Refer to Someone with Expertise

Herbalist

Aromatherapist

Lactation
Consultant

Nutritionist/
Dietician

Therapists

Medical Biller

Patient
Navigator

Guardianship
Attorney

Provide Questions to Ask

How do I know if my condition is improving or worsening?

How will my health issues impact what I do everyday?

What will happen if we don't treat my condition today?

What are my treatment options?

What are the possible benefits and harms of my options?

How likely are each of these to occur?

Are there any non-medication therapies that can support me?

What is the importance of the tests and procedures ordered?

Are there any specialists that can help with my health concern?



Strategy 3:

Ensure that a **patient's wishes** are the guiding force behind **decisions**.

Action Items



Determine Expectations and Goals for the Encounter



Ask Patients for their Wishes and Interests



Determine how involved a Patient wants to be in Decision-Making



Recognize Grey Areas in Evidence and Limitations in Extrapolation



Give Patients Realistic Choices with Empathy

Determine Expectations and Goals for the Encounter



- What are you here for?
- What do you want?
- What do you need?



- What are your expectations or goals for this visit?
- What are you hoping we accomplish today?

- Care for routine surveillance
- Test results
- Discussion of treatment options
- Evaluation of the effectiveness of treatment
- Relief of symptoms
- Causal explanation about the disease or symptoms
- Dispelling of fears (the patient's or the family's) that serious disease is present
- Consideration of decisions about current and future care
- Administrative purposes (work excuse, prescription refill)

Ask Patients for their Wishes and Interests

Medications?

Quantity of Life

Quality of Life

Side Effect Tolerance?

Procedures?

Living with Disease

Cost?

Supportive Care?

Disease Elimination

Comfort

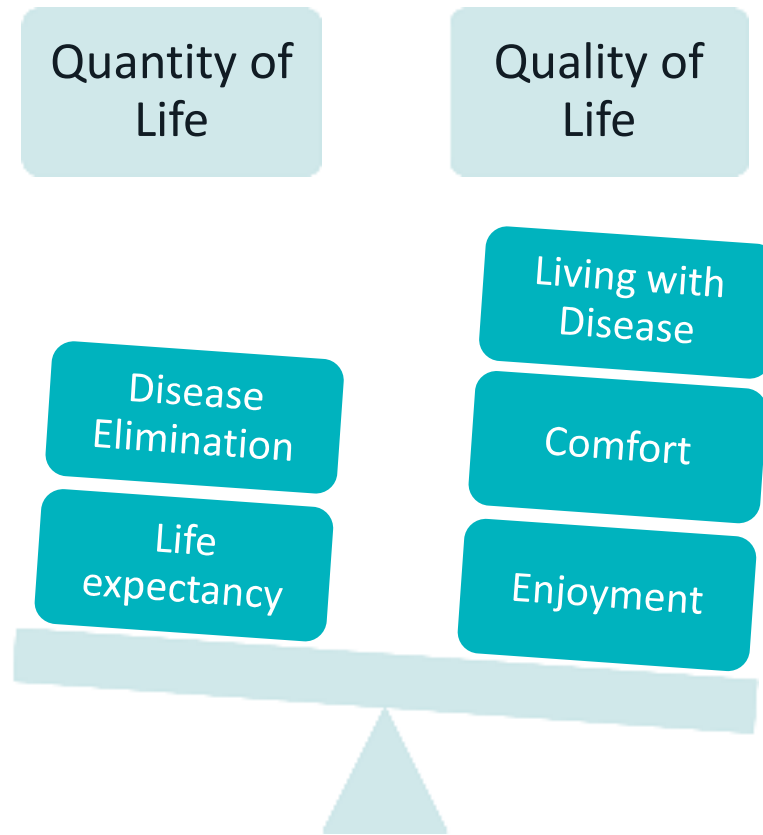
Alternatives?

Life expectancy

Enjoyment

Emotional Effects?

Testing?



Determine how involved a Patient wants to be in Decision-Making

- Healthcare professionals are not good at determining patients' preferences for involvement in decision-making

Decision-making spectrum

Paternalistic

Clinician decides treatment

Shared

Clinician and patient together decide treatment


Informed

Patient decides treatment based on information from the clinician and other sources

Recognize Grey Areas in Evidence and Limitations in Extrapolation

- There is more uncertainty than certainty
 - British Medical Journal clinical evidence summary, 89% (of 3,000 treatments) do not have clear benefits for the majority
- Probabilities of risks and benefits in a population cannot always be applied to the individual patient
 - Out of xx patients, yy will benefit from a treatment— but we do not know which patients these are
- Patient's preferences play an even more important role when there is clinical uncertainty, ambiguity, or simply an absence of sufficient evidence.





*“Wherever the art of
medicine is loved, there is
also a love of
humanity.”*

Hippocrates

FamousQuotes123.com

Give Patients
Realistic
Choices with
Empathy



“What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?”



Strategy 4:

Help patients **navigate** the healthcare system.

Action Items



Help Patients Understand the Healthcare System



Don't Ghost your Patients



Refer to an Independent or Private Patient Advocate

Help Patients Understand the Healthcare System

- Satisfaction: difference between what one expects and what occurs
- Educate patients about expectations for the healthcare system
 - Navigating between multiple care providers
 - Obtaining medication and medication request processes
 - How to follow-up
 - Insurance nuances
 - The roll of healthcare professionals and workers
 - Breakdowns in communication
 - Medical records access and personal record keeping
 - Patients rights



Don't Ghost
your
Patients

Refer to an Independent or Private Patient Advocate

- Patient advocates have a wide array of expertise.
 - Find one that can help with the needs of your patient.
- Websites to find an independent advocate:
 - [Greater National Advocates](#)
 - [Patient Advocate Certification Board](#)
 - [The AdvoConnection Directory](#)
- May need to search the internet too





GET
TO KNOW
US!

GET TO
KNOW ME
FIRST!



We are all PATIENTS!

Stacie Lampkin (she/her), PharmD, BCPPS, BCPA, CA

April 22, 2021

References

- AMA. Medical code of ethics. 1847. Available from: https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/ethics/1847code_0.pdf Accessed Sept 18, 2020.
- Associated Press-NORC Center. Finding quality doctors: how Americans evaluate provider quality in the United States. 2014. Available from [URL:https://apnorc.org/wp-content/uploads/2020/02/Finding-Quality-Doctors-Research-Highlights.pdf](https://apnorc.org/wp-content/uploads/2020/02/Finding-Quality-Doctors-Research-Highlights.pdf) Accessed Sept 17, 2020.
- Beckes's Healthcare. Are patient satisfaction surveys doing more harm than good?. Available from: <https://www.beckershospitalreview.com/quality/are-patient-satisfaction-surveys-doing-more-harm-than-good.html> Accessed Sept 17, 2020.
- Blair L, Légaré F. Is Shared Decision Making a Utopian Dream or an Achievable Goal?. *Patient*. 2015;8(6):471-476.
- Brewminate. A brief history of the pharmacy in the United States. 2019 Available from: <https://brewminate.com/a-brief-history-of-the-pharmacy-in-the-united-states/> Accessed Sept 18, 2020

References

- Butkus R, Rapp K, Cooney TG, Engel LS; Health and Public Policy Committee of the American College of Physicians. Envisioning a Better U.S. Health Care System for All: Reducing Barriers to Care and Addressing Social Determinants of Health. *Ann Intern Med.* 2020;172(2 Suppl):S50-S59.
- DeVoe JE, Wallace LS, Fryer GE Jr. Patient age influences perceptions about health care communication. *Fam Med.* 2009;41(2):126-133.
- Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implement Sci.* 2016;11:114. Published 2016 Aug 8.
- Epstein RM, Street R: Patient-centered communication in cancer care: promoting healing and reducing suffering. National Cancer Institute, NIH Publication No. 07–6225. 2007.
- Fenton JJ, Jerant AF, Bertakis KD, Franks P. The cost of satisfaction: a national study of patient satisfaction, health care utilization, expenditures, and mortality. *Arch Intern Med.* 2012;172(5):405-411.

References

- Fox S, Fallows D. Pew Research Center. Internet Health Resources: Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access. 2003. Available from https://www.pewinternet.org/wp-content/uploads/sites/9/media/Files/Reports/2003/PIP_Health_Report_July_2003.pdf Accessed Sept 21, 2020.
- Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207-214.
- Jung HP, Baerveldt C, Olesen F, Grol R, Wensing M. Patient characteristics as predictors of primary health care preferences: a systematic literature analysis. *Health Expect*. 2003;6(2):160-181.
- Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns*. 2008;73(3):526-535.
- Levetown M, at the Committee on Bioethics. Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information. *Pediatrics* 2008; e1441-60.

References

- Medpage today. Racial bias in flexner report permeates medical education today. Available from:
<https://www.medpagetoday.com/publichealthpolicy/medicaleducation/87171>
Accessed Sept 18, 2020.
- Moseley GB. The U.S. Health care non-system, 1908-2008. *Virtual Mentor*. 2008;10(5):324-331. Published 2008 May 1.
- National Research Council (US); Institute of Medicine (US), Woolf SH, Aron L, eds. *U.S. Health in International Perspective: Shorter Lives, Poorer Health*. Washington (DC): National Academies Press (US); 2013.
- Patient Advocate Certification Board. PACBoard. Patient Advocacy vs Medical Advocacy: View from the PACB. 2016. Available from URL:
<https://www.pacboard.org/2016/03/09/patient-advocacy-vs-medical-advocacy-view-from-the-pacb/>. Accessed Sept 14, 2020.
- Perrault EK, Beal JL. The effect of pharmacy setting and pharmacist communication style on patient perceptions and selection of pharmacists. *J Am Pharm Assoc (2003)*. 2018;58(4):404-411.

References

- Puddifoot K. Stereotyping Patients. *J Soc Philos.* 2019;50(1):69-90.
- Robbins A. The Atlantic. The problem with satisfied patients. 2015. Available from: <https://www.theatlantic.com/health/archive/2015/04/the-problem-with-satisfied-patients/390684/> Accessed Sept 17, 2020.
- Sofaer S, Firminger K. Patient perceptions of the quality of health services. *Annu Rev Public Health.* 2005;26:513-59.
- Tikkanen R, Abrams M. The Commonwealth Fund. U.S. Health Care from a global perspective, 2019: higher spending, worse outcomes. 2020. Available from: <https://www.commonwealthfund.org/publications/issue-briefs/2020/jan/us-health-care-global-perspective-2019> Accessed Sept 19, 2020
- University of California San Francisco. 1919–1939 The Formation of Schools and the Rise of Clinical Science Instruction. Available from: https://history.library.ucsf.edu/1919_pharmacy.html#:~:text=In%20a%20speech%20in%201915,profession%20was%20stung%20by%20this Accessed Sept 18, 2020