


*Shared Decision Making:
The Role of the Health Care Team in Empowering Health Care Consumers*
June 7, 2017

**Shared Decision Making:
The Role of the Health Care Team in Empowering Health Care Consumers**


Archelle Georgiou, MD
President, Georgiou Consulting
Author, Healthcare Choices
June 7, 2017



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Introduction to Today's Topic

Moderator




Mary Jo Jerde, MBA, BSN, RN
Senior Vice President
Center for Clinician Advancement
UnitedHealth Group
Minnetonka, MN

Presenters



Archelle Georgiou, MD
President
Georgiou Consulting, LLC
University of Minnesota
Carlson School of
Management
Adjunct Faculty
Minneapolis, MN



Kristyn VanderWaal Mills,
PhD
Biology Professor
Anoka Technical College
Anoka, MN

Shared Decision Making

- ⇒ Not just a passing trend
- ⇒ Has various names/methods
- ⇒ Improves health care quality and safety
- ⇒ Important for any and all clinicians

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Health (Insurance) Reform

Congressional Budget Office (CBO) analysis of American Healthcare Act (AHCA) (compared to Affordable Care Act (ACA))

- Overall lower premiums in 2026
 - ↓ 4% (states w/o waivers)-1/2 of population
 - ↓ 20% (states w/ moderate waivers)-1/3 of population
- BUT...unaffordable for less healthy
- Uninsured in 2026
 - Under ACA: 28 M
 - Under AHCA: 51 M



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Health Care Continuum



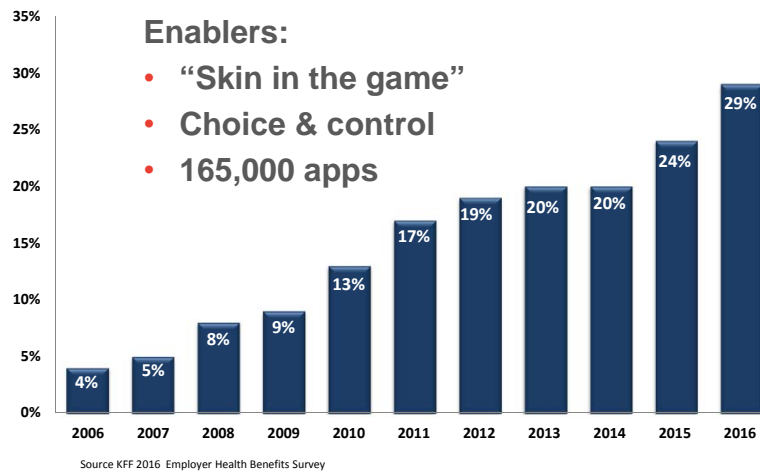
Facts:

- **62%** of patients want to participate in health care decisions;
- Only **20%** of patients raise the topic of treatment alternatives; and,
- Cancer patients' decisions were concordant with clinicians' only **38%** of the time.

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Consumer-Directed/High-deductible Health Plan (HDHP)
Was Designed To Fix This!



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Good News: Cost Sharing Creates Consumers...





Medical Cost:
12-14% decrease

Utilization:
18% decrease

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Good News: Cost Sharing Creates Consumers...

	
Medical Cost: 12-14% decrease	No use of cost comparison tools 15% logged in 1x
Utilization: 18% decrease	Preventive services: 10% decrease

Brot-Goldberg, et al, NBER Working Paper No. 21632, Issued in October 2015

...but not necessarily good consumers

Why Patients Delegate Their Health Care Decisions

- **American core values:**
Traditional
 - Americans ask for permission
 - Language/clothing is hierarchical
 - Perceived power imbalance
- **Complexity of health care**
 - Not confident due to lack of medical knowledge and inability to understand medical jargon.
- **Regulatory definition of “care.”**
 - Doesn't place value on self-care or care/support provided by family, friends, and community.
 - “Find it and fix it”



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Carol

"Hi, guys. You probably guessed that something was up. Bottom line: I was just diagnosed with breast cancer. I have a lumpectomy scheduled next week. Then I'll get radiation. Do you think this is the right decision? I asked my doctor what she would do. She said I could get a mastectomy but she didn't talk a lot about it. I just want someone to tell me what to do. I am too emotional to talk so just let me know what you think by email for now. Thanks. Love you. Carol"

"I just want someone to tell me what to do"



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What Decision-Making Should Look Like

	Clinician	Carol
Need for breast cancer treatment	✓	
• Lumpectomy/radiation vs. mastectomy		✓
• Reconstruction		✓
• Oncologist	✓	✓
• Radiation Therapist	✓	✓
BRCA testing	✓	✓
• Contralateral mastectomy if BRCA+		✓

✓ ONLY Carol can decide

The Reality:

93% of primary care physicians (PCPs) support shared decision-making
10% do it

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Having choices doesn't mean:

...people are *aware* that they have choices

...people feel *empowered* to make choices

...people know how to make *good* choices

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Focusing on the Patient

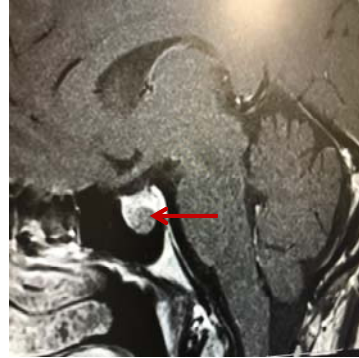
- A change is required to the usual way we do things
- The change will take time for all of us
- We all have a role to play in:
 - Supporting our patients
 - Supporting each other



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Consumer Perspective: Early Experience in Health Care

- Treatment happened *to* me as a patient, not *with* me as a patient
- Felt a lack of personal connection with the medical professional
- As a patient, I wanted to understand what was happening, but did not know the questions to ask or places to research



Prolactinoma next to pituitary gland

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Evolution of Perceptions and Experiences



My miracle baby (now 4)

- There are medical professionals who are willing to truly discuss treatment, but some are not. (I've got good, bad, and ugly stories)
- I have a running log of appointments, tests, discussions, questions, etc. I have my own comments in there as well. Sort of a personal medical journal.

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Consumer Barriers To Making The Right Decision

- Lack of knowledge by me personally – so, I do research ahead of time using reputable sources and bring my questions and sources to the appointment.
- Not all clinicians are willing to work with me and my opinions. It is very frustrating when my voice is not heard – I wish I had a solution to this.
- Unfortunately, cost and insurance coverage are big barriers – so, I need to constantly call insurance carrier.

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Health Care Team: Barriers To Shared Decision-Making

- Not enough time
- Lack of decision aids
- Don't understand SDM
 - NOT: "This is what I recommend–how does that sound"
 - NOT: Informed consent
- Belief/worry that patients aren't capable of understanding the evidence
- Belief that patients don't want to be involved in decision making
- Worry that a discussion will diminish the patient's confidence in the professional expertise

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Making Informed Choices

- ↑ Knowledge
- ↑ Risk Perception
- ↑ Alignment of Values
- ↑ Realistic Expectations
- ↓ Decisional Conflict



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Decisional Conflict

- Definition: Uncertainty about what action to take
- Symptoms:
 - Wavering between choices
 - Concern about bad results
 - Decision delays
 - Distress/anxiety
 - Pre-occupation/with decision



↓
Regret

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Improving Shared Decision Making

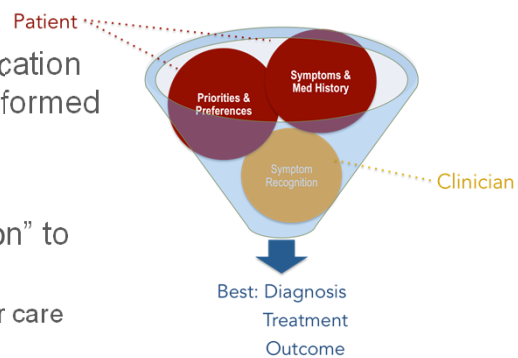
Information is available to:

- Educate yourself and be encouraged so you can...
- Inform and encourage your team to...
- Support and encourage patients, their caregivers and families.



Clinical Professionals Have An Important Role

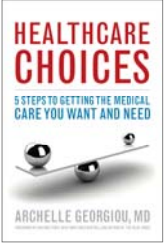
- Clinical/medical experts
- Offer guidance and education to help patients make informed choices
- “Give patients permission” to be
 - active participants in their care
 - experts...in themselves



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CARES MODEL

- C** UNDERSTAND YOUR **C**ONDITION
- A** KNOW YOUR **A**LTERNATIVES
- R** RESPECT YOUR **P**REFERENCES
- E** **E**VALUATE YOUR OPTIONS
- S** START TAKING **A**CTION



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C UNDERSTAND YOUR **C**ONDITION



Explain: “So what?”

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Deb: 56 y.o.

Sx: 4 day history of red, hot, swollen tender knee, fever



“You may have a septic knee!”

SO WHAT?

“You may have an infection in your knee that can quickly destroy the cartilage.”

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Understand Your Condition

- **People overestimate what they really know about their disease**
 - Only 50% of public can identify the location of body organs; fewer know their function
 - Example: 77% of BMT patients thought they had enough information, but only about 52% demonstrated knowledge of the facts.
- **Use the Internet, but avoid Dr. Google**
 - Only 39% of top sites searched give correct health information
 - Recommend “go to” health information sites for your research.
 - MayoClinic.org has a clear, predictable layout across all their health topics.
- **Example:** 90% of patients with DVT purchased the compression stockings that can prevent recurrence
 - <60% wear them consistently for even a month
 - 22% don’t wear them at all

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A KNOW YOUR **A**LTERNATIVES



“What else?”



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Overcome Your Own Bias/Perceptions

DON'T

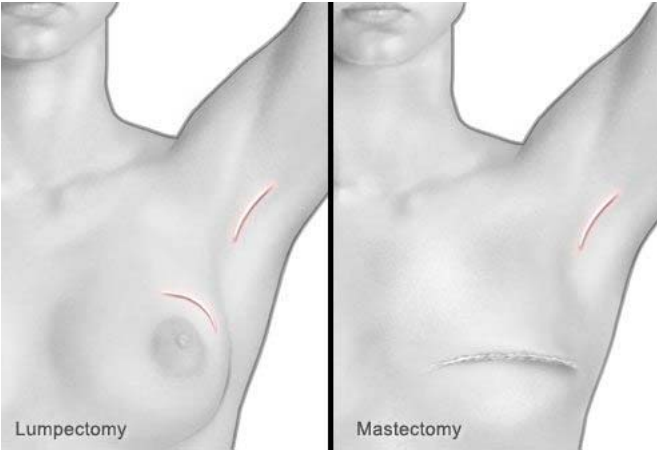
- “This is my recommendation.”
- “This is what I would do.”
- This is the “best” treatment
- Discourage evidence-based alternatives
- Example: Cancer-related nausea

DO

- Be objective
- Describe risk/benefit as “1 in _____”
- Medical risk/benefits
- Social/Quality of Life
- Cost: out of pocket; time away from work
- Encourage them to come prepared with 3 questions

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R RESPECT YOUR **P**REFERENCES



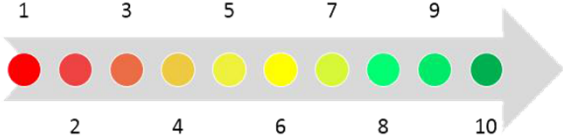
Lumpectomy Mastectomy

“What matters?”

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Preferences & Priorities

- Definitions:
 - Priority: what is most important
 - Preference: what is most desirable
- Encourage patients to articulate their treatment goal:
“Why do you want to get treated?”



1 3 5 7 9

2 4 6 8 10

“On a scale of 1-10, how willing/comfortable/able are you to:

- Take take medical risk?
- Live with short-term quality-of-life (QOL) impact?
- Live with long-term QOL impact?
- Make financial commitment to care?

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E EVALUATE YOUR OPTIONS



“What gives you peace of mind?”

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Deliberate

adjective

də'lib(ə)rət/

done consciously and
intentionally.

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“Dr. Meera, this is my choice”

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S START TAKING **A**CTION



“What next?”

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How have you made health care decisions and what were the results?

- I use CARES model, or similar lines of logical reasoning that also consider my own values.
- I am willing to alter my view when new research data and new medical tests challenge my decision.

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Advice to Health Care Professionals On Supporting Consumers' Care Decisions

- It is empowering to have your voice heard as a patient.
- Many, if not most, patients do not know how to find good information. Provide us a way to research conditions and tests.
- Time spent with the patient is the most valuable. Maximize face-to-face and personal contact.

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Your Role: Enable Consumer Empowerment

...people are *aware* that they have choices

- Encourage patients to be actively engaged/asking questions
- Make it a “prescription”; their responsibility

...people feel *empowered* to make choices

- Separate your professional expertise from personal preferences/bias
- Reinforce importance of shared expertise
- Encourage deliberation; “It’s okay to think about it”

...people know how to make *good* choices

- Direct toward evidence-based resources
- Guide patients through decision-making framework

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CARES MODEL

C

UNDERSTAND YOUR **C**ONDITION

A

KNOW YOUR **A**LTERNATIVES

R

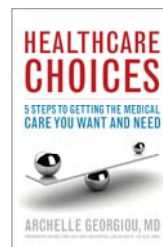
RESPECT YOUR **P**REFERENCES

E

EVALUATE YOUR OPTIONS

S

START TAKING **A**CTION



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More Tools and Resources

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE
Transforming health care through partnerships

Google Custom Search

About Us Our Services Educational Programs Resources Profiles of Change PFCC Best Practices

What is patient- and family-centered care

PATIENT ENGAGEMENT & HEALTHCARE VALUE

Institute for Healthcare Improvement
Improving Health and Health Care Worldwide

ABOUT US TOPICS EDUCATION RESOURCES REGIONS

Person- and Family-Centered Care

Introduction
Overview
Getting Started
Education
Resources

RELATED TOPICS
Analysis Events
"What matters"

Strategies for LEADERSHIP
ADVANCING THE PRACTICE OF Patient- and Family-Centered Care

A Resource Guide for Hospital Senior Leaders, Medical Staff and Governing Boards.

Crossing the QUALITY CHASM
A New Health System for the 21st Century

Questions?

Archelle Georgiou, MD
Twitter: @ArchelleMD



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In Closing

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