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Occupational Therapy and Primary Care: The Role of Patient Engagement

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Disclosure

- Nothing to disclose

In Memory of Jessie C. Gruman, PhD who taught me to be an engaged patient
Learning Objectives

■ Discuss the evidence that supports patient engagement
■ Explain barriers to patient engagement for people with disabilities and multiple chronic conditions
■ Promote patient engagement as a way to improve participation in health management and maintenance and as an element of primary care.

Where’s the Patient?

www.molecularecologist.com
Case Study - Bill

- Bill has a chronic condition called medullary sponge kidney.
- He produces small kidney stones that pass on their own accompanied by a few days of severe pain.
- He recently moved across country for his job.
  - He finds a new primary care provider (PCP) and prepares for his first visit.

Bill Prepares for PCP Visit

- He prints a copy of the National Institute of Health’s (NIH) information sheet on Medullary Sponge Kidney.
- He prints his last kidney function lab results, and the results of his genetic testing for drug metabolism from his electronic health record from his PCP. He takes them for his condition.
He shows up at his first appointment prepared to explain medullary sponge kidney to his new PCP, and the pain meds he takes for his condition.

http://www.kidneystoners.org/information/what_is_medullary_sponge_kidney/

- His new PCP wants to change his pain medication.
- Bill explains that what he takes now works. He is concerned that a different medication might not work because he has had been tested for genetic metabolites.
  - He is also concerned about how a different medication will react with the medications he takes for his type-2 diabetes and high blood pressure.
Some PCPs might appear shocked by Bill’s behavior.

Some might feel that Bill is taking over the PCP visit when the PCPs are supposed to be in control.

Bill is not allowing the PCP to do his/her job. Is this unusual? Should it be unusual?

Bill is an E-Patient

Engaged

Equipped

Enabled

Empowered

E-Patients
E-Patient Defined

- Visionary Tom Ferguson coined the term “e-patients” to describe patients equipped, enabled, empowered, and engaged in their health and health care decisions. (Ferguson, 2007)
- He also coined the term “Participatory Medicine.”

What is Participatory Medicine?

- A movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.
Patient-Provider Relationship

- An equal partnership between e-patients and the health providers and systems that support them (Ferguson, 2007)

Patients & Providers Share Goals

- In the pain world for example:
  - Lessen pain
  - Increase awareness causes of pain
  - Improve treatment of pain
  - Improve quality of life
Medical Community Perspective

- The medical community recognizes the need to treat pain.
- There are initiatives in the literature that focus on quality measures, practice guidelines, and system changes directed at changing actions and behaviors of medical professionals or medical systems. (see ie, Gordon et. al. 2002)

Example

- Fifth vital sign movement
  - VA – asked patients to rate their pain
  - Change in provider/system behavior
  - Study looked at 7 process indicators
  - Subjective provider assessment; pain exam orders to assess pain, new analgesic, change in existing analgesics, other pain treatment or follow-up plans.
  - Did not improve quality of pain management
Joint Commission Initiative

- Recognize the right of patients to appropriate assessment and management of pain
- Screen patients for pain during their initial assessment and, when clinically required, during ongoing, periodic re-assessments
- Educate patients suffering from pain and their families about pain management

Patient Education Not Enough

- Education is only a part of patient engagement.
Patient Engagement

- Center for Advancing Health defines patient engagement as “actions individuals must take to obtain the greatest benefit from the health care services available to them.” (Center for Advancing Health, 2010)

Engaged Patients

- Engaged patients have been called “the blockbuster drug of the 21st century.” (Kish, 2012)
What Does the Evidence Show?

Benefits of the “Blockbuster Drug:” Patient Engagement

- Patient engagement benefits everyone in the health care relationship.
- Research shows patient engagement
  - Improves health outcomes,
  - lowers costs,
  - Improves patient care, and
  - Decreases medical errors (James, 2013)
More Benefits

- Research also shows that engaged patients with chronic conditions are more likely to adhere to treatment regiments. (James, 2013)

What Does it Mean for Patients?

- Patients need to drive their own care.
- They need to become experts in their condition.
- They need to become engaged in their own care or the care of those for whom they serve as caregivers.
What Does it Mean for Providers?

- The realization that
  - Your desired outcome is not necessarily the patient’s desired outcome
  - The health care relationship is an equal partnership
  - Patient’s matter

- Most providers find this difficult to accept and this creates a barrier to patient engagement

Where Does Occupational Therapy Fit In?
The Triple Aim

“Improving the U.S. health care system requires simultaneous pursuit of three aims: improving the experience of care, improving the health of populations, and reducing per capita costs of health care.”

(Berwick, Nolan, & Whittington, 2008)

3-Legged Stool

Population Health

Patience Experience of Care (quality)

Per Capita Cost of Health Care
The Triple Aim

“Preconditions for this include the enrollment of an identified population, a commitment to universality for its members, and the existence of an organization (an “integrator”) that accepts responsibility for all three aims for that population.”

“The integrator’s role includes at least five components: partnership with individuals and families, redesign of primary care, population health management, financial management, and macro system integration.”

“The remaining barriers to integrated care are not technical; they are political.”

(Berwick, Nolan, & Whittington, 2008)
Enter Affordable Care Act

- Emphasis on primary care
- Emphasis on new models of integrative care
- Attempted to remove the political barriers to integrated care
- Incorporated the integrated care philosophy of the “Triple Aim”

Primary Care

“Primary care is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.” (AOTA, 2013)
New Models of Primary Care

■ Patient-Centered Medical Home (PCMH)
  - model was based on “primary care that is accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective” (Patient-Centered Primary Care Collaborative, 2013)
    • Between 2008 and 2014, National Committee for Quality Assurance (NCQA) has accredited over 7000 PCMHs. (Farley, 2014)

■ Health Homes
  - According to ACA, the Health Homes provide coverage to people who receive Medicaid benefits. ACA § 2703 (2010).
  - a Medicaid State Plan Option “that provides a comprehensive system of care coordination for Medicaid individuals with chronic conditions. Health home providers will integrate and coordinate all primary, acute, behavioral health and long term services and supports to treat the “whole-person” across the lifespan” (Centers for Medicare & Medicaid Services, 2012).
Health Homes must provide:
1. Comprehensive Care Management
2. Care coordination;
3. Health promotion;
4. Comprehensive transitional care/follow-up;
5. Patient and family support; and
6. Referral to community and social support services.  
   (Centers for Medicare & Medicaid Services, 2012)

States may elect Medicaid beneficiaries with:
1. two or more chronic conditions;
2. one chronic condition and are at risk for a second; or
3. a serious and persistent mental health condition  
   (Centers for Medicare & Medicaid Services, 2014).

New Models of Care

Accountable Care Organizations (ACOs.)
- Under ACA, ACOs serve Medicare beneficiaries. ACA § 3022 (2010).
- ACOs include groups of doctors, hospitals, and other health care providers that “come together voluntarily to give coordinated high quality care to their Medicare patients” (Centers for Medicare & Medicaid Services, 2013)
  - The goal of the coordinated care the ACOs provides is to ensure patients, especially chronically ill patients, get the right care at the right time, avoid unnecessary duplication of services, and prevent medical errors. (Centers for Medicare & Medicaid Services, 2013)
  - “Accountable care” aims to “make providers more accountable for both the cost, and quality of care” (Cutler, 2013).
Occupational Therapy’s Role?

- Occupational therapists can facilitate patient engagement as part of their role primary care within the new models of care and within practice.
- According to the evidence, this occupational therapy intervention can:
  - Improves health outcomes,
  - Lowers costs,
  - Improves patient care,
  - Decreases medical errors, and
  - Increase adherence to treatment plans.

Why Occupational Therapy?

- According to the Occupational Therapy Framework:
  - Health management and maintenance is an instrumental activity of daily living
  - Defined as: Developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreased health risk behaviors, and medication routines
Why Occupational Therapy?

- Occupational therapy can break down barriers to Patient Engagement.
  - We spend time with patients that traditional primary care providers don’t have
  - We listen to our patients, which traditional primary care providers often don’t have time to do

How do Patients Become Engaged Patients?

- Learn everything they can.
- Tell their whole story
- Ask questions
- Get answers

(Wen & Kosowsky, 2012)
How do Pain Patients Become Engaged Patients?

- Partner with their providers in decision-making – share decision making
- Insert themselves in the provider’s thought processes
- Apply tests rationally
- Use common sense to confirm working diagnosis
  - (Wen & Kosowsky, 2012)

How do Pain Patients Become Engaged Patients?

- Become a bad patient… and occupational therapists can help
Good vs. Bad Patients

“"It is suggested that patients come to be defined as good or bad not because of anything inherent in them or in their behaviour, but as a consequence of the interaction between staff and patients.”


Good Patients

- Worry about insulting the doctor
- Worry about sounding stupid in front of the doctor
- Think repeatedly about leaving & finding a new doctor but don’t

Good Patients

- Are too scared to tell the doctor they’d like a second opinion
- Stick with a doctor who’s been treating them for a long time even though they aren’t getting better
- Stop asking question when they don’t get satisfying answers


Bad Patients

“Being a bad patient is crucial to mastering the skills of an empowered patient.”

Bad Patients:

■ Ask lots of questions.
  - They ask if they don’t understand and ask again until they do
  - They don’t care how annoyed the doc is getting

■ Don’t worry whether their doctor likes them.
  - They don’t care if they upset the doctor if they are putting their health in jeopardy.
  - Being liked is not important to them


Bad Patients:

■ Remember that this is a business transaction.
  - They are paying the doctor for a service and are entitled to good service
  - They should be respectful as they would to anyone providing a service
    • No duty to be the perfect patient.

What do we know about how patients use technology?

- 81% of U.S. adults use the internet and
- 59% say they have looked online for health information in the past year.
- 35% of U.S. adults say they have gone online specifically to try to figure out what medical condition they or someone else might have.

1/3 American adults have gone online for medical condition info

- 35% of U.S. adults say that at one time or another they have gone online specifically to try to figure out what medical condition they or someone else might have.
  - When asked if the information found online led them to think they needed the attention of a medical professional,
  - 46% of online diagnosticians say that was the case.
  - 38% percent of online diagnosticians say it was something they could take care of at home and
  - 11% say it was both or in-between.


- 41% of online diagnosticians say a medical professional confirmed their diagnosis. An additional 2% say a medical professional partially confirmed it.
- 35% say they did not visit a clinician to get a professional opinion.
- 18% say they consulted a medical professional and the clinician either did not agree or offered a different opinion about the condition.
- 1% say their conversation with a clinician was inconclusive.

When asked to think about the last time they had a serious health issue and to whom they turned for help, either online or offline:

- 70% of U.S. adults got information, care, or support from a doctor or other health care professional.
- 60% of adults got information or support from friends and family.
- 24% of adults got information or support from others who have the same health condition.


The vast majority of this care and conversation took place offline, but a small group of people did communicate with each of these sources online.

Mobile Health 2012

- 31% of cell phone owners, and 52% of smartphone owners, have used their phone to look up health or medical information.
- This finding is of particular interest to those interested in trends related to young people, Latinos, and African Americans, since these groups are significantly more likely than other groups to have mobile Internet access.
- 19% of smartphone owners have downloaded an app specifically to track or manage health.


-I don't know, but I can try to find out" is the default setting for people with health questions:
- 35% of U.S. adults say that at one time or another they have gone online specifically to try to figure out what medical they or someone else might have.
- One in five internet users have consulted online reviews or rankings of health care service providers and treatments.
- 18% of internet users, or 13% of adults, have gone online to find others who might have health concerns similar to theirs. People living with chronic and rare conditions are significantly more likely to do this.

People with Chronic Conditions

- One in four internet users living with high blood pressure, diabetes, heart conditions, lung conditions, cancer, or some other chronic ailment (23%) say they have gone online to find others with similar health concerns. By contrast, 15% of internet users who report no chronic conditions have sought such help online.


https://vulcanpost.com/55591/google-healthcare/
“When Dave deBronkart learned he had a rare and terminal cancer, he turned to a group of fellow patients online — and found the medical treatment that saved his life. Now he calls on all patients to talk with one another, know their own health data, and make health care better one e-Patient at a time.”

Patients Today Have Resources

Dr. Google™

I'm Feeling Icky  Second Opinions

http://ciroadamo.co.uk/tag/dr-google/

Facebook Closed Support Communities

https://www.facebook.com/groups/FibroAndPain/

https://www.facebook.com/groups/SurvivingMULTIPLEChronicIllnesses/

https://www.facebook.com/groups/theerwins/
Pinterest Books
https://www.pinterest.com/s4pm/books-written-by-s4pm-members/

Pinterest Blogs
https://www.pinterest.com/s4pm/blogs-written-by-s4pm-members/
Patient Competencies for Shared Decision-Making (SDM)

- Know desired provider-patient relationship
  - Find a provider & develop a partnership
- Give a good history that includes health, feelings, believes, & expectations in a systematic and objective manner

(Bernabeo & Holmboe, 2013)

Patient Competencies for SDM

- Share relevant information with provider during the interview, clearly and at the appropriate time
- Access Information
- Evaluate Information

(Bernabeo & Holmboe, 2013)
Patient Involvement Continuum

Outmoded Paternalistic Model: Clinician makes decisions with no input from patient

Middle Collaborative Model of Shared Decision Making: Providers & Patients Collaborate

Other Extreme Informed Models: Patients make their own treatment decisions

(Bernabeo & Holmboe, 2013)

Provider Competencies for SDM

- Develop a partnership with patients
- Acknowledge patient’s preference for information about his/her health or treatment preference
  - And role in decision making, and uncertainty about course of action to take and how to learn and respond to patient’s ideas, expectation, and concerns.

(Bernabeo & Holmboe, 2013)
Provider Competencies for SDM

- Identify choices and evaluate the research evidence for each patient
- Present evidence to patient
- Help the patient make a decision based on
  - the evidence and impact of alternatives,
  - patients values,
  - quality of life,
- Agree on a course of action

(Bernabeo & Holmboe, 2013)

Becoming a Participatory Provider

- Give your patients a copy of your office visit notes.
- Research shows that when office visit notes are shared with patients, patients become more active in their own care and show better outcomes.
- Knowledge about one’s medical condition levels the playing field.
  myopennotes.org
Becoming a Participatory Provider

- Shared decision making in clinical practice assumes both the patient and the provider need access to the available evidence in order to make a decision
- Modifying the process and power dynamics in the clinical setting through SDM fosters collaboration
- Research shows it works. (Légaré & Witteman, 2013)

Prerequisites to SDM

1. Both patient and provider must recognize a decision is required
2. Both must know and understand the best available evidence re: risks and benefits for each option.
3. Decisions must take into account both the providers guidance and the patient’s values and preferences. (Légaré & Witteman, 2013)
3-Step Model for SDM

1. Choice talk
2. Options talk
3. Decisions talk

(Elwyn, et al, 2012)
Option Talk

- Check Knowledge
- List Options

Describe Options—(Explore Preferences)
- Harm and Benefits

Provide patient decision support
- Summarize

(Elwyn, et al, 2012)

Decision Talk

- Focus on preferences
- Elicit preferences

Move to a decision
- Offer review

(Elwyn, et al, 2012)
Decision Making Aids

“Patient decision aids are tools that help people become involved in decision making by making explicit the decision that needs to be made, providing information about the options and outcomes, and by clarifying personal values.”

- They are designed to complement, rather than replace, counseling from a health practitioner.”
  (Ottawa Hospital Research Institute, 2013)

- You discuss these options with your patient.

Patient Decision Aids

- Make life easier for both Patient and Provider
Option Grids

- Option Grids: short tools for comparing health options.
- Option Grids are brief easy-to-read tools made to help patients and providers compare alternative treatment options.
- Option Grids help you find answers to the questions patients frequently ask.
  - Evidence-based
  - Free to download [http://www.optiongrid.org](http://www.optiongrid.org)

Elwyn, et al, 2013
Sample Option Grid Topics

- Carpal Tunnel Syndrome
- Osteoarthritis of the hip
- Osteoarthritis of the knee
- Sciatica
- Spinal Stenosis
- http://www.optiongrid.org/

Example of a Decision Aid

Sciatia from a slipped (herniated) disc:
Use this Grid to help you and your healthcare professional talk about how best to treat sciatica. It is for people diagnosed with a herniated disc who have experienced sciatica pain for at least six weeks and is not for people with bowel and urine problems due to the disc pressing on their nerves.

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Managing without injections or Surgery</th>
<th>Injections (epidural steroids)</th>
<th>Surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does the treatment involve?</td>
<td>Taking pain relievers that reduce inflammation around the nerve and attempting to be as active as possible. Physical therapy may also help.</td>
<td>A needle is used to inject local anaesthetic and steroid where the nerve is under pressure near the spine. An injection is normally performed at a special clinic and takes around 20 minutes.</td>
<td>The slipped disc that puts pressure on the nerve is removed during an operation on the back. The operation takes approximately 2 hours. Most people stay in hospital for a night or two but some go home the day of the surgery.</td>
</tr>
<tr>
<td>How soon will I feel better?</td>
<td>6 weeks after diagnosis, roughly 20 in 100 people (20%) say they are very or somewhat satisfied with their symptoms.</td>
<td>Most people who experience relief feel better within the first week or so after the injection.</td>
<td>6 weeks after surgery, roughly 60 in 100 people (60%) say they are very or somewhat satisfied with their symptoms.</td>
</tr>
<tr>
<td>Which treatment gives the best long-term results?</td>
<td>1 year after diagnosis, around 40 in 100 people (40%) who manage without surgery or injections say they are very or somewhat satisfied with their symptoms.</td>
<td>It is hard to say: some studies have shown benefits from steroid injections but others have not.</td>
<td>1 year after surgery, around 70 in 100 people (70%) say they are very or somewhat satisfied with their symptoms.</td>
</tr>
<tr>
<td>What are the main risks/side effects associated with this treatment?</td>
<td>All medications have some side effects. Being active is unlikely to make your sciatica harder to treat in the future.</td>
<td>Fewer than 1 in 100 people (0.1%) have complications, which could potentially include bleeding, headache, and infection.</td>
<td>The main risks associated with this surgery are infection (2 in 100 (2%) and blood clots (1 in 100 (1%)) and damage to the nerves (less than 1 in 100 (0.1%)).</td>
</tr>
</tbody>
</table>
You can download these grids free from www.optiongrid.org

Managing Pain From a Broken Hip:

■ Managing Pain From a Broken Hip: A Guide for Adults and Their Caregivers from AHRQ: http://1.usa.gov/1qVvseB

■ Table of Contents
  • Is This Guide Right for Me or Someone I Care For?
  • Understanding Your Condition
  • Understanding Your Choices
  • Additional Ways To Reduce Pain
  • Source
Is This Guide Right for Me or Someone I Care For?

Yes, if:
- You or the person you care for is an older adult (more than 50 years old) who is in a hospital because of a hip fracture (a broken hip that occurs suddenly from an event like a fall).

No, if:
- You or the person you care for is in the hospital for anything other than a broken hip or has hip pain that is NOT from a broken hip.

Where does the information in this guide come from?
The information in this guide comes from a review of many studies on treatments for older adults who have pain from a broken hip. A team of researchers, doctors, nurses, pharmacists, physical therapists, and other experts reviewed the current research. You can read the entire review at www.effectivehealthcare.ahrq.gov/hippain.cfm.

Understanding Your Condition

What is a broken hip? [http://1.usa.gov/1qVvseB](http://1.usa.gov/1qVvseB)

Healthwise

- Decision aids available for purchase
- Should I have an MRI?
- Should I have Spinal Manipulation?
- Should I have epidural injections?
- Should I have surgery for heel pain?
- Healthwise.org
- All evidence-based
Example Should I have an MRI?

- Options: yes or no
- Key points
  - Expensive
  - Most low back pain gets better on its own.
  - MRI is helpful for my doctor to find the source of my pain
  - Why would my doctor want an MRI?
- FAQs – what is an MRI, Why does my provider want one? etc

Ottawa Patient Decision Aid Development eTraining –

- an online, self-guided tutorial that takes people through the Ottawa patient decision aid development process.
  (Ottawa Hospital Research Institute)
  - https://decisionaid.ohri.ca/eTraining/
Examples of Decision Aids

■ Campaign Zero Checklists
  - “This free, printable booklet of all the CampaignZERO Checklists are designed to be kept at your fingertips for times when a friend or family member is in the hospital and needs your help.

Examples of Decision Aids

■ “The Empowered Patient® Hospital Guide For Patients and Families” (The Empowered Patient Coalition) –
  - in a checklist format, it explains many procedures that occur in the hospital; questions to ask, etc.
Becoming an Engaged Patient

- Read The Empowered Patient Coalition’s Your 1, 3, 6, and 12 Month Plan to Becoming an Empowered Patient.
  - A year-long plan to start you and your advocates on the right path to high-quality information and true participatory care.

Advice from E-Patient Nancy Finn

- Actions e-patients should take to insure best outcomes:
  1. Prior to going into the hospital for surgery, research all of your options and be sure to ask the surgeon, as well as your PCP and specialists who may be involved, all of the questions that you have. Be sure you are satisfied that you have full information. (Finn, 2013)
Advice from E-Patient Nancy Finn

2. Appoint a person to be your advocate during those days when you are not well enough to monitor the medications you are given and the procedures ordered. Be sure your advocate understands your release instructions so with the assistance of your advocate, nothing falls through the cracks. (Finn, 2013)

Advice from E-Patient Nancy Finn

3. As your treatment evolves be sure you understand, and are in agreement with everything that is suggested. Do not accept vague explanations. (Finn, 2013)
Advice from E-Patient Nancy Finn

4. When you are released from the hospital, be sure that you have full information on the medications prescribed, the treatment process, follow up appointments and any home services to expect. Double check to see that you have prescriptions for all of your medications and a viable way to get those prescriptions filled quickly. (Finn, 2013)

Advice from E-Patient Nancy Finn

5. As an e-patient you quickly realize that there are always follow up questions even if all of the suggestions above are followed. It is up to you to work collaboratively with your providers to insure that there are open channels of communication for this purpose. (Finn, 2013)
Summary

- Engaged patients realize better outcomes, fewer medical errors, & better care

- Occupations help patients become engaged patients by
  - Increasing knowledge of their condition(s)
  - Helping them becoming e-patients & drivers of their own care
  - Encouraging them to ask questions of healthcare providers
  - Showing them how to use shared decision aids

Summary

- By increasing patient engagement in primary care, in both new and traditional models of care, occupational therapists and perhaps occupational therapy assistants can promote:
  - improved outcomes,
  - improved care,
  - lower costs,
  - fewer medical errors, and
  - better compliance with treatment plans
References

- Bernabeo, E., & Holmboe, E.S. (2013). Patients, providers, and system need to acquire a specific set of competencies to achieve true patient-centered care. Health Affairs 32:2 250-258
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- Hibbard, J.H., Greene, J. (2013, February) What the evidence shows about patient activation: better health outcomes and care cost care experiences; fewer data on costs. Health Affairs. 32:2 pgs 207-214
- Open Notes, http://www.myopennotes.org