In Pursuit of Patient Engagement:
Challenges, Barriers, and Breakthroughs to Partnership

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My plan for today

- A bit of context about me
- The Center for Patient Partnerships
- A story to ground things
- Engaging patients in education – an example
- Engaging patients in research – an example
- Top 12 Keys to Success!
- Q & A
Context: About Me

- 1994 diagnosed with ovarian cancer, metastasized to my liver
- Partner of 5 years, children 3 y.o. & 6 months
- “Go home and think about the quality, not the quantity of your remaining days”
- I “failed” chemotherapy and entered “salvage” therapy…
- Experimental surgery & chemo
Born of a dream...
Infusing Patients’ Voices...

Better Health Outcomes

- Patient Advocacy
- Professional Education
- Service Co-design
- Research/Policy Advocacy
From Case to Cause

EDUCATION

ADVOCACY

PATIENTS’ EXPERIENCES + STUDENTS

SYSTEM CHANGE

RESEARCH

From Voice to Voices
What IS patient engagement?

Adapted from Patterson Kirk Wallace
Why aren’t patients engaged?

- Lack of perceived value: what could patients provide???
- “I’m busy, it’s expensive and time consuming”
- “I’m not an ‘expert’ at this” or “I tried but it didn’t work”
- It’s not measurable
Why does engaging patients in research & education matter?

- These are the grounding of what happens in health care, especially with the turn towards heavy valuing of the “evidence base”

- Education is how we form and shape clinicians, “carers” – those who care for patients

- If our primary goal is to research and measure compliance, certain kinds of communication, and so certain topics, are very hard to reach.
Why engage patients: a story

- A true story of why engaging patients’ voices in research and education matters; what we could learn if we focused in.
Patients’ role in education: Teaching 21st Century skills

1) Partnering & collaboration at all levels: with patients, colleagues, communities, etc.

2) Capacity building – teaching patients to fish…

3) Recalibrating responsibility
   - Empowering patients vs. rescue fantasy
   - Self-care & well-being (need to develop curriculum that teaches clinicians to strive for excellence and address their mistakes)

4) Community collaboration & empowerment
   - Curiosity
   - Respect
   - Compassion
   - Altruism
Database of Individual Patient Experiences (DIPEx)

- UK (Oxford) produced healthtalk.org

Canadian Version
Japanese Version
And 9 other countries

US Version – Health Experience Research Network (HERN)
- produced healthexperiencesusa.org

Yale University
John Hopkins University
UW Madison
Oregon Health Science University

The US Site

The Mothership!

US Version

The 1st US Module

Young Adults’ Experiences of Depression in the US

Course: “Depression & Young Adults: In Their Own Voices”
Learning & Teaching

Our patient experience videos are great resources for teaching & training

Related:
- Using healthtalk.org in teaching
- Create a clip 'playlist'
- Teaching resources

“It takes students out of the lecture theatre to see real, lived experiences.”
HealthExperiencesUSA.org brings patients’ voices to American health care. We seek to describe the widest possible range of individual experiences from the patient’s point of view. HealthExperiencesUSA.org is a non-commercial, non-profit group, part of an international movement (DIPEx International) to provide a place for sharing patients’ stories.

“Personal accounts of the experience of illness provide a particularly potent form of narrative, and one that becomes all the more striking when the reader shares a diagnosis with the author.”
——DIPEx International

LEARN FROM OUR PARTICIPANTS

LEARN ABOUT THE U.S. HEALTH EXPERIENCES RESEARCH NETWORK

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Overview

In this section you can find out about experiences young adults ages 18 - 29 have with depression by seeing, hearing and reading personal stories they shared with us. Our researchers travelled to several regions and many different communities throughout the United States to talk to 38 young people in their own homes or community settings. Find out what people said about issues such as growing up in the shadow of depression, dealing with combinations of depression and anxiety, deciding whether and when to “go public” with their condition, and finding strategies for everyday life or how to maintain hope as they cope with depression.

The young people who shared their stories did so for varied reasons. Their voices and personal experiences differed. But they shared a belief that speaking up and telling their stories would matter – both to themselves and to others.
“Depression & Young Adults: In Their Own Voices” curriculum pilot

- Macy Foundation funded
- Control/Experiment Design
- 3 hours online self-directed curriculum for 3rd year medical students
- One-hour small group meeting with faculty
- Significant impact on stigma and empathy
- Adopted for Medical Curriculum at UW-Madison
"Because you’re in this [depression], you just see a dead end, you know, with a bunch of flowers wilted and nobody there." — Joey (module participant)

"Like you have this huge ball of yarn that you’re never going to unravel but you keep tying anyways and it’s just painstaking." — Ryan (module participant)

Let’s start by taking you to HealthExperiences.US’s landing page for the online patient experience module, “Young Adults’ Experiences with Depression.” Click HERE. From there, you can access the module itself by clicking on the “See and hear these young adults describe their experiences” link box.

Nearly all young adults were interviewed for this depression module. These individuals were chosen to vary in characteristics such as gender, age, and nationality. We want you to have a deeper experience with a few of them.

Go back to the module and click on the tab called “People’s Profiles.” The profiles allow users to learn more about a particular person, as well as listen to, read, or read all of their responses that appear in the module. We want you to see how far the first image and read their true stories. Then, pick one of these stories that you are about to learn more about. Practice your listening and empathy skills by reading and thinking about this person’s experiences. Then, record all of your experiences and share any experience that you think is for the better.

Pause for a moment before we delve further into the module. Let’s reflect a little bit about listening and empathy—skills we sometimes take for granted, but which prove difficult in practice.

Among the most common listening distractions that professionals feel they have to overcome when we get stuck in our own “reasons” for listening, our own intentions—and when we get it wrong, on a call trying to keep up with the exasperations of a clinic schedule. We want to help, we want to get all the information down accurately, we want to diagnose and treat, and we want to be able to do our next patient.

Let us all enjoy the reminder that listening is one of the most important skills we can use in our daily lives. It is an essential ingredient of empathy and understanding.

"On that day, my father taught me empathy, which is not the same thing as sympathy. Sympathy’s easy. You have sympathy for starving children sweating at tills on the late-night commutes. But that’s not the same as empathy. Empathy is getting down on your knees and looking someone else in the eye and realizing you could be them, and that all that separates you is luck.”

— Maya (module participant)

Next, let’s explore the stigma that surrounds depression by exploring the topic entitled “Going public with depression.” As before, please read through the summaries and watch and listen to the embedded clips.

"Empathy is not sympathy. Sympathy is a form of agreement, a form of judgment. And it is sometimes the more appropriate emotion and response. But people often feed on sympathy. It makes them dependent.”

— Steven Covey, The Seven Habits of Highly Effective People

Covey describes empathy as a judgment. Can you see why? If sympathy makes others dependent, how does empathy make them independent? Looking back on recent listening experiences you’ve had, can you find a time when you agreed with someone rather than truly listening to their words? When your judgment—even a positive one—changed the focus from the speaker to you? In the next exercise, also try to notice when your judgments crop up.
"Because you’re in this [depression]... you just see a dead field, you know, with a bunch of flowers wilted and nobody there." – Joey (module participant)

"Like you have this huge ball of yarn that you’re never going to untangle but you keep trying anyways and it’s just painstaking." – Ryan (module participant)

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How Do We Measure Effectiveness?

- Mixed-methods with pre-post survey of 2 intervention and 2 control groups (N=110)
- Survey included
  - Socio-demographics
  - Open-ended questions
  - Validated measures of empathy and stigma
    - Jefferson Empathy Scale
    - Depression Stigma Scale
      - Personal attitudes
      - Beliefs about other’s attitudes
- Debrief with preceptors
Is it effective?

- Pilot data:
  - 91% indicated that the module influenced their work or thinking about depression (vs. 93% for seeing patients in clinic)

- Qualitative analyses indicated an influence on competency in patient care, interpersonal and communication skills and professionalism.

- Empathy increased significantly in the intervention group as compared to the control group (intervention mean 116.39 pre to 119.71 post, control 113.63 pre to 117.67 post; p=0.002), driven by those who scored below the group mean at baseline (p=0.01).
Why engage patients in research?

<table>
<thead>
<tr>
<th>Step in CER Process</th>
<th>Purpose of Patient Engagement</th>
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<tbody>
<tr>
<td>Topic solicitation</td>
<td>- Identify topics that are important to patients, caregivers, and the community&lt;br&gt;- Propose topics to be investigated</td>
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<tr>
<td>Prioritization</td>
<td>- Solicit feedback on relevance and priority of topics&lt;br&gt;- Discuss the urgency of addressing topics</td>
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<tr>
<td>Framing the question</td>
<td>- Ascertain questions’ relevance and usefulness&lt;br&gt;- Assess &quot;real-world&quot; applicability</td>
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<tr>
<td>Selection of comparators and outcomes</td>
<td>- Identify comparator treatments of interest&lt;br&gt;- Identify outcomes of interest&lt;br&gt;- Incorporate other aspects of treatment</td>
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<tr>
<td>Creation of conceptual framework</td>
<td>- Provide a &quot;reality check&quot;&lt;br&gt;- Verify logic of conceptual framework&lt;br&gt;- Supplement with additional factors not documented in the literature</td>
</tr>
<tr>
<td>Analysis plan</td>
<td>- Verify importance of factors and variables&lt;br&gt;- Ascertain whether there is a good proxy for a specific concept&lt;br&gt;- Inquire about potential confounding factors</td>
</tr>
<tr>
<td>Data collection</td>
<td>- Determine best approaches for data collection (e.g., trial, registry, medical charts)&lt;br&gt;- Assist with selection of data sources</td>
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<tr>
<td>Reviewing and interpreting results</td>
<td>- Assess believability of results&lt;br&gt;- Suggest alternative explanations or approaches&lt;br&gt;- Provide input for sensitivity analysis</td>
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<tr>
<td>Translation</td>
<td>- Interpret results to be meaningful&lt;br&gt;- Document which results are easy or difficult to understand&lt;br&gt;- Indicate which results are counterintuitive</td>
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<tr>
<td>Dissemination</td>
<td>- Facilitate engagement of other patients&lt;br&gt;- Help other patients to understand findings</td>
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An example: HERN Ambassadors

STEERING COMMITTEE
• Two patients serve as member advisors

MODULES
• Advisory boards
  • Scoping
  • Interviews
• Ambassadors
  • Dissemination
  • Implementation

healthexperiencesusa.org
HERN Ambassadors

Ambassador Job Description
Ambassador Job Elements

Activities:

- Thoughtfully represent and promote the Depression Module and Health Experiences USA
- Share community resources, and share the Module within your community.
- Work with Health Experiences USA staff to identify specific activities and opportunities.
Ambassador Job Skills

- The ability to **tell others’ stories**, to reach a broader audience
- A good **work ethic** and a **desire to connect**
- **Teamwork.** Knowing your role
- An excitement to **learn** and accept and **give feedback**
- A wish to **be vulnerable**
- The appropriate **marketing and communication skills** to match your efforts (provided in our training).
Ambassadors at work!
Toolkits Available at hipxchange.org

Browse all toolkits
Filter and view toolkits by topics of interest

- Improve Care
  - Toolkits to improve patient and family engagement in care, transitions in care, mental health, cancer screening and care, and chronic condition care.
  - Browse Toolkits

- Improve Research
  - Tools, videos, and data downloads to identify socioeconomic disadvantaged locations, improve patient engagement in research, identify patients with chronic conditions, and more.
  - Browse Toolkits

- Risk of Readmission
  - Enter a 5- or 9-digit ZIP code below to look up whether your patient resides in a neighborhood with a higher risk of readmission. See the Area Disparities Index toolkit for more information.
  - Browse Toolkits

Filter and Sort
- Topic
  - Cancer
  - Children/Young Adults
  - Chronic Conditions
  - Datause & Research Tools
  - Disparities & Research Tools
  - Engagement in Care
  - Implementation in Research
  - Health Equity
  - Health IT
  - Learning Health System

Sort by
- Title

ZIP Code: [ ] 5-Digit [ ] 9-Digit [ ] Submit

Toolkits
- Adding the Community Voice to Mental Health Research
- Bringing Patients’ Voices to American Health Care
- Children’s Hospital Safety Climate Questionnaire
- Deeply Engaging Patients with a Mix & Match of Methods
- Hard-to-Reach Patient Stakeholders An Engagement Guide (HARP)
- Partnering with Parents of Hospitalized Children Using an Inpatient Portal
Top 12 keys to success

Careful preparation is critical.

Engaging patients is resource intensive, invest appropriately.

Organizational culture is a significant determinant of success – leadership matters.

Communication is vital.

Use job descriptions for everyone and fit the patient to the task.

Take the opportunity to reexamine cultural norms.

Create a “Community of Learners.”

Begin slowly, let things grow over time.

Follow human assets and passions, find champions.


Attend to expertise, representation, cooptation.

Remember, perfection is the enemy of the good!
Two decades later...
Thank you!

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