Learning from patients’ experiences: where we have been where we can go

Rachel Grob, Ph.D
Center for Patient Partnerships, University of Wisconsin-Madison

Mark Schlesinger, Ph.D
Yale University
Infusing Patients’ Voices...

Better Health Outcomes

- Patient Advocacy
- Professional Education
- Service Co-design
- Research/Policy Advocacy
CAHPS Clinician & Group Adult Survey 3.0

Your Provider

1. Our records show that you have been seeing the provider named in Question 1.
   - Name of provider: 
   - Is that right?
     - Yes
     - No → IF NO

The questions in this section only apply if you saw the provider named in Question 1. Please think of that person when answering these questions.

2. Is this the provider who usually manages your problems?
   - Yes
   - No

3. How long have you been seeing this provider?
   - Less than 6 months
   - At least 6 months but less than 1 year
   - At least 1 year but less than 3 years
   - At least 3 years
   - 5 years or more

4. How often did this provider ask if you had any other problems?
   - How often did this provider ask about your bowel movements? (Example: "How often did this provider ask about your bowel movements?")
   - How often did this provider ask about your medical history?

Center for Patient Partnerships
University of Wisconsin-Madison
Definition of rigor in the move from anecdote to science:

- Sampling
- Elicitation
- Interpretation
Eliciting Patient Narratives in American Medicine

Applying Rigorous Qualitative Methods to Large-Scale Collection of Patient Experience
Eliciting Patient Narratives at Large-Scale

- **Laying the Groundwork**
  - Developing criteria for rigor
  - Several rounds of elicitation
  - Matched interviews for validation
Eliciting Patient Narratives at Large-Scale

- **Laying the Groundwork**
  - Developing criteria for rigor ➔ 4 criteria
  - Several rounds of elicitations
  - Matched interviews for validation
Criteria for Rigorous Elicitation

- **Complete**: provide a full picture of the experiences that matter to the patient describing them
- **Balanced**: accurately reflect both positive and negative aspects of the patient's experiences
- **Meaningful**: convey a story that is coherent to other patients and allows them to assess its relevance to their own care
- **Representative**: Capture experiences from patients across a range of health status and socio-demographics
Eliciting Patient Narratives at Large-Scale

- Laying the Foundation
  - Developing criteria for rigor
  - Several rounds of elicitations ➔ 758 cases
  - Matched interviews for validation
Eliciting Patient Narratives at Large-Scale

- **Laying the Foundation**
  - Developing criteria for rigor
  - Several rounds of elicitations ➞ 758 cases
  - Matched interviews for validation ➞ 100 cases
Testing (and Refining) the Protocol

**COMPLETENESS** of Reported Experiences
By Elicitation Round and Mode

Overall Match: Round 1

Overall Match: Round 2

- Full Sample
- Phone Sample
- Web Sample
Eliciting Patient Narratives at Large-Scale

- **Laying the Foundation**
  - Developing criteria for rigor
  - Several rounds of elicitations
  - Matched interviews for validation

- **Evaluation**
  - Complete
Completeness of Elicitation

Fidelity of Reported Experiences

Overall Match: 10 Domains
Orientation
Access
Communication
Caring
Ample Time
Thorough
Competent
Shared Decisions
Staff
Coordination

Full Sample
Phone Sample
Web Sample
Eliciting Patient Narratives at Large-Scale

- **Laying the Foundation**
  - Developing criteria for rigor
  - Several rounds of elicitation
  - Matched interviews for validation

- **Evaluation**
  - Balanced
Balance of Elicitation

Fidelity of Positive vs. Negative Assessments

Balance of Positives and Negatives Matches Between Elicitation and Interview

- Full Sample
- Phone Sample
- Web Sample
Eliciting Patient Narratives at Large-Scale

- **Laying the Foundation**
  - Developing criteria for rigor
  - Several rounds of elicitations
  - Matched interviews for validation

- **Evaluation**
  - Meaningful
Coherence of Elicitation

Attributes of the Narratives

- COHERENCE
- Texture
- Completeness

Categories:
- Full Sample
- Phone Sample
- Web Sample
Eliciting Patient Narratives at Large-Scale

- Laying the Foundation
  - Developing criteria for rigor
  - Several rounds of elicitations
  - Matched interviews for validation

- Evaluation
  - Representative
Eliciting Patient Narratives at Large-Scale

- Laying the Foundation
- Evaluation
- Dissemination
  - Pilot-testing: CA and MA
  - Initial Implementation: MA
A Database of Patient Experience: Eliciting Rich Narratives about Health and Health Care
Why DIPEX?

- Identify questions and problems that matter to patients
- Provide support and information to patients and caregivers
- Promote balanced encounter between patients and health professionals
- Be a learning resource for medical students, doctors, nurses and other health professionals
- Inform policy
DIPEX methodology

- Aim is to represent the broadest possible range of perspectives, using rigorous qualitative research methods.
- For each health condition (or module), researchers conduct 40 - 50 interviews, among patients from different backgrounds, recruited through a range of avenues (maximum variation).
- Interviews continue until no new ideas or experiences are voiced (saturation).
DIPEX methodology

- Transcripts coded by theme, with focus on both common and divergent experiences
- Researchers produce ~ 35 summaries in lay language, illustrated with video, audio, or written interviews clips (roughly 350 clips per module)
- Modules disseminated via publicly-available website (e.g. [www.healthtalk.org](http://www.healthtalk.org)); data available for secondary analysis and use (with permission)
Partnership between University of Wisconsin, Johns Hopkins University, Oregon Health & Science University, and Yale University.
Health Experiences Research Network (HERN) Steering Committee

Launched in 2014

Rachel Grob, MA, PhD
Chair
Erika Cottrell, PhD, MPP
Kay Dickersin, PhD
Mark Helfand, MD, MPH
Kate Smith, PhD, MA
Nancy Pandhi, MD, PhD
Mark Schlesinger, PhD
US Health Experiences Modules

Two funded modules

✓ Depression in young adults (UW-Madison)
✓ Veterans with traumatic brain injury (VA/OHSU)

Proposed modules under review

- Gulf War Illness (VA)
- Pediatric cancer (NIH CTSA)
- Adults with congenital heart disease (NIH CTSA)
- Low back pain (Donaghue Foundation)
HERN’s commitment is to:

- Listen to patients to capture a wide range of experiences and priorities
- Empower patients by giving voice to their story and choices about sharing their data
- Bring in voices that wouldn’t be heard through other engagement activities
- Move from voice to voices – synthesizing themes and disseminating to broad audiences— not just peer-reviewed literature
US Module: Young Adults with Depression
US Module: Young Adults with Depression

Study Team
Rachel Grob, MA, PhD
Nancy Pandhi, MD, MPH, PhD
Meg Wise, PhD
Mark Schlesinger, PhD
Natalie Wietfeldt, BA
Cecie Culp, MPA

Funder Acknowledgements
- University of Wisconsin School of Medicine and Public Health
- Wisconsin Partnership Program
- University of Wisconsin Medical Foundation
- University of Wisconsin Institute for Clinical and Translational Research funded by a Clinical and Translational Science Award (CTSA) program, through the NIH National Center for Advancing Translational Sciences (NCATS), grant UL1TR000427
- The Center for Patient Partnerships
- University of Wisconsin Department of Family Medicine and Community Health
- University of Wisconsin-Madison Health Innovation Program
Young adulthood: A critical time of change
Our Recruitment Flyer

As part of a new project, researchers in the Department of Family Medicine at the University of Wisconsin are trying to find young adults (ages 18-29) interested in sharing their experiences of having depression. The project’s goal is to create a module on a website with information for individuals and their caregivers about others’ personal experiences living with depression. You will be compensated $25 for participating. Please call or contact us via text (608-285-2078) or email (healthtalkus@gmail.com) if you are interested.
Where we’ve Interviewed
Live Depression Module

www.healthexperiencesusa.org
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 36 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.

Young adults and depression in U.S.

Having a purpose in life

Building relationships that work when depressed

Depression and sleep

Depression and strategies for everyday life

Cycles of depression and maintaining hope

Depression, spirituality, and faith

Depression and healing

Messages to others (2)

Messages to family and friends about how to support a person with depression

Messages to other young adults with depression

Resources & Information

Credits

Next Topic ➤
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 traveled to several regions and many different communities throughout the United States to talk to 55 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 differ. But they shared a belief that speaking up and telling their stories would matter – both to themselves and to others.

Young adults and depression in US

Young adults who told their stories for this website also wanted to be sure to remind visitors to the website like you that if at any time you need immediate crisis assistance, help is available. Please visit our resources for more information.

Dr. David Rakel of the University of Wisconsin, provides some background on these experiences and offers ideas for how to explore this content.

Dr. David Rakel, Family Physician at The O
In the United States, clinical guidelines and/or DSM-5 Criteria describe specific signs and symptoms professionals can use to diagnose depression. In this section of the website, we focus on something different: how depression feels to young adults while they are living inside of it, as described by those we interviewed. (For summaries of how it feels for young adults to cycle in and out of depression, or how it feels to be “stuck” in depression, see “Cycles of depression and maintaining hope” and “Depression and healing.”)

Young adults have a variety of experiences with depression, but one thing all those we talked to shared is the feeling that they are somehow separated from the rest of the world. Each person described, in one way or another, being in their “own little world,” losing their motivation to do things, and becoming socially isolated. One person talked about “feeling so alien to the rest of the world around me.” Sam said that when he’s depressed he is “stuck in a loop and not really communicating with anyone.”

For many people, that sense of isolation was accompanied by feeling overwhelmed. Some described this as everything becoming unreasonably “annoying to my senses.” Many felt the weight of other people’s noise, daily life. Others talked about everyday responsibilities like school work becoming “frustrating,” or reaching a point where they were left in public without knowing why.

Metaphors about depression
For many of those we interviewed, ordinary language and descriptions were not nuanced enough to describe their experience of depression.

<table>
<thead>
<tr>
<th>Metaphor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling overwhelmed</td>
<td></td>
</tr>
<tr>
<td>Feeling stuck in a loop</td>
<td></td>
</tr>
<tr>
<td>Feeling alien to the rest of the world</td>
<td></td>
</tr>
<tr>
<td>Feeling like they are in their “own little world”</td>
<td></td>
</tr>
<tr>
<td>Feeling like they are “stuck in a loop”</td>
<td></td>
</tr>
<tr>
<td>Feeling like they are “not really communicating with anyone”</td>
<td></td>
</tr>
<tr>
<td>Feeling like everything is annoying to their senses</td>
<td></td>
</tr>
</tbody>
</table>

Print transcript
Depression and work

Many young adults between the ages of 16 and 29 have not yet had time to develop a long or diverse work history, regardless of whether they are depressed. Nonetheless, most people we interviewed talked about the impact depression has on their experiences with work, and/or about how work influenced their depression. Some also described how and whether they "went public" with their depression in professional environments, or what role income or its absence played in their lives.

Work making depression easier

A number of people described how work functions as an effective antidote to feelings of isolation, powerlessness, or low self-esteem that accompany depression. For some, being busy with work and "having a routine" as well as having income serve as important elements of rationalization. To see people organize their life and (having a campus job) has helped a lot, just being connected to something... [even] having a schedule that I can maintain." Other people talked about work as a "productivity distraction" which provides relief from anxiety. "Thinking about how I'm feeling. Norried used his job to prove "he's[ing] up" and being a leader.

A few people mentioned that the substantive focus of their work or the specific requirements of their job challenged them to move through symptoms of depression by making it necessary to "come out of my shell." In other words, "emotionally" or "socially". The opportunity that work creates to meet and spend time with other people was highlighted by several people, as particularly meaningful.
Young Adults’ Experiences of Depression in the U.S.

Men 25 and over

**Pete**
- Pete’s depression became noticeable as a young adult, but looking back he thinks he had...

**Marty**
- Marty has struggled with depression, anxiety, and other issues since childhood. He has...

**Joey**
- Joey had some extended periods of low mood earlier in his life, but the first time he...

**Jason**
- Jason’s first serious bout of depression happened once he was away at college, but looking...

**Jacob**
- Jacob, 25, noticed symptoms in early high school and was diagnosed with depression and...

**Jackson**
- Jackson, 27, experienced childhood abuse, father’s suicide and mother’s imprisonment....

**Ben**
- Ben’s depression began when he was 13. He was diagnosed with depression and schizophrenia..
Empowering patients by giving voice to their story and control over how it is shared

- Ongoing communication to review and approve materials
  - Feeling seen
  - Redacting materials
- Ongoing engagement:
  - e-mail
  - Advisory Group
    - Sampling
    - Topic Summaries
    - Bios
Bringing in voices that wouldn’t be heard through other engagement activities

For example, engaging quiet and diverse voices

“... many of the most important institutions of contemporary life are designed for those who enjoy group projects and high levels of stimulation...”
... and Helping Every Voice be Heard
"One of the things that I wanted to share in this interview was the fact that I think so often we are talking about depression and anxiety as though it's only a negative... But you know, we all have these different ranges. I'm a person when it comes to like, the analogy about a piano, I play all the keys. I have very high highs and I have very low lows."
"[Depression,] it's sort of always a journey, that's a cliche statement but it's sort of a constant thing that you have to deal with . . . [it's] a journey that I'm getting more comfortable with, like easier to navigate. I guess my situation is really unique, coming from this super small place and also being a queer person is interesting, I thought that would be a voice that would be good to have."
From Voice
Thirty-eight young adults across the United States shared their stories about living with depression.
Your Questions?