Learning from patients’ experiences for better culture, health, and care

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National Academy of Medicine
Leadership Consortium for a Value & Science-Driven Health System
Care Culture and Decision-making Innovation Collaborative
Infusing Patients’ Voices...

Better Health Outcomes

- Patient Advocacy
- Professional Education
- Service Co-design
- Research/Policy Advocacy
Potential Contributions to the Framework

- Rigorous qualitative approach to patient experience research
  - Innovation on “understanding preferences, values, and goals”
- Power of internet-based patient experience narratives to improve health
  - Innovation on connections, engagement, decisions
- Eliciting and amplifying little-heard voices
  - Innovation on engagement
Definition of rigor in the move from anecdote to science:

- Sampling
- Elicitation
- Interpretation
Equipping Patients to be “Patient Experience Experts”

Gaps in Engagement Framework

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
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 International
www.dipexinternational.com

Australia
Canada
Czech Republic
Germany
Holland
Israel
Japan
Republic of Korea
Norway
Spain
UK
USA
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
Personal Narratives

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
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*
U.S. Module: Young Adults with Depression
U.S. Module: Young Adults with Depression

Study Team

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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
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 18-20) 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.
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.
# Young Adults' Experiences of Depression in the U.S.

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Overview

- First experiences with depression (2)
- Living with depression (19)
- Getting help: seeking assistance and treatment (5)
- Helping yourself: support, self-care, and feeling better (7)
- Messages to others (2)
How depression feels

In the United States, clinical guidelines and/or DSM-V 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 affects 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 healing from it, 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 isolated 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 has to “unplug and really communicate with anyone.”

For many people, that sense of isolation was accompanied by feeling overwhelmed. Some described this as everything becoming unmanageable “too many things to do,” bright lights, groups of other people, noise, daylight. Others talked about everyday responsibilities like school work becoming “frustrating” or “insurmountable in terms while in public without knowing why.”
# Young Adults’ Experiences of Depression in the U.S.

## People’s Profiles

### Women 25 and over

<table>
<thead>
<tr>
<th>Whitney</th>
<th>Tia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whitney, 25, was diagnosed at age 9, and later with bipolar disorder. Family and school...</td>
<td>Tia, 28, was shy and embarrassed about having no father. She masking her depression and...</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Shayne</th>
<th>Sara</th>
</tr>
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<tbody>
<tr>
<td>Shayne, age 27, began to experience depression in high school. Other mental health issues...</td>
<td>Sara, age 26, experienced depression beginning in middle school and was diagnosed with...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sally</th>
<th>Myra</th>
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<tbody>
<tr>
<td>Sally’s depression began when she was a teenager and her parents separated. She continues...</td>
<td>Myra, age 27, as a child was abused and bullied by peers, but her parents did not believe...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maya</th>
<th>Julia</th>
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<tbody>
<tr>
<td>Maya (age 27) grew up in an emotionally abusive family and was diagnosed at age 16. She...</td>
<td>Julia, age 26, first noticed depression symptoms at age 14 and was diagnosed in college...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Elizabeth</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Elizabeth was a sensitive child. She was diagnosed with depression and an eating disorder...</td>
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</tr>
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</table>
Depression, medication, and treatment choices

People with depression may choose to take prescribed medications to help with depression symptoms. Some people we interviewed managed their depression with medication alone. Others used medication in combination with therapy, lifestyle changes and/or holistic and integrative treatments. Some did not use medication at all and only used other approaches to manage their depression. The ways that people manage their depression can change over time. Many people we interviewed described changing their thinking about medication – some growing more favorable, others less so – in response to personal experiences and growing self-knowledge. (For more about approaches to depression other than medication please see 'Therapy and counseling', 'Depression and strategies for everyday life' and 'Holistic and integrative approaches to depression'.)
Depression, medication, and treatment choices

Meghan talks about wanting medication and having difficulty getting it.

Natasha discusses the process of talking with her doctor about how she was feeling on medication in order to find the medication that worked best for her.
Depression, medication, and treatment choices

Violet says medication helped her feel better than she had in her entire life.

Joey discusses how medications caused a creative block for him.
Nadina describes concerns about becoming dependent on
Depression and pets

Pets are an important source of company, empathy, joy, humor, and love for most of the young adults we interviewed. As Sierra Rose summarized, "animals are perfect. They love you no matter what. Like straight up everyone should own at least one animal." Many people also spoke about the importance of being needed by their pets — "to have something to take care of," as Colin put it, "Instead of needing people to take care of me." For some people, however, the responsibility of caring for a pet was too much during their current phase of life, and the anticipated loss of creatures with short life-spans could also be a source of sadness.

Being loved and accepted

Many people we spoke to said their pets’ unconditional love and acceptance was "a huge factor in life" — a sure way, as Devin put it, "to bring up my spirit... and put a smile on my face." Several people named cats or dogs as their "closest friends" growing up. Kate described her cat, who has moved with her a number of times, as "one of the consistent things in my life," adding "... even though I don’t have anybody to listen or hug, I have this one." Sara said her cat would sleep with her, and she would confide in him because he couldn’t and "... wouldn’t tell anything to anyone."

Some people said that when they are depressed, the comfort of being with their pets can make it even harder to get out of bed, out of the house, or into the company of other people. Others said their pets motivated them to get outside, by making that experience more joyful.
Depression and pets

Sierra Rose says her cats are the main reason she went to the hospital for help when she felt suicidal.

Julia says it’s validating that her pets love her unconditionally. At the same time, her desire to be with them sometimes exacerbates her tendency to isolate herself from other people.
Depression and pets

Jacob got a dog to cope with his depression, but found it was too hard to care for him as needed. The cat he got later requires less work and is a better match.

Teri loved taking her dog places in the car, even when her depression was at its worst.
Teddy wants to keep helping his dog, who has arthritis. Honoring that commitment is one of the things that keeps him going.
**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

Amplifying patients' voices
"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 cliché 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 .....
Young Adults' Experiences With Depression

Thirty-eight young adults across the United States shared their stories about living with depression.

See and hear these young adults describe their experiences.
Your Questions?