

# Learning from patients' experiences for better culture, health, and care

**Rachel Grob, Ph.D**

Center for Patient Partnerships  
Department of Family Medicine and Community Health  
University of Wisconsin-Madison

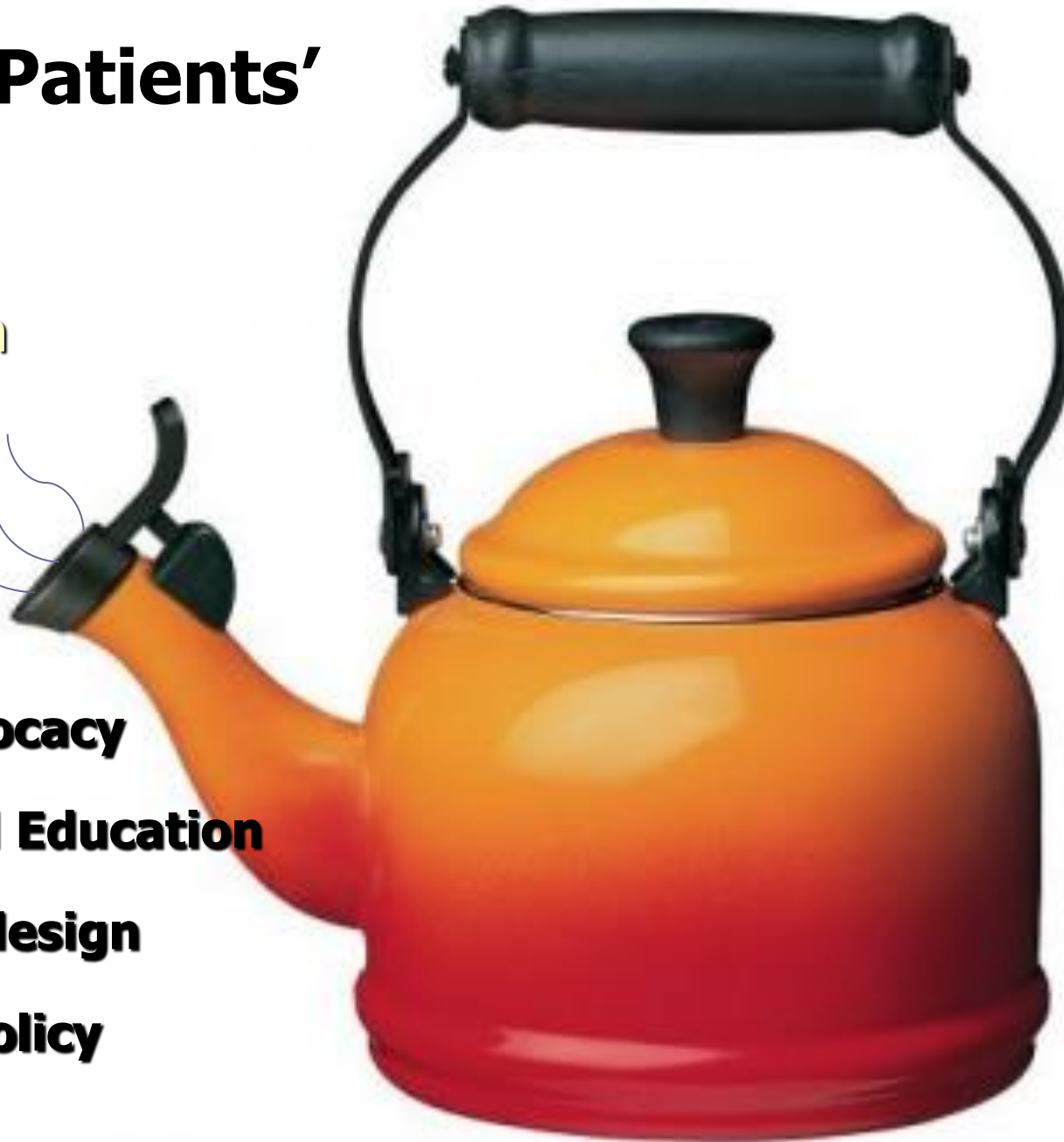
December 7<sup>th</sup>, 2016

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



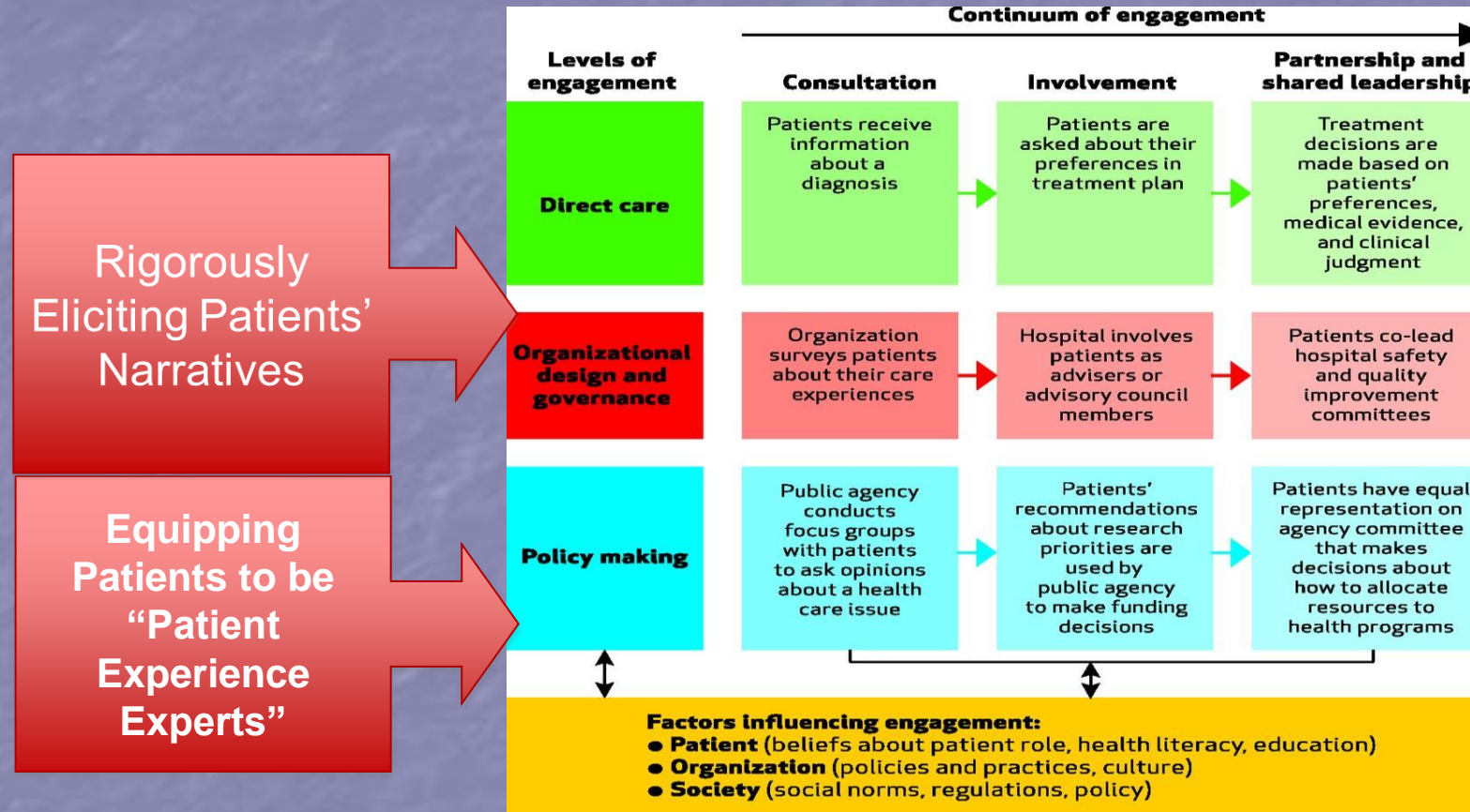
## SOUNDING BOARD

### **Taking Patients' Narratives about Clinicians from Anecdote to Science**

Mark Schlesinger, Ph.D., Rachel Grob, Ph.D., Dale Shaller, M.P.A., Steven C. Martino, Ph.D.,  
Andrew M. Parker, Ph.D., Melissa L. Finucane, Ph.D., Jennifer L. Cerully, Ph.D.,  
and Lise Rybowski, M.B.A.

- Definition of rigor in the move from anecdote to science:
  - Sampling
  - Elicitation
  - Interpretation

# Gaps in Engagement Framework



Carman K, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, Sweeney J. "Patient And Family Engagement: A Framework For Understanding The Elements." Health Affairs. 2013;32(2):223-231.

# 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** International



# DIPEX methodology

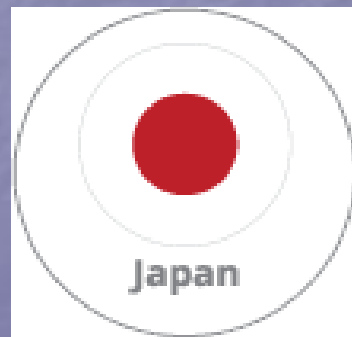
- Aim is to represent the broadest possible range of perspectives, *using rigorous qualitative research methods*
- For each health condition (or module), researchers conduct 40 - 50 interviews, among patients from different backgrounds, recruited through a range of avenues (maximum variation)
- Interviews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





# DIPEX International

[www.dipexinternational.com](http://www.dipexinternational.com)





# Health Experiences Research Network

[healthexperiencesusa.org](http://healthexperiencesusa.org)



*Partnership between University of Wisconsin, Johns Hopkins University, Oregon Health & Science University, and Yale University.*

# Health Experiences Research Network (HERN) Steering Committee

Launched in 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

**H**ealthExperiencesUsa.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.

Authentic Experiences

Patient Voices

**"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

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



Talking about  
depression



**TELL YOUR  
STORY  
TO HELP  
OTHERS.  
FEEL LESS  
ALONE.**



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](mailto:healthtalkus@gmail.com)) if you are interested.

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078

[healthtalkus@gmail.com](mailto:healthtalkus@gmail.com)  
Call or Text: 608-285-2078





# Young Adults' Experiences of Depression in the U.S.

Topics

People's Profiles

Resources &amp; Information

Credits

## Overview

Next Topic ▶

▶ **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)**

## 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.



## EXPERIENCES OF DEPRESSION IN U.S. YOUNG ADULTS



# Young Adults' Experiences of Depression in the U.S.

Topics	People's Profiles	Resources & Information	Credits
--------	-------------------	-------------------------	---------

## 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)**

[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 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.



## EXPERIENCES OF DEPRESSION IN U.S. YOUNG ADULTS





## Topics

### 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)**

---





## Living with depression (18)

### How depression feels

Signs and symptoms of depression

Depression and eating disorders

Depression and anxiety

Depression and obsessive compulsive disorder (OCD)

Depression, substance use and abuse

Depression and self-harming

Going public with depression?

Depression and abuse

Depression and identity

Depression and relationships

Depression and school

Depression and everyday tasks

Depression and work

Depression, bias, and disadvantage

Barriers to care

The positive sides of depression

Depression and suicide

Depression and transitions to adulthood

## First experiences with depression (2)

Depression and feeling different when young

Young adults' views about what causes depression

## Living with depression (18)

### How depression feels

Signs and symptoms of depression

Depression and eating disorders

Depression and anxiety

Depression and obsessive compulsive disorder (OCD)

Depression, substance use and abuse

Depression and self-harming

Going public with depression?

Depression and abuse

Depression and identity

Depression and relationships

Depression and school

Depression and everyday tasks

Depression and work

Depression, bias, and disadvantage

Barriers to care

The positive sides of depression

Depression and suicide

Depression and transitions to adulthood

## Getting help: seeking assistance and treatment (3)

Getting professional help for depression

Therapy and counseling

Depression, medication, and treatment choices

Depression treatment in emergency rooms and hospitals

Holistic and integrative approaches to depression

## Helping yourself: support, self-care, and feeling better (7)

Having a purpose in life

Building relationships that work when depressed

Depression and pets

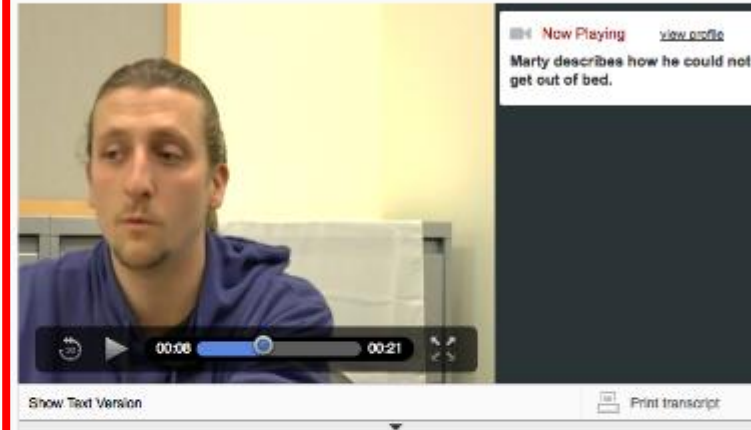
Depression and strategies for everyday life

Cycles of depression and maintaining hope

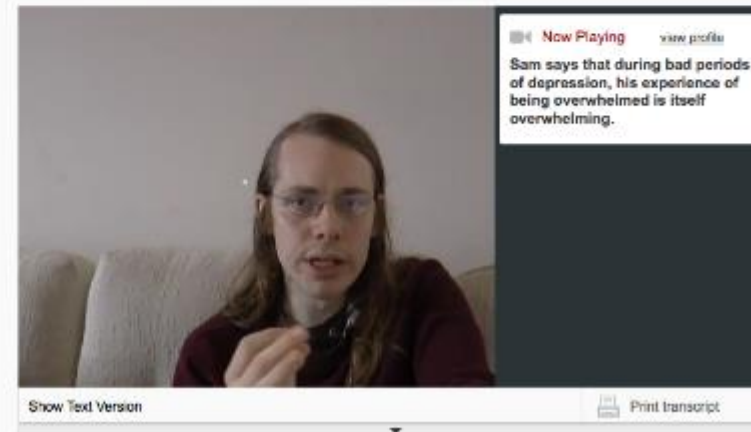
## How depression feels

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 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 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 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 has to "unplug and not really communicate with anyone."



For many people, that sense of isolation was accompanied by feeling overwhelmed. Some described this as everything becoming unmanageably "abrasive to my senses": bright lights, groups of other people, noise, daylight. Others talked about everyday responsibilities like school work becoming "frightening," or dissolving in tears while in public without knowing why.












## Metaphors about depression

For many of those we interviewed, ordinary language and descriptions were not nuanced enough to



# Young Adults' Experiences of Depression in the U.S.

Topics	People's Profiles	Resources & Information	Credits
<ul style="list-style-type: none"><li>▶ Men age 18-20 (3)</li><li>▶ Women age 18-20 (5)</li><li>▶ Men 21-24 (6)</li><li>▶ Women 21-24 (8)</li><li>▶ Men 25 and over (7)</li><li>▼ Women 25 and over (9)</li></ul>	<h2>Women 25 and over</h2> <div><p><b>Whitney</b> Whitney, 29, was diagnosed at age 9, and later with bipolar disorder. Family and school...</p></div> <div><p><b>Shayne</b> Shayne, age 27, began to experience depression in high school. Other mental health issues...</p></div> <div><p><b>Sally</b> Sally's depression began when she was a teenager and her parents separated. She continues...</p></div> <div><p><b>Maya</b> Maya (age 27) grew up in an emotionally abusive family and was diagnosed at age 16.. She...</p></div> <div><p><b>Elizabeth</b> Elizabeth was a sensitive child. She was diagnosed with depression and an eating disorder...</p></div>	<div><p><b>Tia</b> Tia, 28, was shy and embarrassed about having no father. She masks her depression and...</p></div> <div><p><b>Sara</b> Sara, age 26, experienced depression beginning in middle school and was diagnosed with...</p></div> <div><p><b>Myra</b> Myra (age 27), as a child was abused and bullied by peers, but her parents did not believe...</p></div> <div><p><b>Julia</b> Julia, age 25, first noticed depression symptoms at age 14 and was diagnosed in college.....</p></div>	





# Young Adults' Experiences of Depression in the U.S.

Topics	People's Profiles	Resources & Information	Credits
--------	-------------------	-------------------------	---------

## Overview

▶ **First experiences with depression (2)**

▶ **Living with depression (19)**

▼ **Getting help: seeking assistance and treatment (5)**

Getting professional help for depression

Therapy and counseling

Depression, medication, and treatment choices

Depression treatment in emergency rooms and hospitals

Holistic and integrative approaches to depression

▶ **Helping yourself: support, self-care, and feeling better (7)**

▶ **Messages to others (2)**

◀ Previous Topic

Next Topic ▶

## 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’](#).)



Audio only

◀ Now Playing [view profile](#)

Crystal discusses the complexity of mental illness and different treatment approaches including medication.





# 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





# Young Adults' Experiences of Depression in the U.S.

Topics	People's Profiles	Resources & Information	Credits
<b>Overview</b> <ul style="list-style-type: none"><li>▶ <b>First experiences with depression (2)</b></li><li>▶ <b>Living with depression (19)</b></li><li>▶ <b>Getting help: seeking assistance and treatment (5)</b></li><li>▼ <b>Helping yourself: support, self-care, and feeling better (7)</b><ul style="list-style-type: none"><li>Having a purpose in life</li><li>Building relationships that work when depressed</li><li><b>Depression and pets</b></li><li>Depression and strategies for everyday life</li><li>Cycles of depression and maintaining hope</li><li>Depression, spirituality, and faith</li><li>Depression and healing</li></ul></li><li>▶ <b>Messages to others (2)</b></li></ul>	<p>◀ Previous Topic</p> <p><b>Depression and pets</b></p> <p>Next Topic ▶</p> <p>✉ 📄 📄</p> <p>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.</p> <p><b>Being loved and accepted</b></p> <p>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."</p> <p>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.</p>		

◀ Now Playing [view profile](#)



## 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



# Maya

---



"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."

---



# Natasha

---



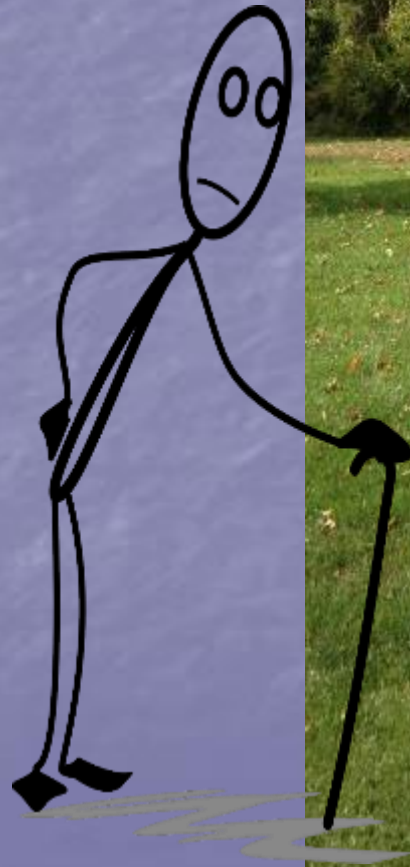
"[Depression,] it's sort of always a journey, that's a cliché statement but it's sort of a constant thing that you have to deal with . . . [it's] a journey that I'm getting more comfortable with, like easier to navigate. I guess my situation is really unique, coming from this super small place and also being a queer person is interesting, I thought that would be a voice that would be good to have."

---



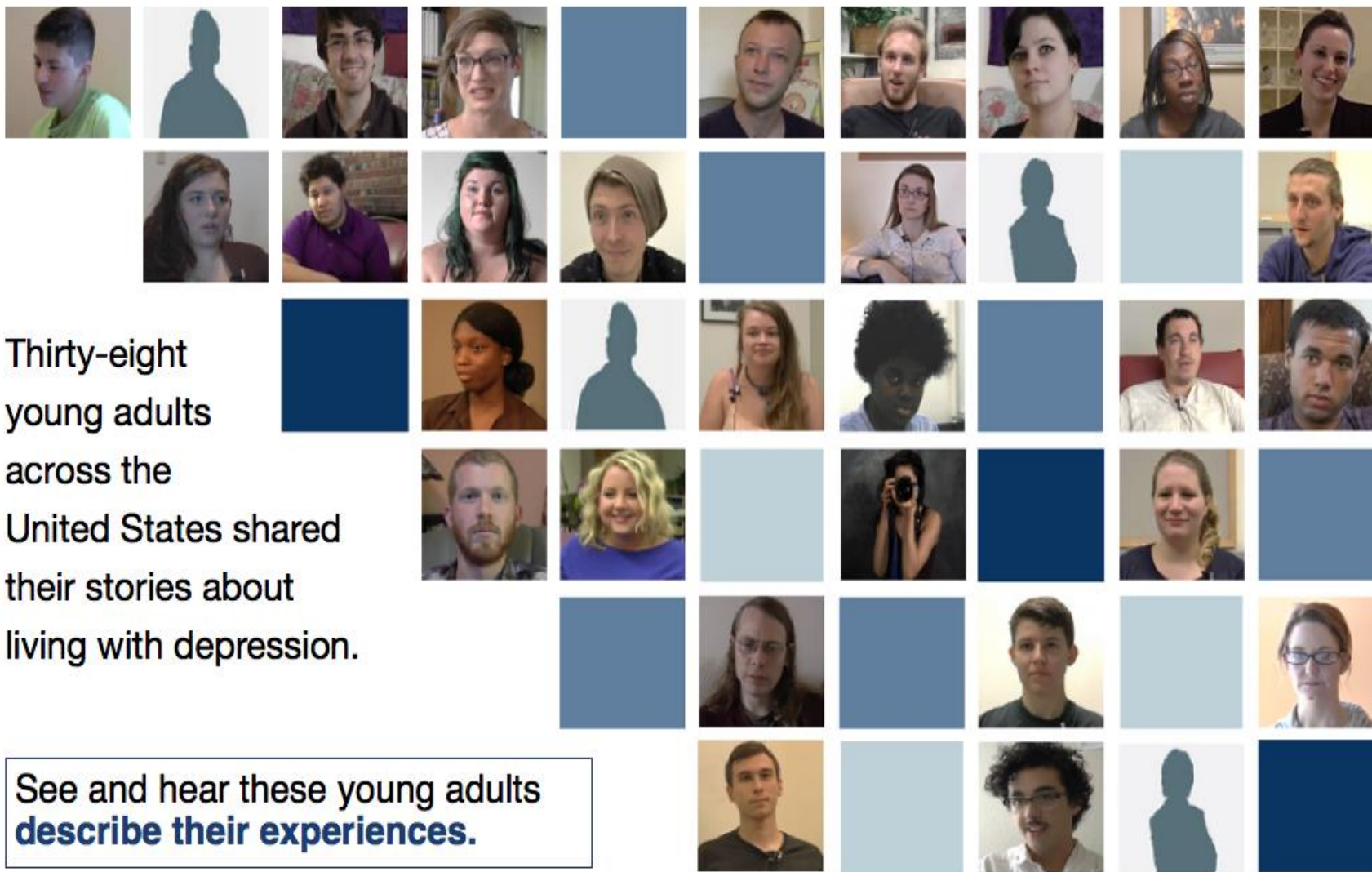


*From Voice .....*



# .....to Voices

## 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.**





 **healthexperiencesusa.org**



Your Questions?