Emotional WellnessOne Pause at a Time

Meghan Beier, PhD

Learning Agenda

What we'll discuss today

- Prevalence and impact of mental health challenges in amyloidosis
- How mental and physical health interact
- Strategies for managing the ups and downs of living with a chronic illness





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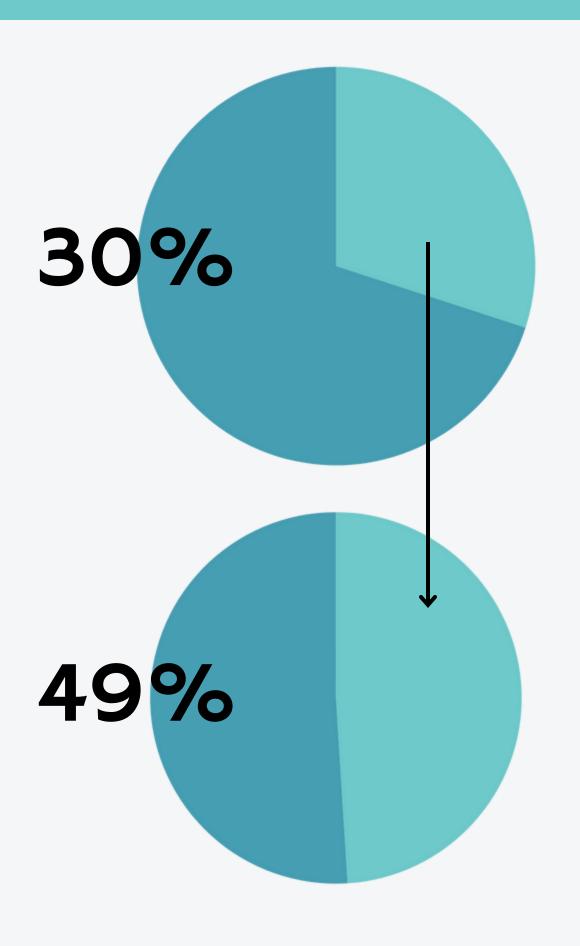


About the Speaker

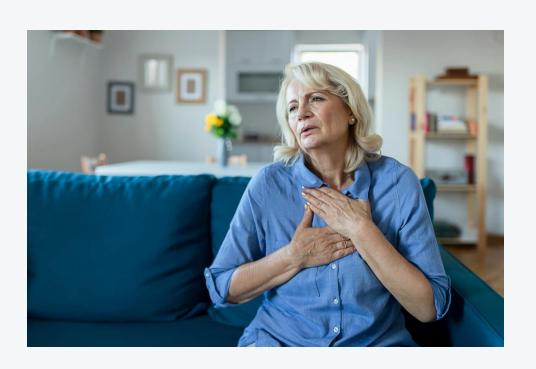
Meghan Beier, PhD

- **Psychologist** at Rowan Center for Behavioral Medicine that specializes in chronic illness and disability
- Faculty at Johns Hopkins
- I **create education** for mental health professionals who want to learn more about working with chronic illness
- Host of the podcast Find Empathy, where I interview researchers, clinicians, and people with lived experience to help bring to light the connection between medical and emotional health





Between one-third and one-half of individuals with amyloidosis experience clinical levels of <u>depression</u>, <u>anxiety</u>, <u>or both simultaneously</u>.



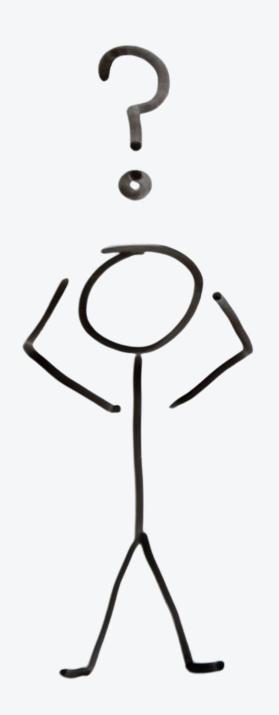


Smorti, M., Ponti, L., Soffio, F., Argirò, A., Perfetto, F., Zampieri, M., Mazzoni, C., Tomberli, A., Allinovi, M., Di Mario, C., Olivotto, I., & Cappelli, F. (2023). Prevalence of anxiety and depression symptoms in a sample of outpatients with ATTR cardiac amyloidosis. Frontiers in psychology, 13, 1066224. https://doi-org.proxy1.library.jhu.edu/10.3389/fpsyg.2022.1066224

Anxiety & Depression Risk Factors

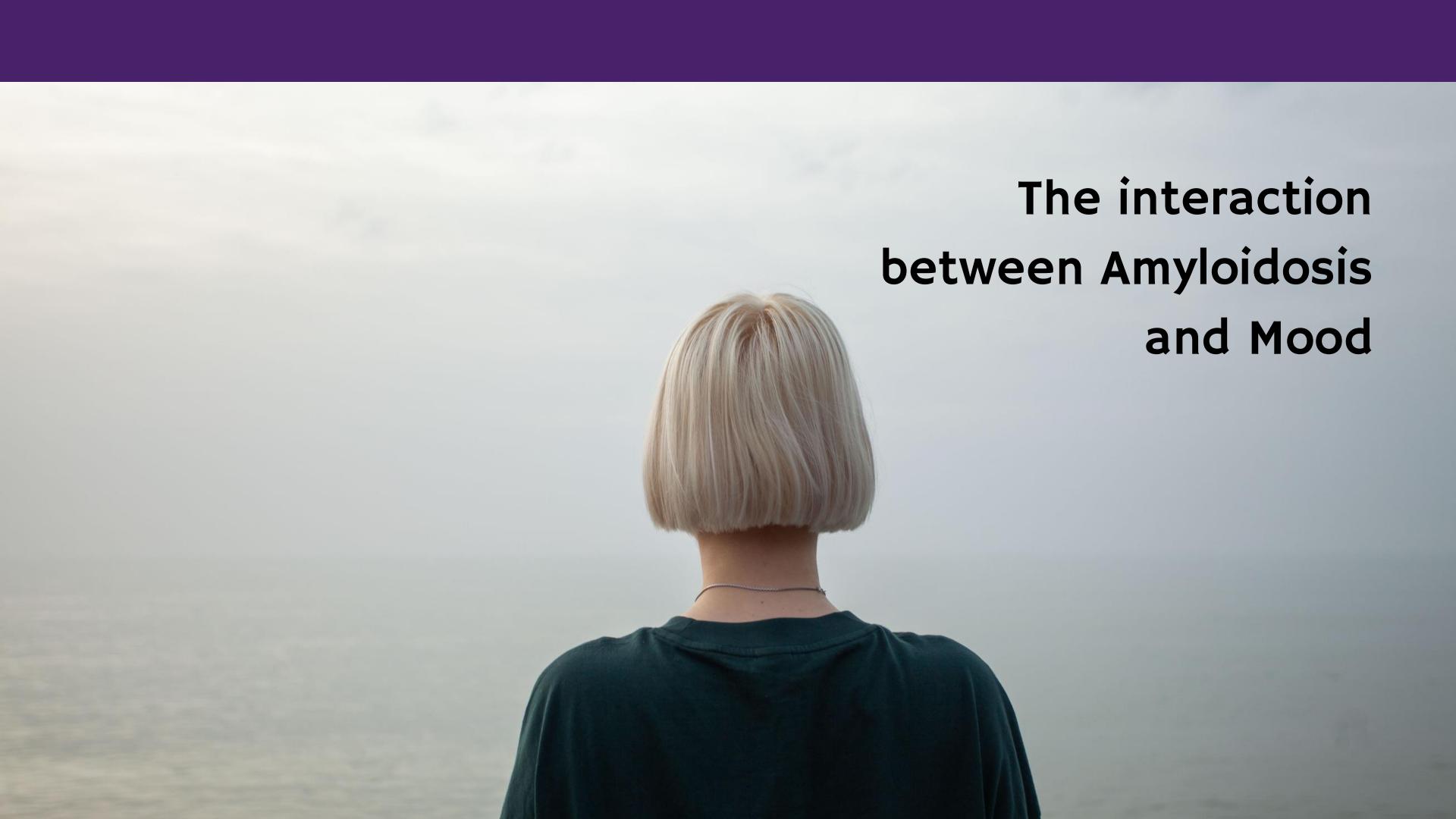
- Older age
- Female
- Experiencing more symptoms
- More advanced disease
- Time since cardiac symptom onset

Polling Question



Have you ever experienced:

- depression
- grief
- anxiety
- stress
- Other Write it in the chat!



Primary

Secondary

Tertiary



Primary

Emotions are directly impacted by the medical condition.

Example:

Damage to brain tissue from bleeding in the brain.



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Secondary

Emotions are impacted by medications, treatments, or symptoms of the medical condition.

Example

- Experiencing mania or hypomania after the use of steroids.
- Irregular heartbeats, racing heart, or shortness of breath.



Tertiary

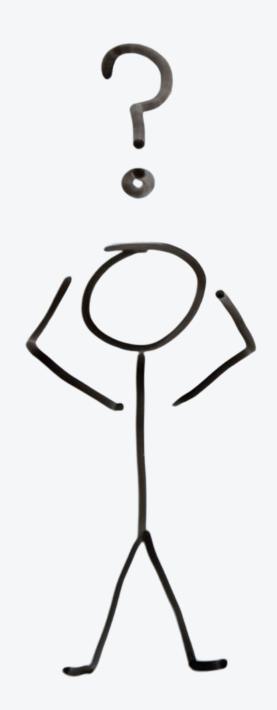
An emotional reaction associated with the challenges of living with the condition, role changes, or environmental stressors.

Example

- Fear of the unknown, uncertainty
- Change in family role may trigger thoughts of not wanting to be a burden



Polling Question

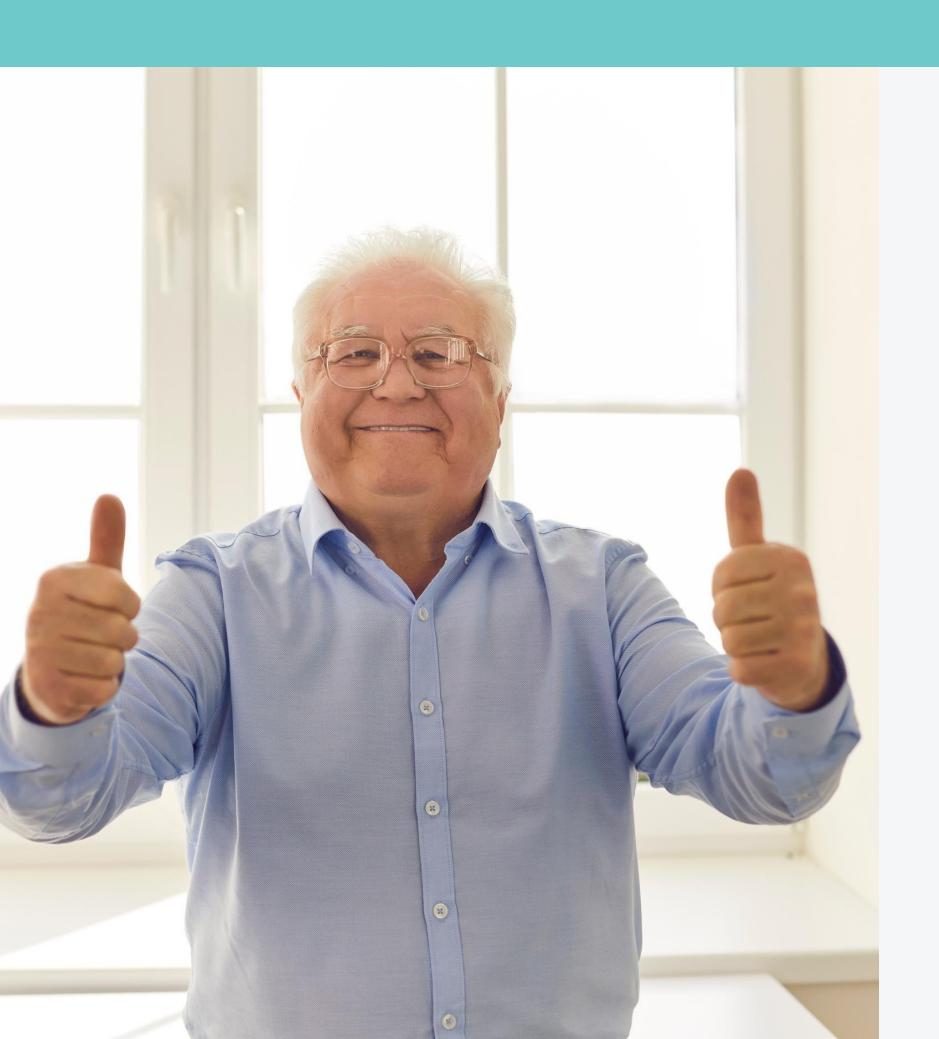


Which of the three areas do you think has impacted your mood:

- Primary the disease itself
- Secondary medications or symptoms
- Tertiary emotional reaction, role changes
- All of the above
- Other Write it in the chat!



Values,
Dialectics, and
Committed
Action



2 Building Block Skills

Identifying Values

Building on what you CAN DO

Dialectics

 Acknowledging both grief & committing to behavior change



Examples of Values:

- Courageous
- Fitness
- Humor
- Kindness
- Curiosity

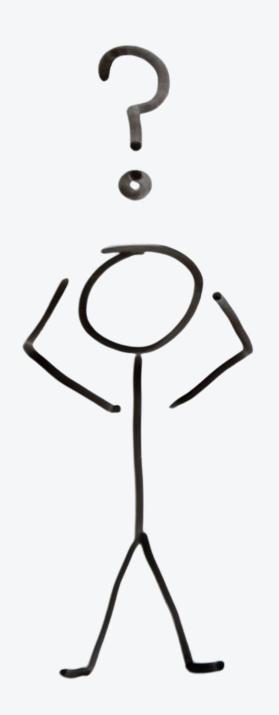
Identify Values

Values can be lived out even if functioning changes over time.

Exercise

- 1. Identify activities that bring joy, satisfaction, contentment
- 2. Identify the underlying core reasons the activity is meaningful
- 3. Identify new ways to incorporate those core values into daily life

Write in the Chat!



Name a VALUE that is important to you.

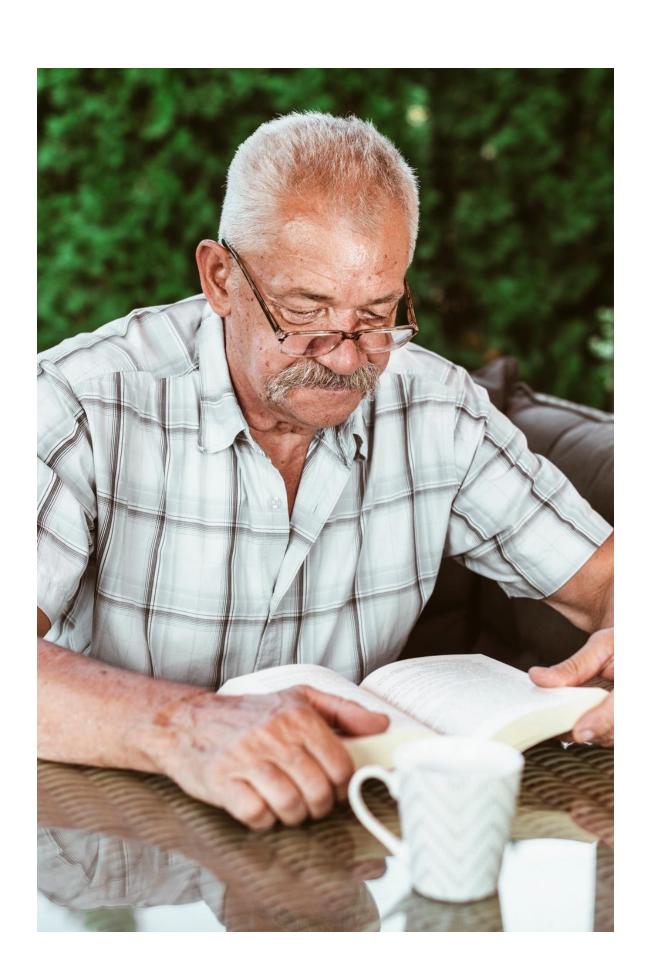
Examples of Values:

- Courageous
- Maintaining Health
- Humor
- Kindness
- Curiosity



Case Example

John, a 62-year-old retired teacher, used to enjoy his morning walks around the neighborhood, but lately, he finds himself stopping every few minutes, struggling to catch his breath. His legs feel unusually heavy, and a strange tingling in his feet makes it hard to keep his balance. Frustrated and confused, he wonders if he's just out of shape or if something more serious is happening.



Case Example

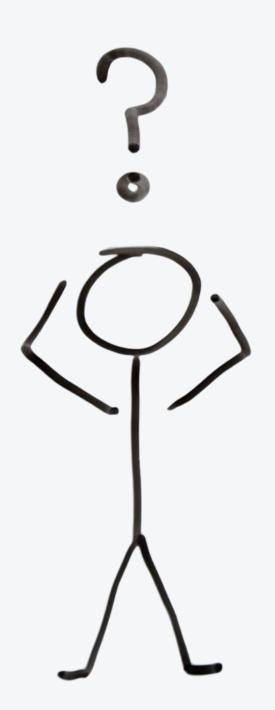
Values Activity - Identified reasons walking was so meaningful:

- opportunity to be in nature
- enjoyed the feeling of the sun and breeze
- enjoyed socializing with neighbors

Alternative ways he can incorporate values

- worked with PT to better understand his symptoms and to feel safer
- invite neighbors over to sit on the porch to socialize and enjoy nice weather

Write in the Chat!



Help John! What are some other activities that John can try to incorporate the things that were meaningful to him:

- being in nature
- feeling the sun and breeze
- socializing with friends

ONE WAY ONE WAY

Incorporating "AND"

Acknowledging Grief + Opportunities for Change = Acceptance

Drawn from DBT dialectics and ACT willingness

It's ok to grieve. It's OK to not want this disease or condition.

AND it's OK to acknowledge those feelings while learning to live with the disease, problem-solve the challenges, and find work arounds.

Incorporating "AND"

Acknowledging Grief + Opportunities for Change = Acceptance

Exercise:

- Flow and move between these seemingly opposite ideas as needed.
- Set aside time (5 15 min) to grieve when frustrations arise.
- Name the emotions, acknowledge their presence
- Without judgement, unhook from that grief and look towards problem-solving or enjoying the present moment

Acknowledging Grief + Opportunities for Change = Acceptance



Emily, a 63-year-old artist, has always found peace in painting, but lately, the stiffness and numbness in her hands make it nearly impossible to hold a brush. **Frustrated** and **grieving** the thought of giving up her passion, she considers putting away her easel for good.

She talks with a friend and names her feelings - fear, frusration, and grief.

She doesn't want to learn a new way to paint AND she doesn't want to give up her passion. She talks with other artists and an OT. She decides to try larger brushes with padded grips and experiment with digital painting.

The unwanted emotions do not go away completely. But each time they come, she acknowledges them AND acknowledges her values and reasons for continuing to try in a new way.



Willingness

- Practice willingness to experience all emotions, as opposed to avoidance or trying to fight unwanted emotions
- Trying something new, or having to relearn how to do everyday activities will bring frustration, uncertainty, and more. Acknowledge this, and commit to trying anyway

Don't hesitate to seek help.

Therapy can be a great option for working through challenges.

Recommended: Work with a health psychologist, rehabilitation psychologist, neuropsychologist, or social worker/LPC with experience in medical diagnoses and/or chronic illness.

Places to find therapists:

- Patient organizations
- National Register of Health Service Psychologists
- American Psychological Association psychologist locator
- Psychology Today
- PSYPACT



Resources

For Care Partners:

- Caregiver Action Network (CAN) https://www.caregiveraction.org/
- Mental Health Resources for Caregivers https://mhanational.org/mental-health-resourcescaregivers
- Family Caregiver Alliance <u>www.caregiver.org/about-fca/</u>

YouTube videos:

- Rutgers University put together videos of different DBT skills in easy to digest videos https://www.youtube.com/@DBTRU
- Self Help Toons has short videos on lots of skills and psychotherapy frameworks https://www.youtube.com/@SelfHelpToons
- ACT videos https://www.youtube.com/@dr.russharris-acceptanceco972/videos
- Applying ACT to Youth and Adolescents (more academic webinar talk) https://youtu.be/y3ClwKNX_as?si=yV3SM9Y_29g-hVp0



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PODCAST

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Between stimulus and response, there is a <u>space</u>. In that <u>space</u> is our power to choose our response. In our response lies our growth and our freedom.

- Viktor E. Frankl