

Development of an Online Intervention to Reduce Internalized Stigma in Epilepsy

Allyson Goldstein, BS¹; Elaine T. Kiriakopoulos, MD²; Geoffrey Tremont, PhD^{1,3}; Kunal Mankodiya, PhD⁴; Sabah Ummie, MS⁴; Seth A. Margolis, PhD^{1,3}

¹Rhode Island Hospital; ²Geisel School of Medicine at Dartmouth College; ³Alpert Medical School of Brown University; ⁴University of Rhode Island

OBJECTIVE

Background

- Internalized health-related stigma stems from embarrassment about having an illness and the fear that one may encounter discrimination based on their condition
- Approximately 50% of people with epilepsy (PWE) internalize stigma
- Stigma is linked to poor epilepsy self-management, reduced quality of life (QOL), anxiety and depression, and suicide risk
- The World Health Organization declared epilepsy stigma a worldwide public health concern and the Institute of Medicine encouraged efforts on reducing stigma through behavioral health interventions

Study Aims

- Identify critical components of a behavioral health intervention to teach PWE strategies to reduce stigma and enhance QOL
- Determine shortcomings of past anti-stigma interventions and create a platform that systematically addresses these issues

METHOD

Procedures

- Targeted review of empirical and theoretical research on epilepsy stigma was leveraged to determine critical intervention components
- Two neuropsychologists, a neurologist, and a computer engineer with experience in epilepsy care, intervention development, and digital health engaged in iterative, weekly meetings for 1 year to develop an intervention appropriate for adults with epilepsy

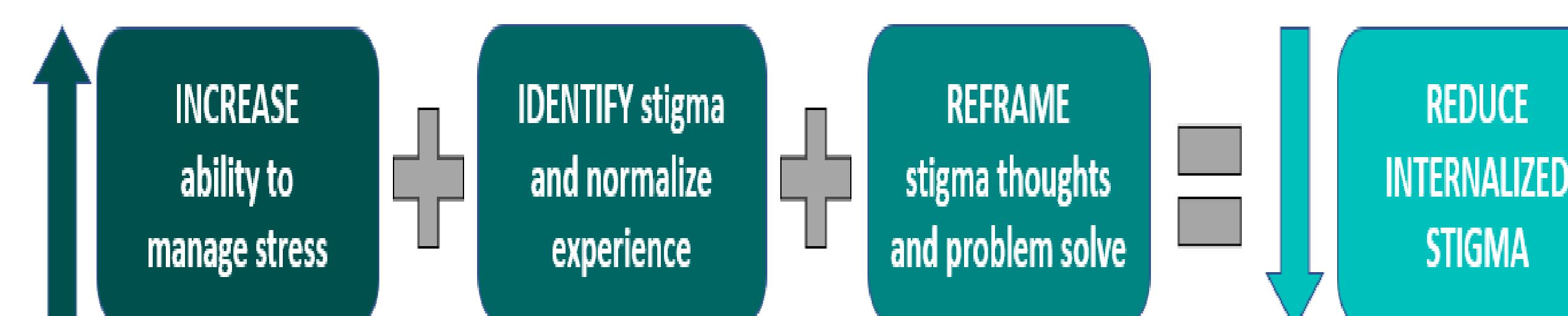
RESULTS

- Stigma manifests in education, work, healthcare and relationships
- Table 1 highlights critical components and gaps in prior interventions
- A self-administered, modular, online platform with built-in demonstration and interactive practice exercises was developed, called: **RISE ABOVE: Reducing Internalized Stigma in Epilepsy: A Behavioral Online Video Education**

| Intervention Components | Nurse Led Conversation During ER Visits | Parent-Child Education Sessions | Peer Support Groups | RISE ABOVE |
|---|---|---------------------------------|---------------------|------------|
| Psychoeducation | ✓ | ✓ | ✓ | ✓ |
| Focused on Psychosocial Aspects of Epilepsy | | ✓ | ✓ | ✓ |
| Co-Produced by People Living w/ Epilepsy | | | ✓ | ✓ |
| Teaches Evidence Based Coping Skills | | | | ✓ |
| Self Administered | | | | ✓ |
| Mobile Format | | | | ✓ |

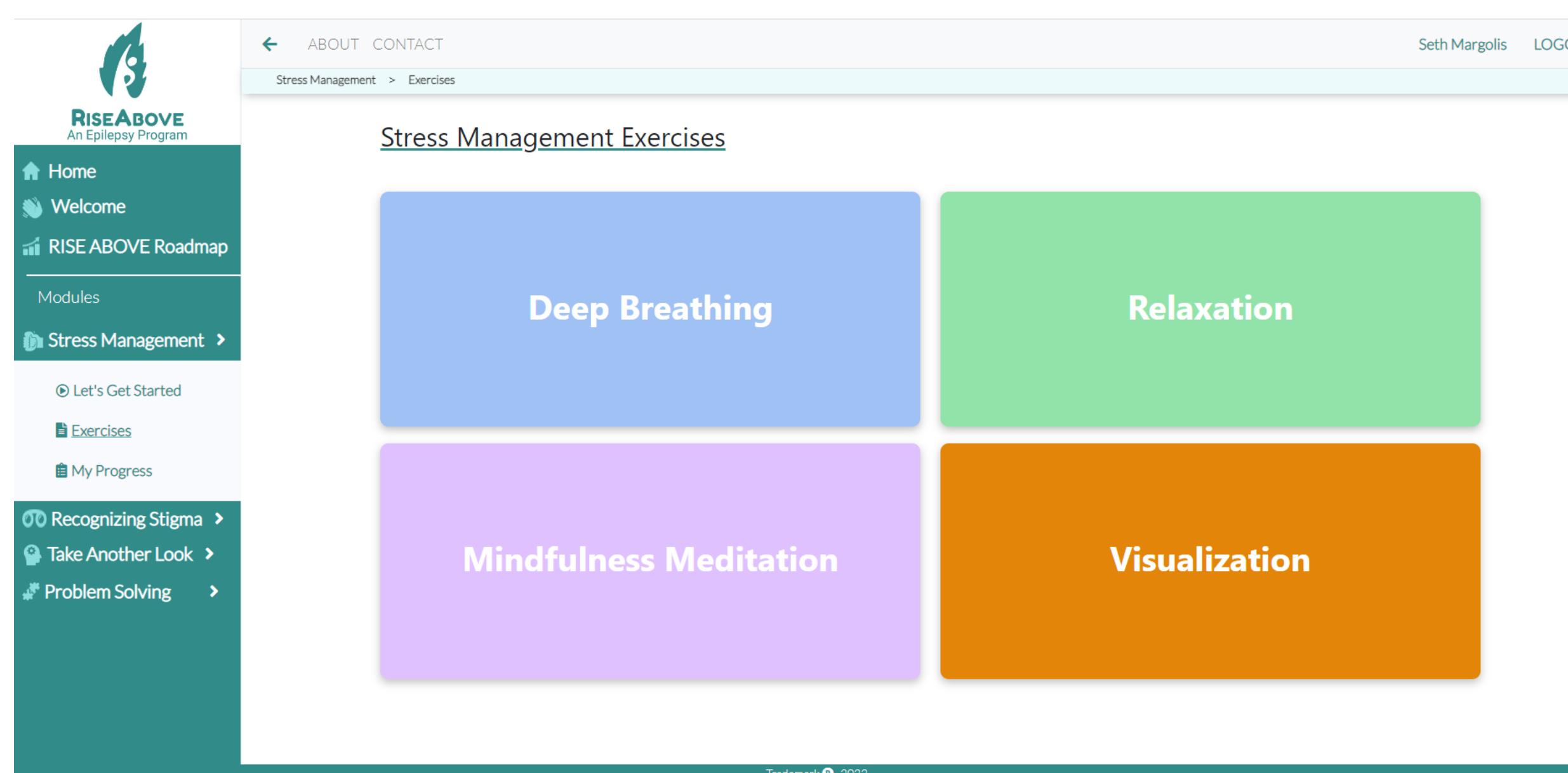
RESULTS

- RISE ABOVE** aims to help PWE:



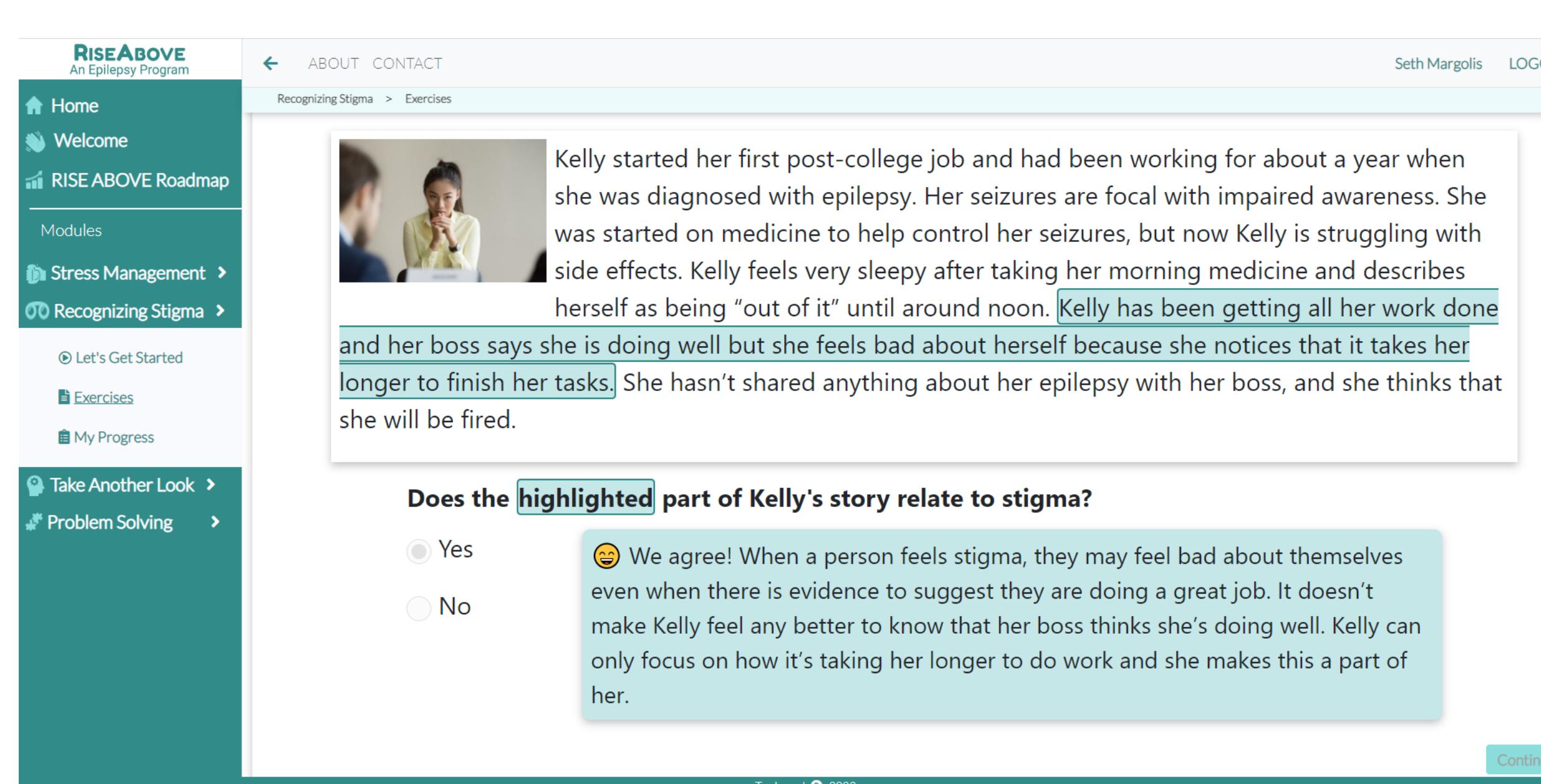
- Module 1, **Stress Management**, teaches deep breathing, progressive muscle relaxation, visualization, and mindfulness techniques via guided demonstration and practice exercises (Fig. 1)

Figure 1: Stress Management Exercises



- Module 2, **Recognizing Stigma**, uses stories adapted from the lives of PWE to teach users to identify and understand stigma-related thoughts, feelings, and reactions, and how these thoughts impact QOL (Fig. 2)

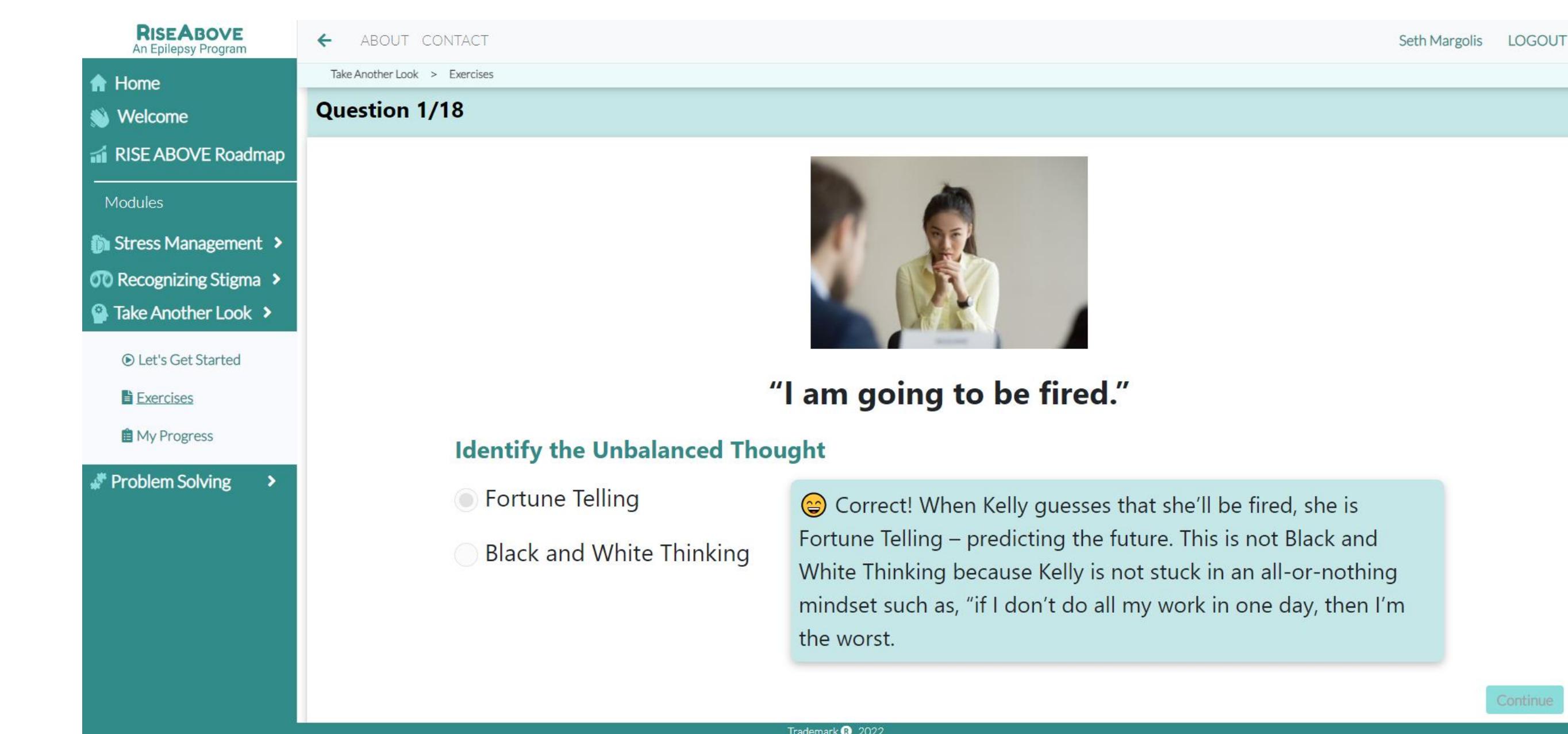
Figure 2: Recognizing Stigma Vignette Exercise



RESULTS

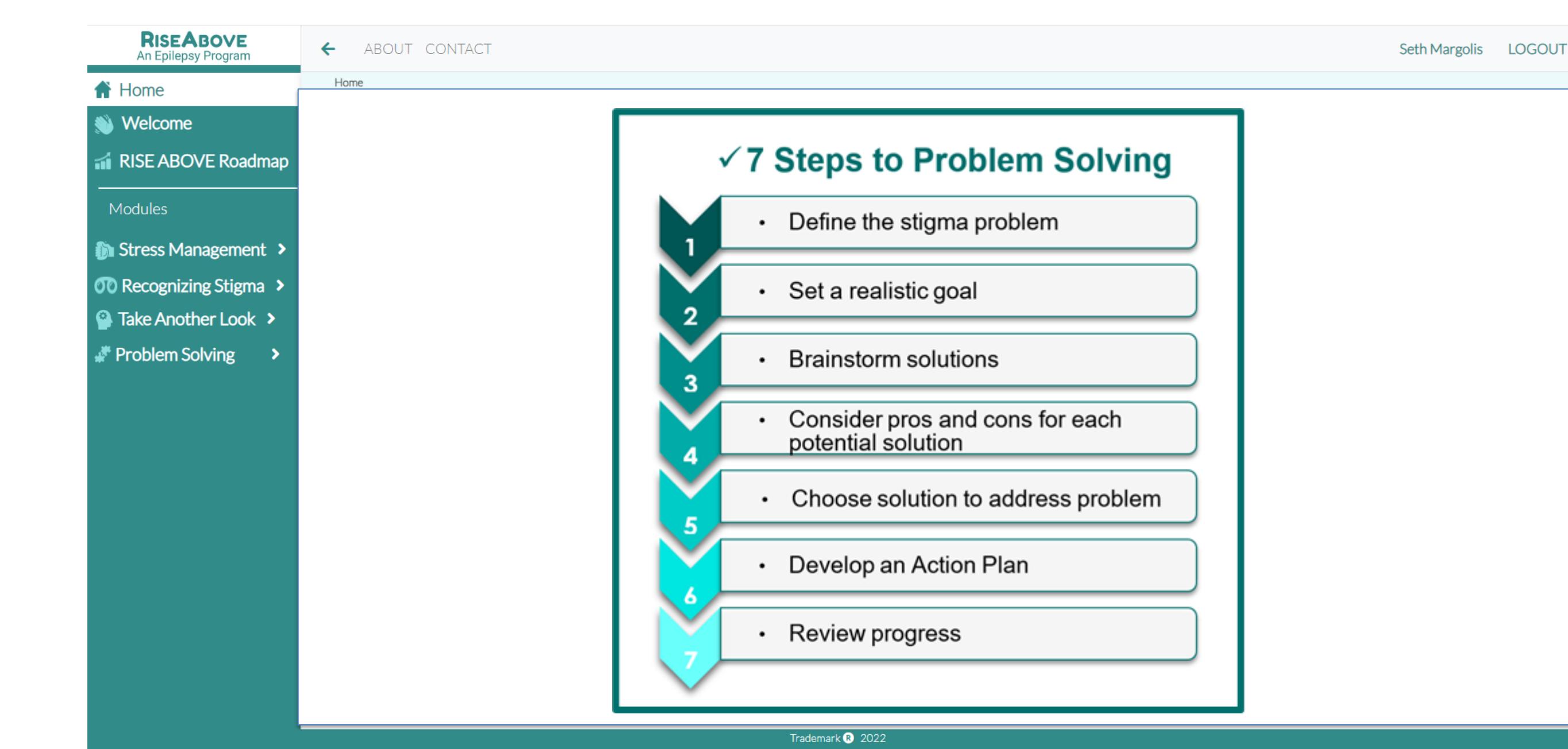
- Module 3, **Take Another Look**, explains the concept of cognitive distortions and how they relate to stigma, then teaches 2 strategies to reframe unbalanced thoughts (Fig. 3)

Figure 3: Take Another Look Cognitive Reframing Exercise



- Module 4, **Problem Solving**, guides users to apply problem solving skills to stigma situations via a step-by-step process (Fig. 4)

Figure 4: Problem Solving Exercise



CONCLUSION

- Drawing on research, theory, and collaborative multidisciplinary interaction, psychoeducational content employing a cognitive-behavioral framework was adapted to a self-administered, modular, online platform to mitigate the stigma felt by PWE
- Future research will elicit feedback from community stakeholders and beta test RISE ABOVE to guide its final optimization

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