

# Mental Health Challenges of Heart Failure Patients & Caregivers: A Needs Assessment Study

**Authors**  
Soyun Oh<sup>1,2</sup> BEng BA, Geetika Babbar<sup>3</sup>, Noor El-Dassouki<sup>2</sup> MSc, Elham Hashemi<sup>4</sup> MSc, Lindsay Jibb<sup>4,5</sup> PhD, Alicia Kilfoy<sup>4,5</sup> RN MSc, Raima Lohani<sup>2</sup> RN MSc, Olivia Metcalf<sup>6</sup> PhD, Enid Montague<sup>7</sup> PhD, Meaghan O'Donnell<sup>6</sup> PhD, & Quynh Pham<sup>1,2</sup> PhD

**Affiliations**  
1: Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Canada; 2: Centre for Digital Therapeutics, University Health Network, Toronto, Canada; 3: University of Western Ontario, Canada; 4: SickKids, Toronto, Canada; 5: Bloomberg School of Nursing, University of Toronto, Toronto, Canada; 6: University of Melbourne, Melbourne, Australia; 7: Department of Mechanical and Industrial Engineering, University of Toronto, Toronto, Canada



## Background

Both **heart failure (HF) patients** and **their caregivers** face significant **mental health challenges**. Digital health interventions (DHIs) offer accessible, 24/7 support to help address these challenges. This needs assessment study forms a foundational sub-study of the **Medly-SOLAR research project**, which aims to design an app-based DHI that supports the mental well-being of people affected by HF. **Medly-SOLAR** will be created by adapting SOLAR and integrating it into Medly. **Medly** is a remote HF management system used as a standard of care at UHN—Canada’s top research hospital. **Skills for Life Adjustment and Resilience (SOLAR)** is an evidence-based DHI designed for mental health management. This needs assessment study explored the unique mental health challenges experienced by Medly end-users to ensure that Medly-SOLAR is tailored to their specific needs.

## Objective

To **identify and understand** the mental health challenges and needs of Medly end-users—HF patients and their caregivers.

## Research Question

“What are the **mental health challenges and needs** of HF patients and their caregivers?”

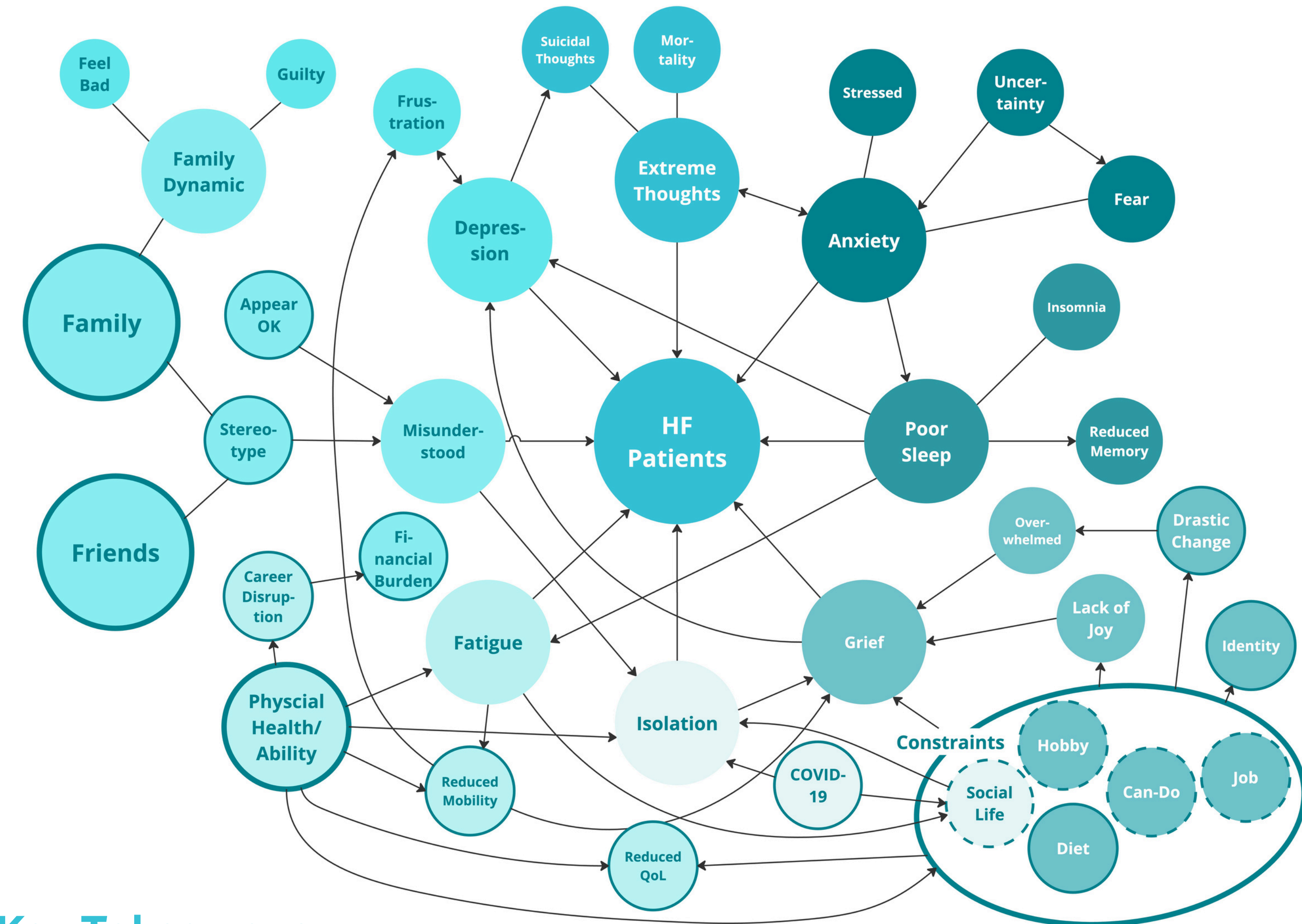
## Methods

Eight participants—**five patients** and **three caregivers**—completed semi-structured, virtual interviews. Each interview was recorded and transcribed for analysis. Data analysis involved **thematic analysis, modeling, and narrative synthesis**. Thematic analysis identified and highlighted their key mental health challenges. Modeling further examined how these challenges are interconnected, demonstrating their interrelationships. Narrative synthesis comprehensively summarized the findings.

## Results

For heart failure patients, eight key mental health challenges were identified: **(1) anxiety, (2) extreme thoughts, (3) poor sleep, (4) fatigue, (5) feeling misunderstood, (6) isolation, (7) grief, and (8) depression**. For caregivers, four key mental health challenges were identified: **(1) anxiety, (2) feeling overwhelmed, (3) trauma, and (4) mood fluctuations**.

**Figure 1.** Major Mental Health Challenges of HF Patients and Their Interrelationships



## Key Takeaways

- Anxiety as a Central Mental Health Challenge:** For both HF patients and caregivers, anxiety emerged as the most prevalent challenge and often served as a trigger for subsequent issues (e.g., extreme thoughts, poor sleep). Therefore, targeting anxiety may be an efficient strategy, as it could help alleviate other related mental health challenges.
- Tailored Design for Distinct User Groups:** Given the distinct needs of HF patients and caregivers, the team decided to create two separate versions of Medly-SOLAR, each with tailored content and design to better address their specific challenges and needs.
- Adapting SOLAR Features for HF-Specific Needs:** While most identified challenges can be addressed using existing SOLAR features, certain adaptations need to be developed in consultation with psychiatrists (e.g., grief support) and cardiologists (e.g., breathing techniques, fluid intake, physical activity guidelines) to accommodate HF-specific needs.

## Conclusion

This needs assessment study provides valuable **insights** into the **mental health challenges** experienced by **HF patients** and **their caregivers**. The identified challenges underscore the importance of developing targeted DHIs that consider these specific needs and unique circumstances of the HF journey. These findings directly **inform the development of Medly-SOLAR**, as well as other DHIs designed to manage the mental health of people affected by HF. By addressing these specific mental health challenges, the Medly-SOLAR research project will offer tailored solutions and support the well-being of HF patients and their caregivers.

## Acknowledgment

This study was funded by the Manchester-Melbourne-Toronto Research Partnership Development Fund, KITE-Toronto Rehabilitation Institute Student Scholarship, and TRANSFORM HF Trainee Award. The funders had no role in the study design, collection, analysis, or interpretation of data, or in the writing of this poster.

**Table 1.** Top Eight Mental Health Challenges of HF Patients

Challenges	Key Findings	Quotes
Anxiety	• A lot of anxieties are <b>rooted in uncertainty</b> and not knowing what the HF journey would look like, and thus patients have the greatest anxiety following their diagnosis.	“I did not get information. ...there was nothing—no course, no hospital program to educate me or other patients similarly diagnosed about HF, and so I think <b>my anxiety</b> for a time <b>was a lot higher</b> than probably what was warranted and that was <b>[because of] a lack of information.</b> ”
Extreme Thoughts	• HF patients are often <b>preoccupied with extreme thoughts</b> like those about mortality, aging, or accidents. They think about catastrophic scenarios over and over.	“...my dad...he said, ‘Oh yeah, your grandfather died of congestive HF,’ and I’m like, ‘oh my god, what? Am I gonna die of this stupid thing?’” “...I’ve done everything I need to do. <b>‘Should I pop off?’</b> I say that to my son. If I pop off, everything is done.”
Poor Sleep	• HF patients <b>don’t get quality sleep</b> due to aging and sleep apnea, as well as extreme thoughts and anxiety.	“I’ve started taking little naps in the afternoon because <b>I’m just exhausted because I haven’t slept</b> , you know, the night before. I get up during the night, ...the lack of sleep overtime—I feel the effects— <b>I’m depressed, I’m listless.</b> ”
Fatigue	• HF patients feel easily <b>tired and fatigued</b> due to their poor physical health and limited physical ability.	“...my two biggest symptoms still are shortness of breath exercising, so if I walk too quickly, I have to stop, get my breath, and the other is <b>tremendous fatigue—I’m so tired.</b> ”
Feeling Misunderstood	• HF patients are frequently <b>misunderstood, even by their friends</b> , due to stereotypes and a lack of awareness surrounding HF. • Unlike those with other chronic conditions (e.g., cancer), HF patients <b>appear healthy and unaffected</b> , which deepens these misunderstandings.	“...on the outside <b>I don’t look different—I look healthy. ...I look normal</b> , I look like there should be nothing wrong with me <b>and that’s deceptive</b> because at the same time I’m so aware, ...and will get together with friends and so on and I’m very aware at those times of how my life has become more constraint. I’m not as free spirited as I was.”
Isolation	• The HF journey can be incredibly <b>lonely</b> , as it largely revolves around self-care and independently navigating the healthcare system.	“...HF could be <b>a very lonely experience.</b> ” “... <b>there’s this thing that you feel like really alone.</b> ...Because part of the diagnosis and getting treated and getting better is like <b>you find your own support systems.</b> ”
Grief	• HF patients often <b>grieve their pre-diagnosis lives</b> as they encounter new limitations and challenges along the HF journey.	“I was always very active—I danced. ... <b>that’s gone.</b> ” “I’d say currently I have <b>less joy</b> . I’m trying to get back into it.”
Depression	• The constant <b>constraints of HF contribute to depression</b> in many patients. • <b>Feelings of hopelessness</b> can persist as HF is lifelong and mostly incurable.	“ <b>I became depressed</b> , yes! And it’s just I guess like any disease, it affects your caregiver, it affects your social life, <b>it affects such a big window outside of your little heart.</b> ”