

# Coping with Challenges of Living with Primary Sclerosing Cholangitis



**Dr. Sara Ahola Kohut, PhD, CPsych**  
Clinical and Health Psychologist, Hospital for Sick Children  
Project Investigator, SickKids Research Institute  
Assistant Professor, Dept of Psychiatry, University of Toronto



Ahola Kohut 2025

## There are multiple 'right' answers

- This is not about having all the answers, instead focusing on knowing that the future version of you will be able to handle what arises because they will know more and have more skills.

*This is hard because it is hard, not because you are doing it wrong.  
...and you are not alone.*

- Offer a framework to guide decisions, questions to consider, and a choose your own adventure ...

Ahola Kohut 2025

## Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

- Resilience is innate and also modifiable trait
  - Decreased anxiety and depression in adults with IBD (Philippou et al., 2021)
  - Mindfulness and optimism mediated relationship between resilience and QOL in teens with IBD (Hare et al., in review)
  - Predicts transition readiness in teens IBD (Carlsen et al., 2017)
- GRITT model in IBD (Keefer et al., 2022)
  - 71% fewer ED visits
  - 94% fewer unplanned admissions
  - 49% less opioid use
  - 73% less corticosteroid use
- Qualitative work supports resilience as core to self-management of IBD (Mendiola et al., 2024)

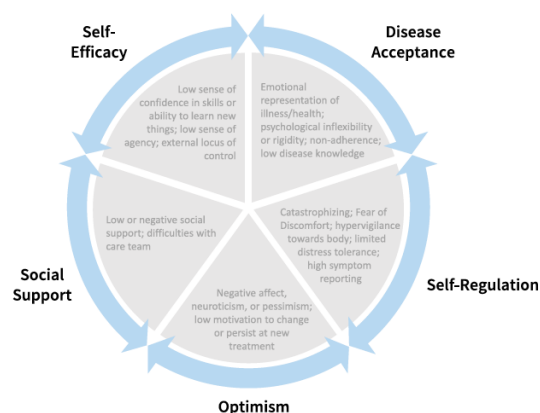


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

## Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

### Disease Acceptance

- Active process – acknowledge and work with realities of PSC
  - NOT resignation
  - A willingness
- Allows you to better identify when to pull back vs push through
- Increases psychological flexibility in the face of disappointment or setback

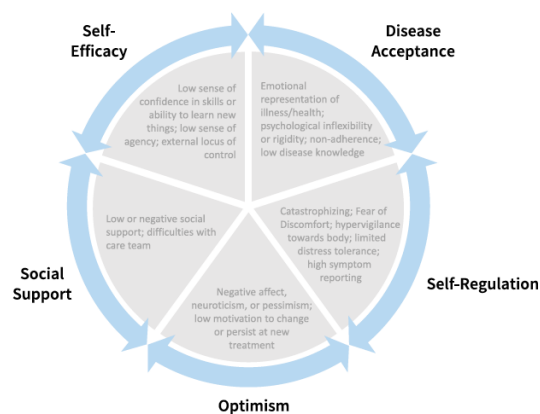


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

## Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

### Self-Efficacy

- Confidence in your ability to figure it out
- This is not about having all the answers, instead focusing on knowing that the future version of you will be able to handle what arises because they will know more and have more skills

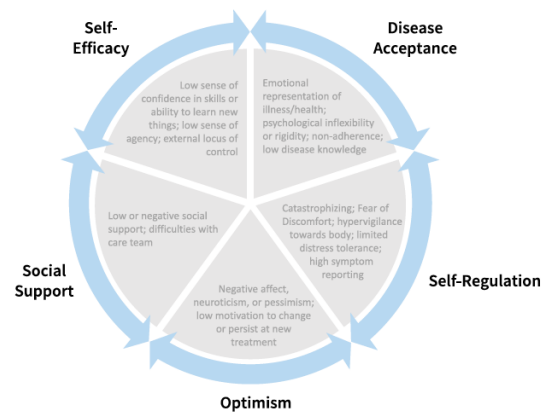


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

## Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

### Self-Regulation

- Strategies that allow you to manage unwanted or uncomfortable internal experiences in service of a goal
  - Anxiety loves the least solveable problem
  - Depression hates a moving target
  - Catastrophizing
  - Hypervigilance of your body and symptoms

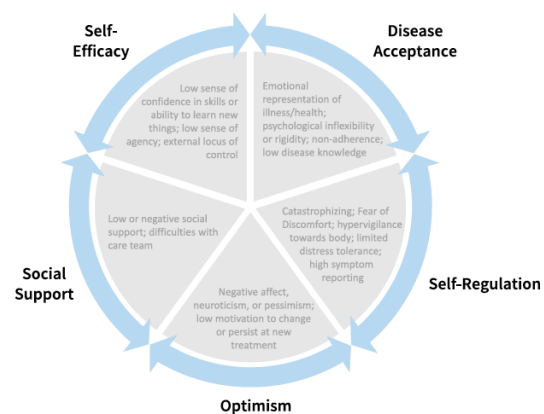


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

# Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

## Optimism

- Adopting a hopeful outlook on life
- This is trainable
- NOT toxic positivity or silver lining
- 3 Ps approach
  - Pervasive ← Isolated
  - Permanent ← Temporary
  - Personal ← Not personal

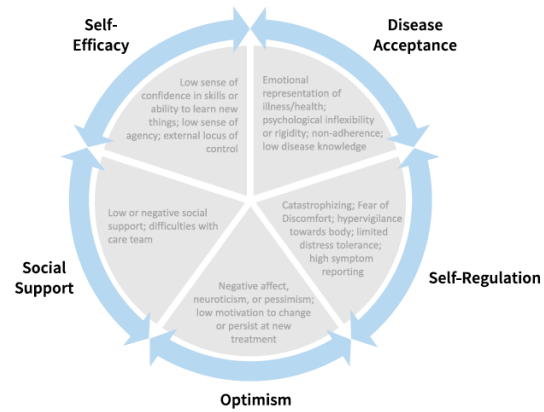


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

# Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

## Optimism

- Adopting a hopeful outlook on life
- This is trainable
- NOT toxic positivity or silver lining
- 3 Ps approach
  - Pervasive → Isolated
  - Permanent → Temporary
  - Personal → Not personal

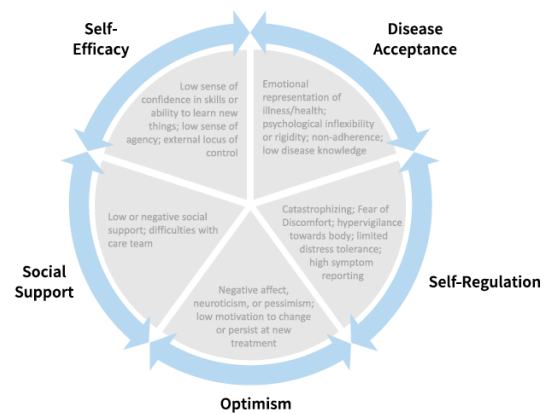


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

# Resilience 5 Approach (Ahola Kohut & Keefer, 2023)

## Social Support

- You are here 😊
- Build your team, both within medical system and outside of it
- Support system to also help with logistics
- Do not take the opportunity to love you away from your family, friends, colleagues, neighbours

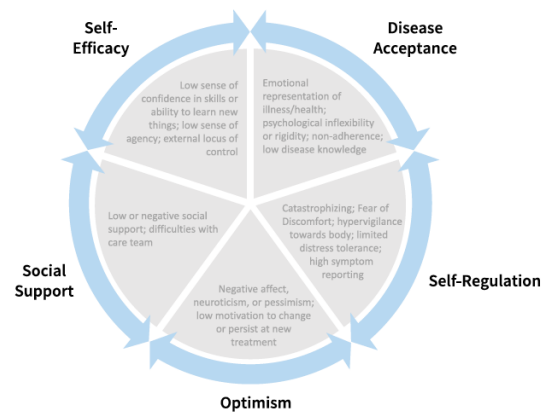


Fig. 1. Resilience5 components and risk factors they can prevent and/or remediate.

Ahola Kohut 2025

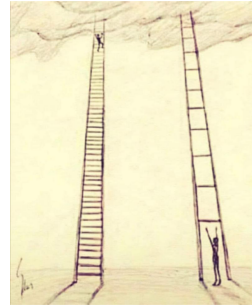
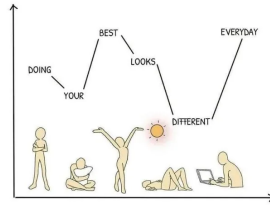
## Where to start?

### What is your favourite song?

- I want to acknowledge values and resonance. Knowing your why or your values helps give meaning to choices.
- “Is this moving me *toward* the person I want to be (my values) or away from them?”
  - If it’s valued but depleting, plan it intentionally (prepare, shorten it, arrange help, lengthen recovery).

Ahola Kohut 2025

Consider asking yourself...



What would you be doing if you weren't living with or worried about PSC?

How do you want to show up? What qualities do you want to display?

What small steps would you be willing to take to move towards acting on that?

***Knowing and acting on this information are two different things, may sound simple but not easy***

Ahola Kohut 2025

Progress and permission...not perfection

It is **OK** to take a **sick day**  
It is **OK** to take care of **yourself** and **your needs**  
You are not 'lesser' if you **take your time**  
Being busy  $\neq$  success



You are **not** a burden  
Others can go find less, you find your people  
Boundaries are about **self-compassion**  
This IS hard.  
You are **not** the only one

***You are allowed to start building your life in the way it works for you***

Ahola Kohut 2025



Ahola Kohut 2025

## One Approach to Pacing

- Track your daily activities
  - Energizing/Nourishing = leaves you feeling better or recharged (mood or energy)
  - Neutral = little change in energy or mood
  - Depleting = uses energy or leaves you more tired or emotionally drained
- This can be as detailed as you wish: brushing teeth V morning routine
- Change activities if you can, if you cannot change the activities within a day:
  - Map out whether there are patterns to work with
  - Space out depleting activities, pair it with recovery, schedule rest
  - Micro breaks and recovery
  - Try to level up tasks, increase pleasant experience

**GOAL: Move towards values in a sustainable way**

Ahola Kohut 2025