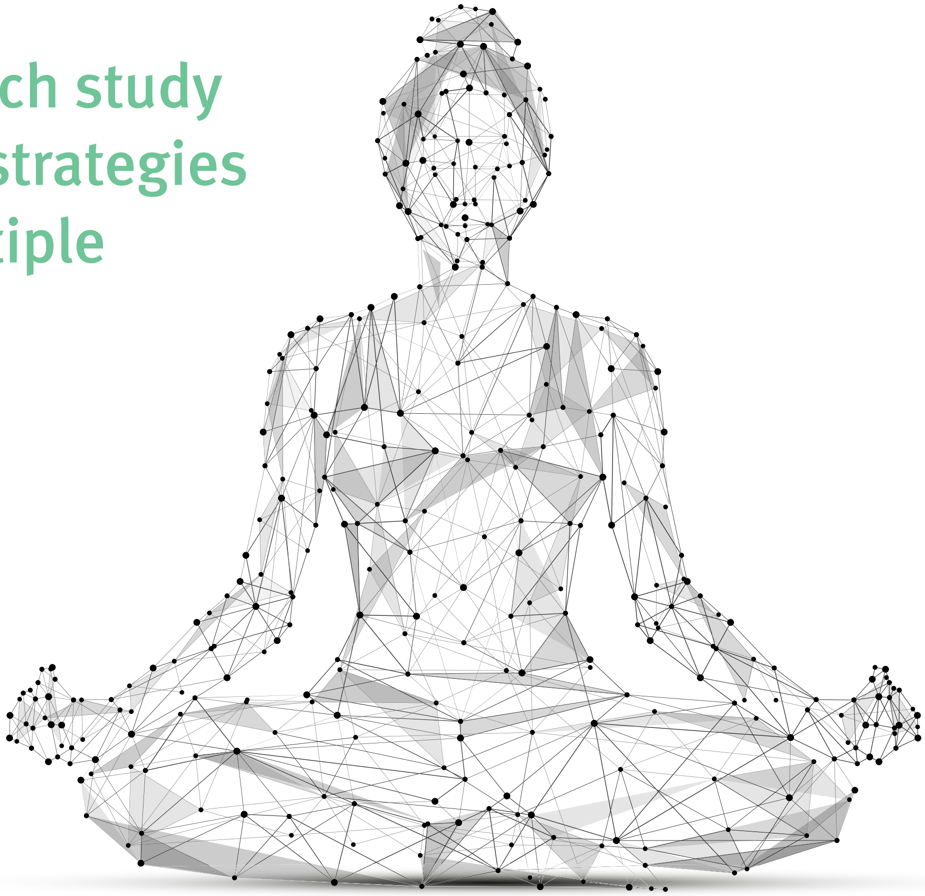
A Model for Living With IC/BPS

The IC Hope research study highlights coping strategies proven across multiple chronic illnesses.



A picture is worth a thousand words.

One of the participants in a research survey focused on living with IC/BPS included a photo of a box in her written reflections. "It's like this closed off, sealed off box," she wrote. "And that's how I feel sometimes with IC because so many people don't really understand it or have a misconception… and people can't get in because they don't understand, or maybe part of it is even that I don't want to let them in."

But that's not the only picture of life with IC/BPS. Other study participants shared photos of warmed blankets and soothing natural surroundings, loved family members and pets, water flasks and smartphone apps showing the number of steps they walked in a day—even snapshots taken with a friend before skydiving and a tattoo that reminds its owner of the healing power of music.

Conducted by ICA Vice Chair Dr. Laura Santurri, PhD, MPH, CPH, and colleagues at the University of Indianapolis with the assistance of ICA, the IC Hope study focused on identifying IC/BPS patients who report average to above average physical and mental health—"people living with this condition who are doing fairly well…. to learn about how they cope with the condition," Santurri said during a webinar held by ICA earlier this year.

In 2019, ICA solicited responses to an online survey for the study; more than 540 IC/BPS patients responded. As a group, respondents had lower self-reported physical and mental health scores than the general population—as one might expect when living with a chronic pain condition. But researchers ultimately narrowed responses to a smaller group of participants with physical and mental health scores comparable to the general population. Nine were ultimately selected for a qualitative study, which included interviews, journals, and photography. While the group was small and homogenous—mostly female, middle aged, and all white—all also have lived with IC/BPS for between one and thirty years.

What Santurri and researchers learned from this group lined up with a broader model of coping with chronic pain called THRIVE. First published in the peer-reviewed journal *Health Psychology Open* in 2018, the model is based on a literature review suggesting that patients found common biological, psychological, and social coping strategies across a wide range of chronic illnesses. Among them:

Therapeutic interventions
Habits and routines
Relational and social factors
Individual differences
Values and beliefs
Emotional factors

Therapeutic Interventions

Medical treatments and other healthcare-provided interventions can be a challenging area for IC/BPS patients, given the difficulties of being diagnosed and the complexity of overlapping conditions. Multiple participants discussed the feeling of relief from getting diagnosed, followed by the sense of grief and loss from knowing there's no known cure for IC/BPS. Said one, "I have to live with it, and it's not going to go away."

Patients spoke about treatments that did work for them, including Interstim, antihistamines, and pelvic floor physical therapy. Their experiences with providers also suggest how they can help in the face of a lack of medical treatments that work equally well for every patient, which remains the reality with IC/BPS. Said one, "I think it's important for [healthcare providers] to understand that a doctor that is willing to put in the time and effort to learn and do research on their own… means so much. Because we want people to support us, and we want to feel like even if our doctors don't know all the answers, they're willing to go look for them vs. just writing us off."

Habits and Routines

Regular habits and routines are not just important in managing a condition like IC/BPS—they actively involve patients in their care. "Right now, nobody is managing my IC but me," one participant said. "Everybody's going to give you their opinion, but you have to try different things and see what works best for you."

Participants talked about supplements such as aloe vera and acid reducers, as well as taking hot baths, using heating pads, staying hydrated, exercising, wearing less restrictive clothing, controlling their diets, and being in nature as ways they managed symptoms.

Overall, "most of these strategies came with a sense of personal power and control," Santurri said. "Once people figured out what worked for them, they had a variety of tools in their toolkit they could go to."

Relational and Social Factors

For IC/BPS patients, relationships can be challenging and rewarding in equal parts. For example, some participants pointed to a lack of understanding among those around them with unflinching honesty: "Those are the people you want to punch." Physical intimacy was singled out as a challenge. But others focused on the support they received from friends and family: "With diet, I try really hard. I find I cheat if it's around. So my family pretty much follows the IC diet, too."

In similar fashion, participants saw online communities and social media as both good and bad, depending largely on whether those groups focus on the negative or the positive. "I try to associate myself with the more positive and uplifting people in those groups," one said. "It might give me something to add to my toolbox," another added. "I just feel like, okay, if they made it through the day, then I can make it through the day too."

Individual Differences

A common thread among this group of IC/BPS patients: an emphasis on hope, resilience, perseverance, courage, and confidence. "I feel hopeful…. we will conquer IC during my lifetime," one said. "What gives me hope is that I've been able to deal with this so far, and I think deal with it in a positive way and find options and just ways to cope," another said. "So that makes me feel hopeful that I can continue on like this."

Participants' responses suggest that mindset can make a difference. "I definitely know that I'm in a place, emotionally, spiritually, where I can live a good life with IC, and IC doesn't control me anymore," one said.

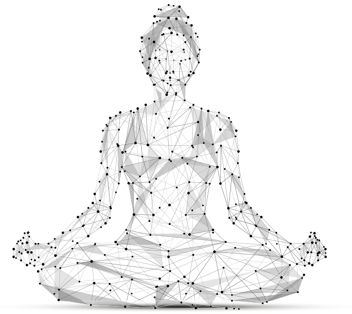
Values and Beliefs

Study participants emphasized the importance of spirituality—either with or without a religious element—as providing a sense of control, comfort, and joy. A second, equally important element involves acceptance. "I've certainly gone on a journey, and this journey will continue," one said. "It's not going to go away, you know, [so I] enjoy the time that I have when it isn't so bad."

Emotional Factors

The final letter in THRIVE involves a range of emotions, both positive and negative. Among them is loss and grief for a normal life: "It feels like part of your identity was taken away," one said. Embarrassment in social settings and frustration about receiving medication and the lack of sleep and other symptoms associated with IC/BPS rounded out the negative emotions.

However, "a lot of gratitude and hope was expressed," Santurri said. "I am not my illness," one respondent said. "I believe that the universe supports me, is teaching me, and helping me to lead a healthy life," another added.



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Ways to THRIVE

Participants' responses suggest that IC/BPS isn't an outlier in terms of how people can successfully manage chronic pain conditions. Their experiences suggest that "there are internal and external factors that influence how we cope, and thus likely influence our outcomes with our condition," Santurri said.

The authors of the THRIVE model agree, stating that "focusing on relevant internal factors (such as personal habits, individual differences and preferences, values and beliefs, and emotional factors), as well as seeking out relevant external resources (such as therapeutic interventions and social support) is a fruitful strategy to think about coping as a complex and multifaceted task. We note that internal and external factors are not mutually exclusive of each other and often work together in a synergistic fashion."

Where to start? Two potential areas include:

- Focusing on habits and routines that support self-management—although with IC/BPS, what those look like vary from person to person.
- Paying close attention to relationships with others, including focusing on positive elements of online communities and social media, and the family and friends who help them live their lives.

Doing so can lead to a dramatic shift in perspective. Going back to the image of the box we began with, the participant who described how isolating IC/BPS felt offered a silver lining. "It does have latches and a combination… there is a way to open the box and open myself up to the challenges of feeling closed off."

To watch a webinar about the IC Hope study by Laura Santurri, visit bit.ly/ICHopeStudy. *To read more about the THRIVE framework, visit* bit.ly/IC-THRIVE.