



Center for
Psychosocial Research
in GI

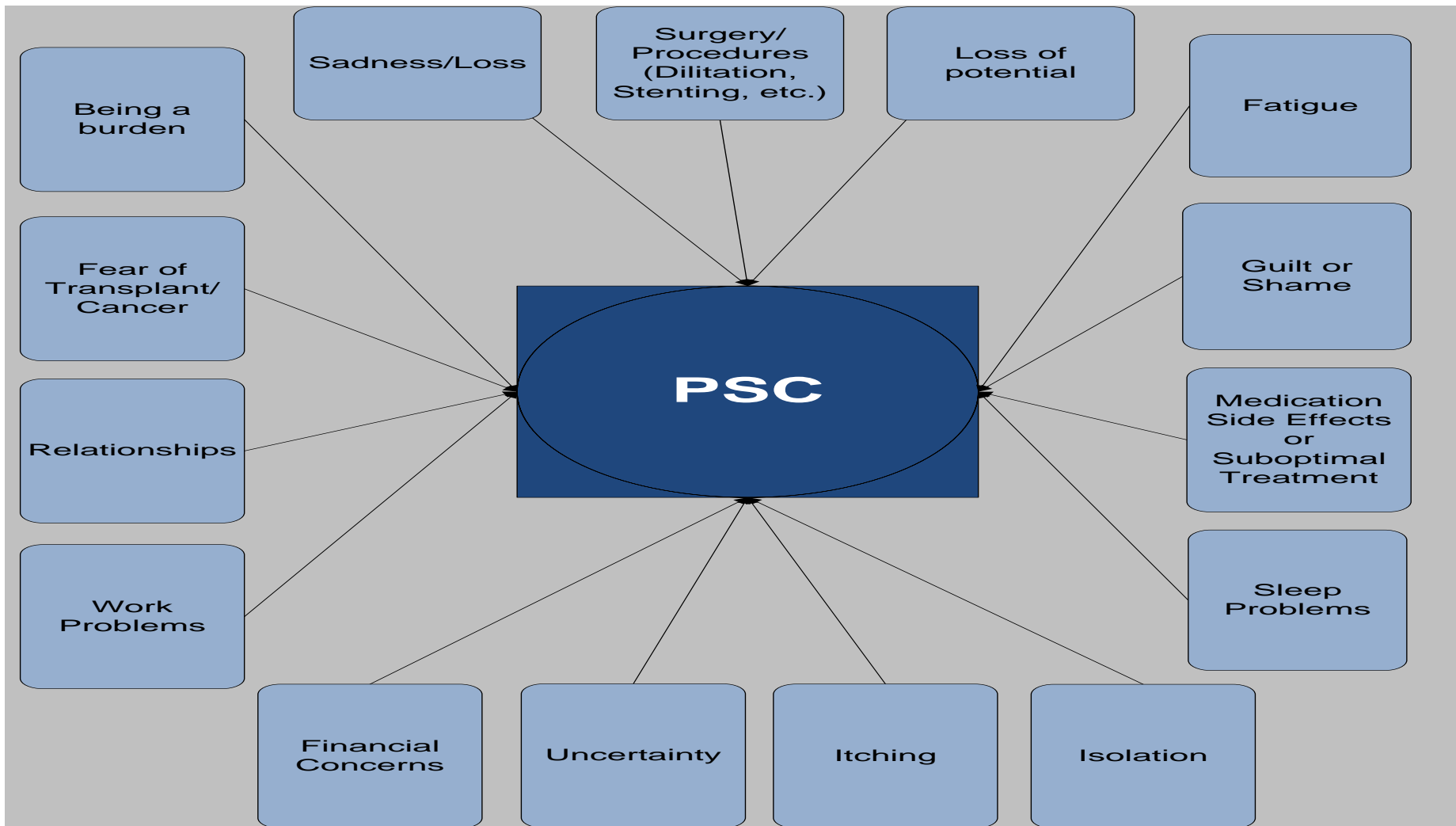


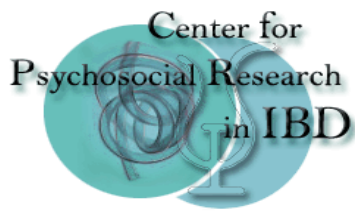
NORTHWESTERN
UNIVERSITY

Behavioral Strategies for Coping with PSC

Laurie Keefer, PhD
Director, Center for Psychosocial Research in GI
Northwestern University
Division of Gastroenterology
Chicago, IL

PSC Concerns





PSC Requires a Shift in Coping for Patients and Caregivers



- Uncertainty (loss of potential, relationships, transplant/cancer, finances)
- Fatigue (sleep, medication)
- Emotions (shame, guilt, feeling like a burden, isolation, sadness/loss, stigma)

Center for
Psychosocial Research
in GI



NORTHWESTERN
UNIVERSITY

Uncertainty



Types of Disease-Related Uncertainty

- Past regrets
 - How/why did I get this?
 - What will people think of me?
 - What could I have done to prevent this?
 - What if I hadn't ignored my symptoms for so long?
- Future concerns
 - What is going to happen to me?
 - When will I need a transplant?
 - Will I develop liver cancer?
 - What if I can't work?
 - What if my children get this disease?
 - What about dating and relationships?
 - What about my career?

Pros and Cons of Worry

- Worries make us feel like we are “doing something” about a problem that we may not have control over.
- Sometimes, we are reinforced for worrying
- Getting too far ahead of yourself or too focused on the past interferes with your ability to make sound decisions in the present.

Improving Tolerance of Uncertainty

- Watch for Unhelpful Worry Talk
 - If only..... (caught up in the past)
 - What if..... (predicting the future)
- Be realistic about your ability to handle a situation
 - Don't catastrophize
 - Don't avoid
 - Ask for help
- Schedule time to focus on the uncertainty so it does not bleed over into other areas of your life

Improving Tolerance of Uncertainty

- Feelings aren't necessarily facts
 - Just because you are anxious about something doesn't mean that it is going to happen or that you can't handle it if it does.
- Ask yourself....
 - Does worrying make the situation better?
 - Can I cope with the _____ minutes/days of stress before this resolves (blood work, procedure, awaiting news)?
 - Have I been able to handle things like this in the past?
 - Do I know other people who have had similar situations?
 - Even if I can't control _____, I can control my reaction

Center for
Psychosocial Research
in GI



NORTHWESTERN
UNIVERSITY

Fatigue



PSC-Related Fatigue

- Fatigue is the most common complaint of patients with PSC, even when their disease is under control
- Fatigue is a significant predictor of poor quality of life in PSC/IBD¹
- Fatigue in PSC is real²
 - Changes in circadian function have been demonstrated in patients with inflammatory diseases, including changes in cortisol and melatonin which influence a person's energy level, sleep-wake cycle and mood
 - Fatigue can also be related to the immune system secreting high levels of proinflammatory cytokines as part of the disease process
- There aren't really any good treatments for fatigue

Non-inflammatory triggers of Fatigue

- Insomnia
- Dehydration
- Nutritional Deficiencies
- Alcohol
- Lack of exercise/Too much exercise (worn out)
- Excessive workload
- Shift work (changing shifts, night shifts)

Management of Disease Related Fatigue

- Realistic Expectations/Acceptance
 - Be nice to yourself– this is not your fault!
 - Schedule Pleasurable Events
 - Don't be afraid to Rest
- Appropriate Allocation of Resources
 - Balance of Energy
 - Time Management
 - Being Assertive
 - delegate, ask for help
- Stress Management/Energy Boosters



Pleasurable Event Scheduling

- Soaking in the bathtub
- Seeing a movie during the week
- Listening to music
- Watching something that makes you laugh
- Leaving work early
- Dressing up
- Go to the beauty parlor
- Going for a long drive
- Photography
- Reading fiction
- Writing in a diary
- Light candles
- Rearrange furniture
- Sitting in a sidewalk café and people watch
- Take a fun class
- Lunch with a friend
- Talk on the phone
- Volunteer

Appropriate Allocation of Resources: The Project

Management Approach to PSC

- Identify the circumstances surrounding your disease
 - determine areas for improvement
 - clarify areas where change is not/should not be expected
- Identify your primary disease-management goal
 - Being able to return to work
 - Spending more time with my family
 - Establishing a healthier lifestyle
- Assemble the team and identify stakeholders
 - doctors, dieticians, counselors, family/friends
 - Who can you rely on for what?
 - Instrumental v. Emotional v. Perceived support

Appropriate Allocation of Resources: The Project

Management Approach to PSC

- Risk Identification/Management Plan
 - What can go wrong and how can I minimize the risk to me?
- Be specific but flexible
 - Manage competing and changing demands
- Schedule milestones towards your goal

Energy Boosters & Stress Busters

- Exercise
- Mental Health Days
- Meditation
- Massage
- Acupuncture
- Prayer
- Vacation
- Formal Relaxation Training
 - hypnosis, biofeedback, progressive muscle relaxation



Medical Hypnosis

- Deep physical relaxation and intense mental focus
- Mental and Physical relaxation allow patient to be more open to suggestion
- Hypnotic suggestions alter the focus of our attention, change meaning about sensations arising from the body and encourage the body to restore itself to a healthier state
- Modifies physiological arousal
- Initially performed in a doctors office but can eventually be self-guided





Center for
Psychosocial Research
in GI



NORTHWESTERN
UNIVERSITY

Emotions

Emotions

- Most emotions are NORMAL and should be expected
 - Depression and Anxiety can be serious and should be monitored
- Most emotions are time limited
- Emotions change over time as one adjusts to the disease
- Psychotherapy and other forms of counseling can help one express emotions so that they do not interfere with relationships, work productivity, quality of life or even physical health

Final Points

- PSC is a chronic and unpredictable illness
 - Most of us have not had to cope with this type of stressor before
- In the absence of optimal treatments, people who develop PSC must be proactive in their disease management in order to live a satisfying life
 - Asking for help
 - Self-care
 - Manage emotions
- Effective disease management requires acceptance of one's strengths and limitations and a conscious plan to manage PSC in the context of your other goals– PSC should not define you!

Center Staff

<http://www.ibdpsych.org>



Laurie Keefer, PhD
Director



Sarah Kinsinger, PhD
Health Psychologist



Jennifer Zinke, PhD
Health Psychology
Research Fellow



Bethany Doerfler, RD
Dietitian



Jason Bratten, BS
Research Administrator



Tiffany Taft, MS
Doctoral Candidate
in Health Psychology