

Coping with the Emotional Aspects of PI

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Introduction

Facing life transitions can be challenging in and of themselves without the added pressure of a rare, chronic illness.

PI requires significant life adjustments which not only influence our physical lives, but our emotional well being.

This presentation will explore how to better cope with the emotional aspects of living with PI.

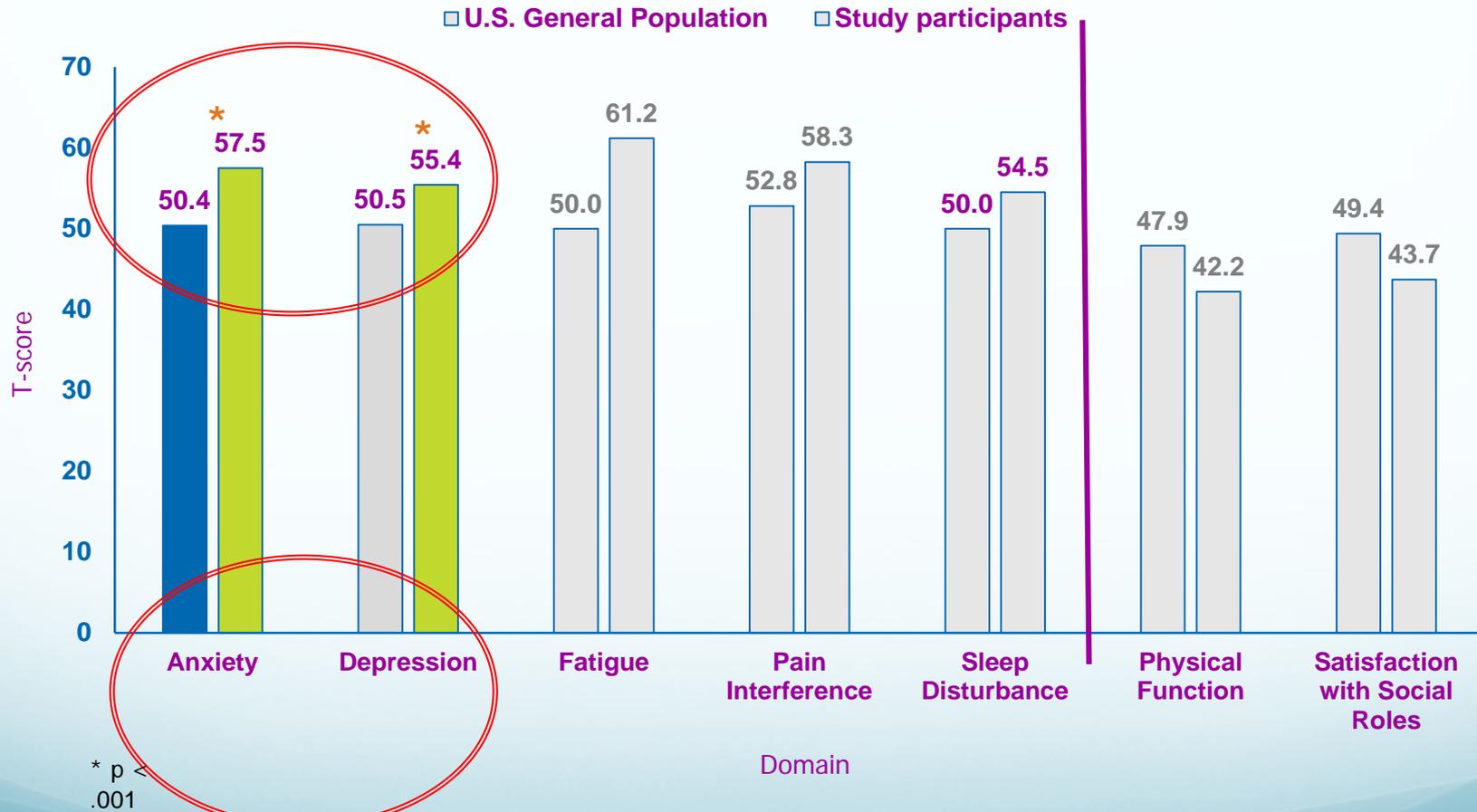
Who Does PI Impact?

- Patients
- Parents/Caretakers
 - Siblings
- Spouses/Significant Others
- Friends/Co-Workers
- Recent studies have shown that patients with PI have a higher rates of Anxiety and Depression. (3)
- The more severe the illness(severity of symptoms), the poorer the psychosocial symptoms in children. (1)
 - Increased elevations in caretaker psychological distress. (4)

Emotional Issues Impacting Loved Ones

- Parents/Caretakers: Compassion Fatigue, Guilt, and Anxiety about the Patient's well being/Stress from financial, free time, and medical burdens (4)
- Siblings: Jealousy and Resentment/Fear and Guilt. Feeling that their own needs are being overlooked by their parents.
- Spouses/Significant Others-Stress from Caretaking/Intimacy Issues/Additional Stress on typical relationship issues/Isolation.
- Patients-Initiate conversations around how to integrate modifications into your relationships. Be compassionate and recognize that PI may be stressful upon your support team. Strategize together how to cope with issues as they arise.

Mindfulness in PI



Chronic/Rare Disease and Anxiety and Depression

- Financial burdens
- Relationship burdens
- Limitations in Productivity: School and Work
- Isolation: Physical and Emotional Isolation
- Decreased understanding and ability to identify the illness.
“Although not ill intended, people do not understand how their comments, minimization of the illness and lack of understanding can really undermine your sense of self worth and leave you feeling misunderstood or alone. (2)

Triggers

- Developmental and life transitions
- Changes in work or school status
- Shifts in medical care
- Grief or loss
- Missed life events due to illness
- Anticipation of an oncoming illness

Signs and Symptoms of Depression

- Children Vs. Adults, Males Vs. Females
- Acting Out: Anger, rage, irritability, low tolerance for daily stressors, negative thinking
- Turning In: Social isolation, finding it difficult to participate in school, work, or social activities, poor hygiene
- Tearfulness, feelings of intense sadness, hopelessness, and perseveration of thoughts
- Feeling “bored”/Not enjoying activities
- Physical symptoms
- Shift in overall level of functioning

Signs and Symptoms of Anxiety

- Ruminating about future events which are out of your control
- Ambivalent thoughts/difficulty making decisions and concentrating
- Obsessions and compulsions: counting, checking and hoarding
- Disruption to sleep patterns/restless sleep/difficulty falling asleep/waking up early
- Physical Symptoms: Rapid heart beat, difficulty catching your breath, uncomfortable energy, panic attacks

Coping and Support

- Stay connected to friends and family.
- Explore talents and interests.
- Make modifications so you that you can attend events.
- Connect to the PI peer community; decreases isolation and enhances connection and understanding.
- Worrying about missing events can lead to both anxiety and depression. Participating in work, school, and social events can help you to feel that you are living a valuable life with purpose.

PCORnet: Healthy Mind Health You

- MOOD Network PPRN (Harvard)
- Which is more effective for improving well-being?
 - an online, standard mindfulness intervention (8 sessions) or a brief mindfulness intervention (3 session)
 - A brief mindfulness intervention (3 sessions)

When to Seek Professional Help and Resources

- Impacts school, work, family and close relationships
- Inability to attend to daily responsibilities/self-care
- Emergency: Suicidal thoughts or attempts, injury to self or others
- Talk therapy, psychotropic medication, and MBSR (Mindfulness Based Stress Reduction), or MBCT (Mindfulness Based Cognitive Therapy)
- Genetic testing for psychotropic medications
 - www.genesight.com
- Mindfulness study open to PI patients in late 2018

References

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3. Heath, Jacqueline L. et al. Anxiety and Depression in Adults with Primary Immunodeficiency (PID's)---How Much Do These Patients Experience and What Factors May Increase Patients' Risk? Journal of Allergy and Clinical Immunology , Volume 137 , Issue 2, AB256. Available: [http://www.jacionline.org/article/S0091-6749\(15\)02665-2/abstract](http://www.jacionline.org/article/S0091-6749(15)02665-2/abstract)
4. Piazza-Waggoner, Carrie & Duncan, Christina & Muchant, Dianne & Wilson, Nevin & Hogan, Mary. (2006). Children With Primary Immunodeficiency Disorders: Family Functioning, Coping Strategies, and Behavioral Functioning. Children's Health Care - CHILD HEALTH CARE. 35. 191-208. 10.1207/s15326888chc3503_1.

Closing

If you are feeling emotionally healthy, it will help you to better cope with physical illness.

With the support of family, friends, and an appropriate treatment team, patients can lead a fulfilling and productive life with PI!