Psychosocial Care in Pediatric IBD: Importance in Quality Initiatives

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Objectives

- Discuss psychosocial concerns of pediatric patients with IBD and their families

- Identify specific psychosocial tools that can be used in screening pediatric patients with IBD and their use in quality improvement
Why is Quality Improvement Needed?

- Unwanted variation in how care is delivered
- Quality of care more than measuring process and outcomes; about patients being able to do what they want in life
- Need screening tools in clinic to assess
Background: Need for Psychosocial Screening

- Increased depression/anxiety, social isolation, altered self-image in children/adolescents with IBD

- Up to 25% of adolescents with IBD show symptoms of depression (Szigethy et al. *J Pediatr Gastroenterol Nutr*, 2004, 2014)

- Depression in children with IBD linked to pain, diarrhea, weight loss, elevated ESR (Karwoski, CA, Keljo, D, Szigethy, E. *Inflamm Bowel Dis*, 2009)

- Increased depressive severity in those with more severe disease course (Lindfred et al. *J Pediatr Nurs*, 2012)
Background: Need for Psychosocial Screening

- Quality of life (QoL) and social interactions impacted: ~1/3 – 1/2 have limitations in ADLs (Engelmann et al. Child Psyc Human Devel, 2015)

- Lower health related quality of life (HRQoL) impacts healthcare utilization (Ryan et al. Inflamm Bowel Dis, 2013)

- Children with IBD have poorer school functioning (Mackner et al. J Clin Beh Psyc, 2012)
Psychosocial Screening

- Appropriate screening can have considerable influence on clinical outcome and HRQoL.

- Providers with concerns about ongoing mood changes, behavior or school performance should perform screening for depression. Positive screening should result in mental health referral.
Specific Issues Facing Children/Teens with IBD

- Defining what it means to have a chronic illness
- Coping with procedures, clinic visits, hospitalizations
- Adhering to complicated medical and dietary regimens
- Affecting QOL and social interactions
- Impacting body image and disordered eating patterns
Psychosocial Assessment at Your Center?

- Are you assessing?
- What are you assessing?
- What instruments?
- How often?
- How administered? In clinic, or online prior to visit, pen and paper/iPad?
- How are you tracking?
- Resources/referrals
What to Assess?

**Health related quality of life:** subjective perception of impact of chronic medical condition on physical, emotional, social well being

- Depression
- Anxiety
- Social functioning
- School functioning
- Family functioning
- Adherence
- Self-management

Case Study: Rachel

13 year old with Crohn’s Disease

History
- Always smiling
- Pleasant and interactive in clinic
- Recent exacerbation of Crohn’s symptoms
- Consistently disliked school

Mother’s Observations
- “She was not herself”
- “Seemed depressed over the past few months”
- “Broke down and cried”
- “Told parents she’d had thoughts of suicide”
Case Study: Rachel

Psychologist’s Meeting with Rachel and Mom

- Mood low, cried often, also laughed at times
- Described increasing symptoms of depression including difficulty sleeping and concentrating, decreased energy, and appetite
- Spent summer at the beach with extended family, but she was usually in her room reading
- Mother described her as increasingly withdrawn and sad
Case Study: Rachel

Psychologist’s Meeting with Rachel and Mom

- Recent “suicide intervention” at school, learned about depression and heard stories about how local students had committed suicide

- Recurring nightmares about passive suicidal ideation (SI)

- No active SI or self-injurious behavior (SIB). Noted several reasons she wants to be alive
Case Study: Rachel

Psychologist’s Plan

- Medications locked
- Rachel agreed to talk with parents about suicidal thoughts
- Possible hospitalization if symptoms worsen
- Possible medications to help with mood
- Melatonin to help with sleep
- Spend time with family/friends; limit time in room; not home alone
- Coping strategies including relaxation (guided imagery), CBT
- RTC 1 week
How to Assess Psychosocial Status?

The items below focus on subjective assessment measures. Our clinic is piloting additional objective measures to more comprehensively and specifically assess depression in our adolescent patient population.

<table>
<thead>
<tr>
<th>Provider Asks of Each Patient</th>
<th>Provider Assesses</th>
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<tbody>
<tr>
<td>General well-being</td>
<td>Psychosocial risk factors that significantly impact patient’s medical care</td>
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<tr>
<td>Activity level</td>
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PDSA Cycle

Plan your change

What to do differently based on results

Analyze results

Try it out

Act

Plan

Study

Do
What and How We Screened

2 Goals:

1. ID clinically significant depressive symptoms
2. Link patients to appropriate referral

Screening Tool Used:
Modified PHQ-9 for teens
How We Screened – the Process

- Two providers administered PHQ-9 during routine visit for patients age 12 and older over one month
- Reviewed results with patient/family at visit
- Referred to mental health professional as needed
- Will follow up with patient/family at or before next visit re: outcome
Our Practice:

20 patients screened: 13 female, 7 male

- Ages 12-21 years, 15 with CD, 5 with UC

**RESULTS:**

- Minimal depression: 1
- Mild depression: 5
- Moderate depression: 3
- Severe depression: 0
- 45% warrant further assessment
Interventions

Goal: Improved QoL, level of functioning

- Referral to mental health professional
- Cognitive behavioral therapy
- Hypnosis
- Psychotropic medications
- Support groups/web-based therapies
- Assess family stress/support/family coping
- Improve social support network – Camp Oasis
- Establish 504 plan
Take Home Messages

- Differentiate short-term distress from long-term compromised functioning

- Assess HRQoL with changes in disease status or treatment plan, or at some regular interval

- Assess multiple areas: social functioning, athletic activities, school attendance/perform ance

- Use screening tools, or some form of assessment

- Assess family coping. Family involvement critical

- Provide support, resources
Other Self-Report Screening Tools

- **Children’s Depression Inventory: Short version (CDI:S)**
  - 10-item assessment of cognitive, emotional, behavioral signs of depression in children ages 7-17 years

- **Beck Depression Inventory-Second Edition (BDI-II)**
  - 21-item assessment tool used in adolescents/adults ages 13-80 years

- **Pediatric Quality of Life Inventory, V 4.0 (Peds QL 4.0)**
  - 23-item assessment tool of physical, emotional, social, and school function used in ages 10 and older

- **IMPACT-III**
  - 35-item, IBD specific measure of HRQoL, including general well-being and symptoms, emotional functioning, social interaction, and body image used in children ages 10 and older
Resources

- Book of Hope
- Smart Patients
- CCFA
- NASPGHAN (Main Site)
- NASPGHAN (GI Kids)
- Improve Care Now
- Starlight Children’s Foundation
- UCB and NASPGHAN