



# Understanding the Psychosocial and Emotional Needs of Younger Patients with IBD : A Literature Review

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# Introduction

**20-25% of all IBD patients will have been diagnosed as younger patients, moving with time from the care of the pediatric specialist to mainstream adult care.**

**Many of the issues they grapple with are already difficult issues for young people because of profound changes in their stage of growth. The presence of chronic illness makes it harder for them and their parents/caregivers.**

**Understanding their psychosocial and emotional needs can help in their transition to adulthood, and coping with a lifetime of chronic disease.**

**Self-esteem/Self Perception**

**Depression/Anxiety**

**Anger**

**Low Locus of Control**

**Interrupted Independence**

**Vulnerability**

**Maternal Matters**

**Family Function**

**Interventions**



# Self-Esteem

**1. No difference in self-esteem between UC or CD patients.**

**2. Self-esteem adversely affected by more**

- i. severe disease**
- ii. parental discordance**
- iii. female gender**



**3. Boys tended to have more social and behavioural issues, more withdrawn, or anxious/depressed.**

Lindfred H Saalman R, Nilsson S, Reichenberg K. Inflammatory Bowel Disease and Self-Esteem in Adolescence, *Acta Paediatrica* 2008 97, pp 201-205

De Boer MA, et al. Health-related Quality of Life and Psychosocial Functioning of Adolescents with Inflammatory Bowel Disease. *Inflamm Bowel Dis* Vol11, Number 4, Apr 2005.

# Self Perception and Peers

In a qualitative study using in-depth interviews, patients perceived their lives as different from their peers :

Due to their different physical appearance caused by meds -

***“They’ve name-called me to death saying fat girl.”***

Due to embarrassing symptoms -

***“Kids make fun of my problems.”***

***“I don’t want them to laugh at me.”***

Due to withdrawal/avoidance of company and the possibility of getting hurt –

***“I don’t want to hear from friends because I’m not part of it. They’re getting on with their lives and I’m going through a horrible time.”***



Nicholas DB, Utley A, Smith C, Avoid J, Monk Marla, Griffiths AM. Challenges and Strategies of Children and Adolescents with Inflammatory Bowel Disease : A Qualitative Examination. *Health and Quality of Life Outcomes* 2007, 5 : 28.

# Depression and Anxiety Are a Problem

**In a study involving 36 newly diagnosed patients :  
5 had a major depression, and 10 had a history  
of anxiety disorder.**

**Depressed children had less severe illness, more  
life events, and poorer family functioning.**

**Patients with depressed mothers more likely to experience depression.**

**Another study involving 62 patients with IBD and FGI complaints:  
IBD patients were well adjusted, less depressed, and had fewer  
behavioral problems as compared to the FGI patients. Attributed to  
the professional support from the IBD clinic, and a known diagnosis of  
Illness.**



Burke. PM, Night D, Cockshies S, Chandra, R, Sauer J. Correlates of Depression in New Onset Pediatric Inflammatory Bowel Disease. *Child Psychiatry and Human Development*, Vole 24 (4), Summer 1994.

Gold N, Iceman R, Roberts, J, Watt Swell-Adjusted Children: An Alternate View of Children with Inflammatory Bowel Disease and Functional Gastrointestinal Complaints. *Inflammatory Bowel Diseases* 6 (1): 1-7 2000

# Anger Aroused: Avenues of Expression Needed

**Inability to be like their peers, and to do the many things they want to, and problems with schooling, and parents can cause some patients to become angry.**

**Do they have avenues to express their anger? Within families this may lead to conflicts.**

**Greater expressed hostility inversely related to ESR suggesting that patients who are able to express their anger may actually feel and be better.**

**The expression of positive emotions leads to immune enhancement. Unclear whether the expression of negative emotions does so.**



# Low Locus of Control (LOC)

**Patients have a low locus of control, and perceive events and circumstances in their lives to be beyond their influence, though acknowledging that stress exacerbates the disease.**

**Low LOC is correlated with severity of disease, increased psychiatric problems, and family dysfunction.**

**When the disease is severe or flares up, patients with a low LOC may psychologically interpret it as having little to do with their actions and more to do with fate, bad luck or even punishment.**



Engstrom I. Family Interaction and Locus of Control in Children and Adolescents with Inflammatory Bowel Disease  
*Adolesc Psychiatry*, 30:6, Nov 1991

# Independence Interrupted : Patients Need to Grow Up

**Adolescents with IBD do not follow a normative developmental pattern. The supplantation of peers and the weakening of family connections does not take place as smoothly.**

**Emotional support sought from family members, and the interpersonal boundaries become blurred resulting in enmeshment. They do not use their own coping strategies to deal with stressors, but depend on parents**



**Some may generate situations that prolong emotional support from the family and encourage “parental rescue .**

**Parents remain the primary communicators, but patients must assume more treatment related responsibility as they age. Emotional maturation and emancipation from the family social circle is delayed.**

MacPhee M, Hoffenberg EJ, Feranchak A. Quality of Life Factors in Adolescent Inflammatory Bowel Disease. *Inflamm Bowel Diseases*. 4(1):6-11

# A Heightened Sense of Vulnerability

Many patients experience vulnerability and a lack of control in their lives :

***“I was so afraid I was going to throw up, I couldn’t leave the house.”***

***“You never know what is going to happen...”***

***“I wish I could do things, but I don’t do anything. When you are not healthy you can’t do anything.”***

***“IBD makes me feel frightened. I know what they are going to do, but do I really want them to do this to my body?... I feel like I have no control over my body whatsoever.”***

***“My Mom comes by when I’m on the toilet to see what is wrong. I don’t want to ask for help. It’s uncomfortable to have my Mom watch me on the toilet.”***

Nicholas DB, Otley A, Smith C, Avolio J, Munk Marla, Griffiths AM. Challenges and Strategies of Children and Adolescents with Inflammatory Bowel Disease : A Qualitative Examination. *Health and Quality of Life Outcomes* 2007, 5 : 28.

# Maternal Matters : Depression Is Real

**Mothers of patients more distressed than fathers with symptoms of depression, anxiety and somatization.**

**Children with depressed mothers more likely to have depression.**

**Chicken and egg situation : which came first, Mum's depression or child's illness? NO answer.**

**More important to focus on whether there is a reciprocal relationship between the Mum's depression and illness symptoms in the child.**

*Engstrom I, Parental Distress and Social Interaction in Families with Children with Inflammatory Bowel Disease, J Am Acad Child Adolesc Psychiatry, 30: 6, Nov 1991*

*Burke. PM, Neigut D, Kocoshis S, Chndra, R, Sauer J. Correlates of Depression in New Onset Pediatry Inflammatory Bowel Disease. Child Psychiatry and Human Development, Vol 24 (4), Summer 1994.*

# Maternal Matters : Mums Need Support Too

**Mothers have perceptions of lack of support and feeling isolated though this may not be the actual case as fathers report otherwise.**

**They tend to suffer vicariously for their child while the child does not seem to suffer as much.**

**Mothers tend to report more negatively when rating symptoms in their child as compared to the child's own ratings.**

**Mothers need help and support too.**



Engstrom I, Parental Distress and Social Interaction in Families with Children with Inflammatory Bowel Disease, *J Am Acad Child Adolesc Psychiatry*, 30: 6, Nov 1991

# Family Function: A Strong Family Bond Helps



**More important than the mother's mental condition is the strong bonds between the parents.**

**Patients from dysfunctional families more likely to have behavioural problems.**

**Families tend to be unable to express their difficulties and prefer to isolate their feelings.**

**Parents request both peer support for their child and parent support for themselves.**



**Engstrom I, Parental Distress and Social Interaction in Families with Children with Inflammatory Bowel Disease, *J Am Acad Child Adolesc Psychiatry*, 30: 6, Nov 1991**

**Day AS, Whitten KE, Bohane TD, Childhood Inflammatory Bowel Disease: Parental Concerns and Expectations. *World J Gastro* Vol.11: 7. Feb 2005**

**Akobeng AK, Miller V, Firth D, Suresh-Babu NV, Mir P, Thomas AG. Quality of Life of Parents and Siblings of Children with Inflammatory Bowel Disease. *J Pediatr Gastroenterol Nutrl* 1999, 28: S40-42**

# Interventions Involving Patient and Family

**Adolescence a critical time of development, and change is the defining feature. Behaviours learnt that they carry with them into adulthood. Interventions at this time can be very successful in helping them learn to cope through their lifetime.**

**Re-negotiation of communication patterns between parents and children is vital, to encourage shared responsibility and constructive adolescent coping strategies.**

**Manual based Cognitive Behavioural Therapy (CBT) has been shown to help treat depression in adolescents with IBD. While illness severity measures remained constant, perceptions of their general health and physical functioning improved.**

Nicholas DB, Otley A, Smith C, Avolio J, Munk Marla, Griffiths AM. Challenges and Strategies of Children and Adolescents with Inflammatory Bowel Disease : A Qualitative Examination. *Health and Quality of Life Outcomes* 2007, 5 : 28.

Szigethy E, Whitton SW, Levy-Warren A, DeMaso DR, Weisz J, Beardslee, WR. Cognitive Behavioural Therapy for Depression in Adolescents with Inflammatory Bowel Disease : A Pilot Study. *J Am Acad Child Adolesc Psychiatry* 2004, 43: 1469-77

# Interventions Involving Patient and Family

CBT sessions include individuals working on personal issues, eg by

1. Constructing physical illness narratives
2. Applying a problem solving approach to illness coping
3. Identifying negative cognitive distortions and modifying them
4. Practising positive reframing of thoughts
5. Developing social problem solving skills.

Family based educational components involving

1. The family's illness narrative, to teach family problem-solving
2. Psycho education about expressed emotion and communication strategies, identifying depressive symptoms.

**Both patients and their families need help and support.**

Szigethy E, Whitton SW, Levy-Warren A, DeMaso DR, Weisz J, Beardslee, WR. Cognitive Behavioural Therapy for Depression in Adolescents with Inflammatory Bowel Disease : A Pilot Study. *J Am Acad Child Adolesc Psychiatry* 2004, 43: 1469-77

# Summary

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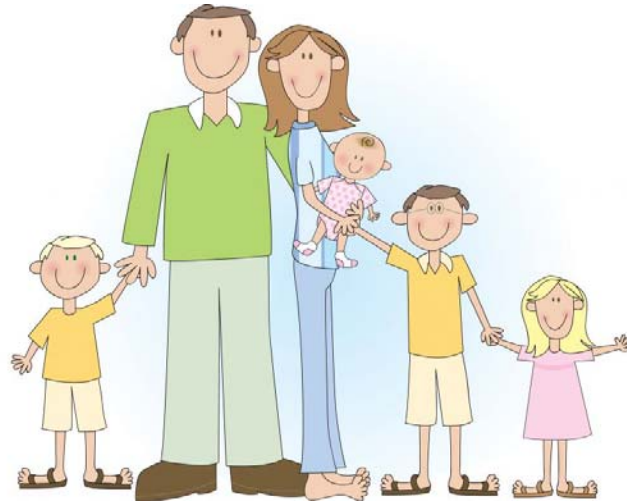
**Maternal Matters**

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# THANK YOU



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