

# Strategies to Improve Quality of Life in Adolescents with Inflammatory Bowel Disease

Christine A. Karwowski, MD,\* David Keljo, MD,\* and Eva Szigethy, MD, PhD\*<sup>†</sup>

**Abstract:** Inflammatory bowel disease (IBD), which encompasses Crohn's disease (CD) and ulcerative colitis (UC), are chronic and debilitating conditions with unpredictable courses and complicated treatment. Pediatric IBD carries implications that extend beyond the health of the gastrointestinal tract. When these lifelong illnesses are diagnosed during adolescence, a critical developmental period, the transition to adulthood can be even more turbulent. Like other chronic diseases of childhood, patients with IBD are at risk for depression, anxiety, social isolation, and altered self-image, which can all negatively affect health-related quality of life (HRQOL). The review will draw from pertinent adult and pediatric literature about HRQOL over the past 10 years using a PubMed literature search to summarize instruments with which HRQOL is measured, and address factors that affect HRQOL in adolescents and young adults with IBD. Psychosocial interventions that have been utilized to improve quality of life in this population will also be covered. Identifying patients with impaired quality of life is of paramount importance, as is implementing strategies that may improve HRQOL, so that they may have an easier transition to adulthood while living with IBD.

(*Inflamm Bowel Dis* 2009;15:1755–1764)

**Key Words:** inflammatory bowel disease, health-related quality of life, adolescent

Inflammatory bowel disease (IBD), which encompasses Crohn's disease (CD) and ulcerative colitis (UC), are chronic and debilitating conditions with unpredictable courses and complicated treatment. In recent years the prevalence of IBD has been increasing in children and adolescents, with more than 10% of patients diagnosed before age 18 and 30% before age 21.<sup>1</sup> The estimated healthcare costs associated with IBD exceed \$1.7 billion annually, with higher

rates of medical care utilization than any other gastrointestinal (GI) disease.<sup>2–4</sup> Pediatric IBD carries implications that extend beyond the health of the GI tract including osteopenia, joint and skin manifestations, growth retardation, and pubertal delay. Furthermore, adolescence is a critical developmental period that is marked by the establishment of identity, honing of cognitive abilities and social skills, and shaping of belief systems.<sup>5</sup> Like other chronic diseases of childhood, patients with IBD are at risk for depression, anxiety, social isolation, altered self image, family conflict, medication adherence problems, and school absences.<sup>6–11</sup> Collectively, these manifestations of IBD, as well as the related effects on development, can negatively impact health-related quality of life (HRQOL).

HRQOL has been broadly defined as a concept that includes the physical, emotional, and social aspects of health perception and health functioning.<sup>12</sup> The World Health Organization defines quality of life (QOL) as “an individual's perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns.”<sup>13</sup> While in adults sociological, economic, philosophical, and ethical perspectives can also influence HRQOL during childhood, not all of these aspects are as applicable. While adult HRQOL can be influenced by sociologic, economic, philosophical, and ethical factors, these are not all applicable to childhood HRQOL.<sup>14</sup>

Even without the presence of a chronic physical illness, adolescence can be a challenging life phase with significant changes in both psychological (e.g., emotional regulation, cognitive processing, maturation of self-image) and physical (e.g., pubertal changes, growth) realms. With chronic illness, the transition to adulthood can be even more turbulent. While some of the challenges faced are similar to those of adults with IBD, some are unique to the adolescent's developmental stage. For example, youth with IBD can have altered physical appearance, pain, diarrhea, fecal incontinence causing social embarrassment and withdrawal, and decreased sexual intimacy; these effects in turn can negatively influence the consolidation of a healthy self.<sup>5</sup> Although knowledge and consideration of HRQOL in pediatric IBD has been slower to evolve compared to adult IBD, it has been the focus of much research in recent years and has become an important outcome measure in pediatric IBD studies.

This review will draw from pertinent adult and pediat-

Received for publication February 5, 2009; Accepted February 5, 2009.  
From the \*Children's Hospital of Pittsburgh, Division of Gastroenterology, †University of Pittsburgh School of Medicine, Department of Psychiatry, Pittsburgh, Pennsylvania.

Reprints: E. Szigethy, University of Pittsburgh School of Medicine, Department of Psychiatry, 3705 Fifth Ave., Pittsburgh PA 15213 (e-mail: szigethye@upmc.edu).

Copyright © 2009 Crohn's & Colitis Foundation of America, Inc.

DOI 10.1002/ibd.20919

Published online 26 May 2009 in Wiley InterScience (www.interscience.wiley.com).

ric literature about HRQOL over the past 10 years using a PubMed literature search to summarize instruments with which HRQOL is measured and address factors that affect HRQOL in adolescents and young adults with IBD. Finally, psychosocial interventions that have been utilized to improve QOL in this population will be covered. Identifying patients with impaired QOL is of paramount importance, as is implementing strategies that may improve HRQOL, so that they may have an easier transition to adulthood while living with IBD.

### HRQOL INSTRUMENTS

Several instruments are now available to measure IBD-related HRQOL. In the adult literature there are 3 possible instruments that may be used: the global assessment, the generic instrument, and the disease-specific. The global assessment may employ an analog scale or graded summary where the patient reports his or her overall condition as "excellent," "good," "fair," or "poor." Generic assessments are multidimensional problem lists and are designed to be applied to any population, those with and without chronic illness. While these instruments are not sensitive to detect changes in QOL in any 1 illness, they are able to compare QOL in populations with different diseases.<sup>12</sup> Commonly used generic measures include the Medical Outcomes Study, Short Form (SF-36), a 36-item health survey in adults, and the Pediatric Quality of Life Inventory or Child Health Questionnaire in children. When these measures are applied to healthy populations, normative data can be gathered.<sup>15</sup> These normative data can then be used to compare the burden of illness of a specific condition to that of other chronic illnesses, and also healthy populations.<sup>16</sup> Generic measures have been utilized in HRQOL studies in both adults<sup>17,18</sup> and children with IBD.<sup>19,20</sup>

Disease-specific instruments are also multidimensional problem lists, but focus on concerns relevant to a particular illness. It can measure changes in HRQOL over time or with treatment, which is not possible with generic measures.<sup>12</sup> In adults, the most commonly used disease-specific tool in adult IBD is the Inflammatory Bowel Disease Questionnaire (IBDQ). This measure assesses 4 areas: GI symptoms, systemic problems, emotional dysfunction, and social difficulties.<sup>21</sup> The questionnaire contains 30 IBD-specific problems from these categories that had the most prevalence and importance from an initial list of 150 problems. There are items that have higher impact scores, and these tend to pertain to bowel and systemic symptoms, as opposed to emotional and social problems.<sup>22</sup> The Inflammatory Bowel Disease Stress Index has also been used in some adult studies but is less validated than the IBDQ.

There are items on adult disease activity scales (e.g., Crohn's Disease Activity Index) that are not pertinent to the child or adolescent, and the same can be said for adult

HRQOL measures. A pediatric instrument was subsequently designed and validated. The IMPACT questionnaire is the most commonly used disease-specific measure in pediatric IBD. It is designed for use in youths age 10 years and older. It has undergone some modifications since its initial development, and the most recent form, IMPACT-III, consists of 35 questions encompassing 6 domains: IBD symptoms, body image, functional/social impairment, emotional impairment, treatment/interventions, and systemic impairment. It can be self-administered in ages 10 and above, or given by an outside party. There are 5 Likert response options per question that reflect on the previous 2 weeks.<sup>15</sup> Each question is equally weighted and higher scores signify better QOL.<sup>23</sup> The IMPACT scores have been shown to correlate highly with the patient's global assessment of HRQOL. It is believed that the patient's current health status has the greatest influence on responses on the IMPACT questionnaire.<sup>15</sup> While the IMPACT questionnaire is the most widely used and validated tool available, it is still in evolution, with studies utilizing large numbers of subjects in order to evaluate the factor structure of the measure.<sup>24</sup>

In an effort to examine the IBD subjective experiences outside traditional HRQOL measures, Wolfe and Sirois<sup>25</sup> asked 282 adult subjects about the daily impact of IBD. The results showed that the dimensions previously discussed were important to subjects, as well as several others, including cognitive, self-regulation, and practical. This study communicated that while the current approach to evaluate HRQOL in IBD is adequate overall, there is still room to expand our understanding of the existing measures and to include developmental aspects of illness perceptions of adolescents.

### FACTORS THAT AFFECT HRQOL

#### Disease Characteristics (Type and Severity)

Many studies have reported that adult patients with IBD activity also have an impaired HRQOL when compared to patients in remission.<sup>26-33</sup> Patients with active IBD tend to have more bowel symptoms that interfere with daily activities, more disease-related worries, perceived stress, and emotional distress. Casellas et al<sup>28</sup> noted that worsening disease activity led to further impairment of HRQOL.

When IBD type is considered, adults with UC report better HRQOL and less psychological distress than their CD counterparts.<sup>22,26,34</sup> CD patients have reduced well-being, are more depressed, and perceive more severe GI symptoms.<sup>30</sup> One study, however, noted that when disease activity was controlled for, CD and UC patients did not significantly differ in their psychological functioning or HRQOL.<sup>31</sup>

Similarly, several pediatric studies have found that adolescents with IBD symptom exacerbation are more likely to express greater psychosocial difficulty.<sup>34,35,36</sup> In terms of IBD type, UC and CD were shown to affect the lives of children differently,<sup>37</sup> with bowel symptoms having greater effect on

QOL in youths with UC, and systemic symptoms and body image concerns weighing heavier in patients with CD. Interestingly, steroid exposure, hospitalizations, and time from IBD diagnosis have not been shown to significantly impact HRQOL in pediatric IBD.<sup>36</sup> College students with active IBD had significantly poorer adjustment to college and students with IBD had lower physical QOL compared to normal controls,<sup>38</sup> suggesting that this transition is important to monitor.

In addition to traditional disease activity, studies suggest that adolescents are also markedly affected by the necessity for ostomy surgery. Nicholas et al<sup>39</sup> interviewed 20 adolescents with an ostomy or J-pouch. Themes that arose from these interviews included body intrusion and body image challenges, decreased independence, secrecy about the ostomy, and family challenges. The youths, however, did experience personal growth despite the challenges.

### Comorbid Irritable Bowel Syndrome (IBS)

Both adult and pediatric IBD patients in remission may still experience severe GI symptoms similar to those present in IBS (abdominal pain, bloating, abdominal distention, diarrhea, urgency, loose stools, constipation, hard stools, and incomplete bowel movements). In adults, approximately one-third of patients with UC and two-thirds of patients with CD report these symptoms.<sup>30</sup> The patients with comorbid IBS also reported higher levels of anxiety, depression, and had lower QOL scores, compared to their remission counterparts without IBS-like symptoms. However, IBS had no effect on coping behavior.<sup>30,32,40</sup> In a larger study of 149 adults with inactive IBD, 81.9% had some type of functional GI disorder while  $\approx 30\%$  had major depressive disorder.<sup>41</sup> Age greater than 40 years and anxiety independently predicted functional GI symptoms and both functional symptoms and depression were associated with impaired HRQOL and increased use of health services. In children with inactive IBD, these IBS symptoms have been associated with visceral hyperalgesia and anxiety,<sup>42</sup> but there are no studies to date assessing the effects on HRQOL.

### Patient Characteristics (Age, Gender, Socioeconomic Status [SES], Ethnicity, and Culture)

In adults with IBD, gender, SES and ethnicity have all been shown to be determinants of HRQOL.<sup>13</sup> In a large-scale study assessing pediatric HRQOL, age, but not gender, was shown to impact HRQOL.<sup>36</sup> Younger children (age 8–12 years) showed less impairment in HRQOL compared to adolescents.<sup>36,43</sup> Adolescents are also more apt to dislike their self-image compared to latency-age children. Self-esteem was a predictor of HRQOL.<sup>10</sup> Gender differences in HRQOL, however, have also been reported. Boys significantly differed in total HRQOL, emotional, physical, and family functioning realms while girls only differed in family functioning com-

pared to normal controls. There are several reports that suggest females report more disease-related concerns than males, particularly regarding self-image and relationships.<sup>44,45</sup> De Boer et al<sup>10</sup> report that boys have a significantly reduced HRQOL, with significantly more internalizing problem behavior compared to healthy peers. Boys are more focused on reduced strength and short stature, while girls are more concerned about weight gain.<sup>35</sup> While this is a typical developmental issue for healthy adolescents, IBD can exacerbate this through the disease process itself (e.g., delayed puberty) and therapeutic regimen side effects. In terms of cultural differences, HRQOL concerns were similar between children with IBD from England and Canada.<sup>46</sup> In adults with CD, poorer HRQOL was reported in black compared to white patients, although these differences were explained in part by lower levels of SES and education.<sup>47</sup> Effects of ethnicity on HRQOL require more study in pediatric IBD populations.

### Psychosocial/Psychological Factors

Apart from disease activity, Larsson et al<sup>26</sup> reported that other factors also diminished adult IBD patients' HRQOL: stress, sleeping problems, depression, or other psychological distress, pain, and work-, school-, or family-related conflicts. A specific source of stress may be disease-related worries or concerns.<sup>48</sup> While initially most children deny that IBD interferes with their lives, with persistent questioning many admit frustration and anger about their IBD symptoms and treatment.<sup>49</sup> Children with IBD were also concerned about fatigue, body image, and lack of control over activities (e.g., school, sports, work).<sup>37,50–52</sup>

There are conflicting results about the relationship of psychological functioning and IBD status. Some studies show that adults with IBD in remission experience psychological well-being similar to that of the general population.<sup>30</sup> A similar result was found in pediatric IBD by Mackner and Crandall.<sup>53</sup> This study showed that patients in remission or with mild disease for at least 1 year reported normal psychosocial functioning, similar to that of healthy children. This included behavioral/emotional functioning, social competence, self-esteem, coping strategies, and social support.<sup>53</sup>

In other studies, psychological functioning (e.g., perceived stress, health anxiety, and pain anxiety) and catastrophizing were not significantly affected by IBD activity either acutely or longitudinally over a 2-year period in adults.<sup>33,54,55</sup> This study suggests that psychological functioning is independent of disease course. Guthrie et al<sup>55</sup> found the prevalence of probable psychological disorder to be 26% in adults with IBD. Depressed mood was also significantly associated with anxiety and impaired HRQOL and more IBD relapse in adults with IBD.<sup>56</sup> Several studies have found that adolescents with IBD are more depressed than children with other diseases<sup>57–60</sup> with rates up to 25%.<sup>20</sup>

In adults with IBD, sleep quality was significantly inversely correlated with IBD activity<sup>61</sup> and could also have a significant impact on HRQOL. Furthermore, abnormal sleep patterns were reported even in patients with inactive IBD compared to normal controls. Disturbed sleep could have an even greater impact on adolescents who need more sleep, and adversely affect QOL, psychological functioning, and coping ability.

### Personality Traits

Personality traits such as neuroticism and alexithymia (inability to describe feelings) have been shown to predict HRQOL and outcome of surgery in adults with IBD.<sup>62–64</sup> A few studies have reported differences in personality traits according to IBD type, with CD patients being significantly more extroverted and having higher psychoticism personality scores than UC patients, but neuroticism scores were similar.<sup>62,65</sup> Personality traits have not been addressed in the pediatric HRQOL literature.

### Coping Strategies

Coping has been defined by Lazarus and Folkman<sup>66</sup> as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person.” As noted, it is an active process, one where the efforts and strategies change depending on the stressor presented. Much debate exists in the literature as to whether specific coping skills used by IBD patients may influence HRQOL.

Moskovitz et al<sup>67</sup> found that patients who undergo IBD-related surgery experience a lower HRQOL when they have maladaptive coping behaviors such as lack of self-control, self-blame, and escape. They also found that the presence of adaptive coping skills did not differ between those with higher and lower QOL scores. Larsson et al<sup>26</sup> found that the majority of patients with active disease used optimistic, self-reliant, and/or confrontational coping strategies to manage stressors. No differences were found in coping strategies between patients with active and inactive disease, or between CD and UC. Finally, in this study there was no correlation between coping and HRQOL.

In another adult study, however, coping styles were found to impact HRQOL.<sup>44</sup> Specifically, depressive coping, characterized by irritability, self-pitying, musing, social withdrawal, and feelings of helplessness and resignation played a role in reduced QOL in adult IBD patients.<sup>44</sup> In comparing adults with IBD or IBS and healthy controls, patients with these GI disorders showed less problem-solving and positive reappraisal and more escape-avoidance strategies than normal controls.<sup>68</sup> Both GI groups showed more psychiatric distress and poorer QOL, suggesting that these factors reflect illness behavior rather than a disorder-specific process.

In adolescents with IBD, several studies found an as-

sociation between coping styles (e.g., avoidance behavior) and HRQOL compared to normal controls.<sup>45,69</sup> Adolescents who utilize a positive outlook and predictive cognitive control have improved HRQOL.<sup>35,45</sup> This requires them to have a more positive view of their future with IBD and to agree with such thoughts as “I consider my future to be on the bright side,” “When I think about my illness, I assume all will go well.”<sup>45</sup> As mentioned above, while use of avoidant coping styles or depressive reaction patterns is common in IBD, less use of these strategies can lead to better HRQOL.

### Illness Perception

Mussell et al<sup>44</sup> studied 72 adult outpatients with IBD and identified the most commonly ranked disease-related concerns as: effects of medications, having an ostomy bag, and the uncertain nature of disease. Maunder and Esplen<sup>9</sup> noted that bowel dysfunction may lead to social isolation and surgical intervention such as ileostomy may negatively impact body image. Another study assessed the relative contribution of illness perceptions as determined by an interview, and coping strategies in explaining adjustment to IBD in 80 adults. Adjustment was measured from the perspectives of psychological distress, QOL, and functional independence.<sup>70</sup> Illness perception, particularly perception of negative consequences of IBD, most predicted adjustment to IBD. Coping style was not a significant mediator. In another study of 111 adults with IBD, the degree of disease symptoms predicted HRQOL but not illness representation, probed using the Illness Perception Questionnaire.<sup>71</sup>

Several studies have probed illness perception in children and adolescents. In a study examining the lived experience and QOL in children with IBD ages 7–19 years using an interview about the impact of IBD on their daily lives,<sup>35</sup> themes of discomfort from symptoms and treatment, vulnerability, and diminished control over their lives and future, and seeing themselves as different from healthy peers were common. Additional difficulties noted were lack of energy, food restriction, medication side effects, lack of control, diminished self-perception, and less social interaction. Positive attitude, active coping, and social support were associated with better QOL.

In a study consisting of 20 adolescents, qualitative illness narrative analysis of perception of IBD experience was conducted using responses to 10 questions in a structured interview to probe themes of pessimism, contingency, and coping with IBD. This study found significant correlation between clinician-rated depressive severity and ambivalence about having IBD and between self-reported depression and guilt over being a burden. Maternal report of depression was significantly correlated with child’s report of damaged self (Polanec and Szigethy; unpubl. obs.). These correlations were not affected by age, gender, or IBD severity. In another study examining how 17 adolescents (ages 11–17 years) with IBD

respond to their parents' concern for them, ambivalence was the most prevalent theme described. There was an oscillation between seeking close contact with one's parents and pushing them away. The other theme categories that emerged were ability/inability, compliance/resistance, and trust/distrust, suggesting that it is important to have an awareness of the simultaneous existence of conflicting attitudes, reactions, and emotions.<sup>72</sup> Finally, in youth ages 16–21 years with IBD in New Zealand, themes of stress related to CD and ambivalence were common.<sup>73</sup> Collectively, these studies support the relationship between illness experience and perception and HRQOL in adolescents and young adults.

### Family/Social Support

HRQOL is not only limited to the health and emotions of the patient. Tojek et al<sup>8</sup> suggest that patients can be negatively influenced by family health status. Family dysfunction was positively correlated with pain/fatigue and with increased frequency of bowel movements in the adolescent patient. Additionally, maternal positive affect was inversely correlated with adolescent depression, functional disability, and increased frequency of bowel movements.

There has been limited research on how parental QOL is affected by IBD. Recently, Greenley and Cunningham<sup>74</sup> performed a cross-sectional study of 49 IBD youths aged 10–18 years and measured parental QOL using the RAND 36 Health Survey 1.0. This was the first study known to compare the parental QOL to that of a normative population. It was found that parental QOL was actually higher in domains corresponding to physical well-being and energy. When considering disease activity, parental QOL scores decreased in the mental and physical health domains with increased disease activity in the child. The implication of this study is that parents of a child experiencing an exacerbation in symptoms should receive an assessment of QOL. Since it is known that family support is an integral part of coping with illness, it may be helpful to the HRQOL of adolescents if their parents' QOL is maximized.

In summary, the literature to date supports complex interactions between physical, psychological, social, and demographic factors in determining HRQOL in adolescents and young adults. Perhaps the best approach is to consider a biopsychosocial model by which certain IBD factors, environmental stress, psychological symptoms, and coping style interact to influence both HRQOL and disease course.<sup>75</sup>

## PSYCHOSOCIAL STRATEGIES TO IMPROVE QUALITY OF LIFE

### Education/Self-Management

A primary focus in treating IBD is to treat with medical therapy that is best tailored to the disease process itself. The quality of health care should be of the highest standard.

Casellas et al<sup>76</sup> surveyed IBD patients about the healthcare they receive and discovered that, overall, patients found the care to be good. However, some shortcomings were found. Patients noted that obtaining an urgent visit to address flare symptoms was difficult, necessitating otherwise avoidable emergency room visits. Having telephone clinics could also obviate some emergency room visits. Virtually all patients in that survey considered having adequate information about their disease process very important, but only half of those patients thought they had sufficient information. Having inadequate information has been found to result in poorer reported QOL.<sup>77</sup> In 1 study, 69 adults with IBD were randomly assigned to either an educational intervention focused on IBD, or treatment as usual.<sup>78</sup> The educational group had greater knowledge about IBD, increased satisfaction, and improved medication adherence, but there was no significant difference in HRQOL between the 2 groups.

Self-management training has been shown to improve HRQOL.<sup>79,80</sup> In 1 such study of 700 adults with IBD, patients randomized to a self-management approach to illness by providing information designed to promote patient choice had decreased healthcare visits, better QOL, and increased confidence in being able to cope with their IBD compared to those in the usual treatment group.<sup>79</sup> Another study assessed a brief psychosocial group intervention consisting of education and group therapy versus usual medical treatment in 44 adults with inactive IBD and found no significant improvement in HRQOL or coping ability over 12-month period.<sup>81</sup>

In a study of 60 adults with UC randomized to either a comprehensive lifestyle modification program (stress-management, education, self-care strategies) or treatment as usual, the intervention group had significant improvement in HRQOL and anxiety score but no change in disease activity or hospitalizations at 3 months. There was no significant difference between the groups at 12 months,<sup>82</sup> stressing the need for ongoing intervention to sustain results. The improvement of HRQOL as a life-long process is also supported by the definition of self-management given by adults with chronic illness as an integrative process by which they learn to manage a chronic, life-long illness, while at the same time live personally meaningful lives.<sup>83</sup>

Although the effects of self-management techniques on HRQOL have not been studied in adolescents, the overall goals of this developmental phase can be enhanced by the acquisition of skills to manage their illness. These goals include striving for autonomy and self-regulation and identity formation by learning from trial and error. By helping adolescents take an active part in their treatment, the incorporation of health-related behaviors such as taking medication can be better coordinated into their social, educational, and vocational long-term goals.

In treating patients with IBD, or any chronic illness, the healthcare team must consider all facets of the patient, and

not merely the physical. The emotional and social aspects of a chronic disease must also be taken into account. HRQOL measures can provide information to this end, and identify patients who may need further services.

### Exercise and Sleep

In adults with IBD, exercise may be beneficial in reducing stress and symptoms of IBD, as well as counteracting IBD-specific complications like decreased bone density, immunological response, and psychological problems.<sup>84</sup> It is noted that care must be taken in determining the intensity of exercise that is most helpful. In 1 study, 32 adults with either mild or inactive IBD were randomized to low-intensity exercise (walking) or no exercise and followed over 3 months. The exercise group had significantly greater improvement in QOL (measured using both IBDQ and IBDSI), with no detrimental effect on disease activity.<sup>85</sup> Sleep hygiene is important to address in the clinical management of adolescents with IBD as sleep disturbances are common and can adversely affect both HRQOL and coping with illness.

### Psychotherapy

Psychotherapy studies targeting HRQOL in adults with IBD have mixed results.<sup>86,87</sup> Overall, psychosocial interventions have been shown to positively affect QOL, coping with illness, and anxiety/depression, but do not seem to alter IBD course. Cognitive behavioral therapy (CBT) has the most empirical evidence in patients with IBD. In a study of 28 adults with IBD receiving group CBT, there was a significant decrease in disease-related concerns, with depression improving in women, but not men, over the 9-month follow-up.<sup>88</sup> In another study of adults randomized to either group CBT ( $n = 33$ ) or wait-list control ( $n = 24$ ), patients receiving CBT had significant reduction in anxiety and depression.<sup>89</sup> Adults randomized to 8 sessions of stress-management, a type of CBT, had a significant reduction in pain and tiredness compared to a control group receiving conventional medical treatment.<sup>80</sup> In a study of 80 adults with IBD, patients in a stress-management group had significant improvement in CD activity and psychosocial functioning (as measured by the IBD Stress Index) compared to a control group.<sup>90</sup>

Deter et al<sup>91</sup> studied adult CD patients with a recent history of active disease. The intervention group underwent 20 hours of basic short-term psychodynamic psychotherapy and a relaxation treatment program. The psychotherapy provided health education and health-promoting behaviors, and improved patients' coping skills. Patients were urged to have greater responsibility and control over their treatment. This study showed that psychotherapy led to a decrease in annual hospital and sick leave days in the treatment group.

In adolescents, results from psychotherapy are more positive. In depressed youth with IBD, those receiving CBT with focus on illness perception had significant improvements

in depression and perceived control over IBD compared to those receiving their usual medical treatment. This was the case even after controlling for change in IBD severity and steroid treatment.<sup>92</sup> The model of CBT utilized was based on helping adolescents determine appropriate locus of control (e.g., what they could and could not control in themselves and their environment) and adjusting their behaviors and thoughts accordingly.<sup>93</sup> Cognitive reappraisal and developing interest in activities that can exist within the limitations of their disease process (e.g., crafts) was found to be helpful to adolescents in times of illness or health.<sup>35</sup> The more positive effects of psychotherapy in adolescents may be due to their more flexible behavioral repertoires and less-engrained maladaptive coping strategies.

In addition to improving HRQOL, several adult IBD studies have concluded that identifying patients who are at risk for poor outcome after surgery can undergo psychosocial intervention that may improve surgical outcome.<sup>67</sup> The European Crohn's and Colitis Organization recommends that physicians should assess patients' psychosocial status and refer them for support when indicated or that integrated psychosomatic care should be provided in IBD centers.<sup>94</sup>

### Hypnotherapy

Fifteen adults with severe IBD refractory to corticosteroid treatment received 12 sessions of hypnotherapy with promising effects on IBD course and QOL.<sup>95</sup> In patients with UC, hypnotherapy was shown to significantly improve IBD-related inflammation.<sup>96</sup> There are no studies assessing hypnosis in adolescents with IBD, but given the higher hypnotizability of children compared to adults, the therapeutic use of hypnosis holds promise in aiding with abdominal pain and emotional symptoms in pediatric IBD.

### Social Support

Social support has been noted to be beneficial with respect to coping and stress management in patients with IBD.<sup>31,34,76</sup> Specifically, family support has been reported by patients as being helpful with managing IBD. Graff et al<sup>31</sup> found that patients with active disease reported lower perceived support, although causality between the 2 could not be determined. Nicholas et al<sup>35</sup> revealed that social support had a positive effect on coping with IBD. In that study, adolescents valued honesty and open communication from their families, regarding their diagnosis, sensitive issues like bowel symptoms, and their treatment. This led to the development of more effective coping strategies and adaptation, theoretically by lessening social isolation, increasing feelings of control, permitting IBD dialogue, and alleviating unfounded fears about IBD. Excessive surveillance and lack of age-appropriate interaction were found to be unfavorable.

Social support from other adolescents with IBD can also be valuable. Shepanski et al<sup>97</sup> found that adolescents that

attended a summer IBD camp experienced improved social functioning, improved total QOL, and better acceptance of IBD symptoms. This may act to normalize the illness experience. In another study, female teens and their mothers were invited to participate in monthly support groups for 1 year consisting of education and social interaction.<sup>98</sup> The adolescents and their mothers reported that the sessions were helpful and the adolescents showed significant improvement in emotional and social functioning subscales of IMPACT-III from baseline to posttreatment. There are several Web-based interactive internet sites available for children and adolescents with IBD that also provide educational materials and opportunities for social interaction and sharing IBD experiences. These sources include: [www.ccfa.org](http://www.ccfa.org); [www.myibdu.org](http://www.myibdu.org); [www.experiencejournal.com](http://www.experiencejournal.com); [www.ibdsf.com](http://www.ibdsf.com); [www.starlight.org](http://www.starlight.org); and [www.ucandcrohns.org](http://www.ucandcrohns.org). Future studies need to assess these promising interventions for efficacy using randomized controlled trials.

Another important aspect of social support for adolescents is family functioning. If it is possible that a family's dynamic is influencing the adolescent's health status and thereby HRQOL, therapy should be implemented to examine and potentially improve family functioning and parental affect. Parents of children with IBD reported significantly less social support and mothers reported greater distress compared to parents of healthy children.<sup>6</sup> The lack of social support, but not parental distress, was correlated with increased behavioral problems in the children with IBD.

### Medication Adherence

Treatment of pediatric IBD consists of lifelong maintenance medications with the utilization of rescue therapy at times of disease flare. While having to take daily medication can adversely affect QOL (social burden, side effects), the consequences of medication nonadherence can lead to more severe disease and QOL outcomes. It may also increase the risk of surgery.<sup>99</sup> It is important to educate patients, simplify dosing regimens, and utilize new formulations for drug delivery to improve patient adherence and therefore long-term clinical outcomes. Mackner and Crandall<sup>100</sup> noted that it is critical to recognize and treat depression in adolescents in association with medication nonadherence. This study found that medication adherence rates in pediatric IBD were 38% according to parents, and 48% according to the children studied. Family dysfunction and poor child coping strategies were associated with worse adherence. Medication adherence was assessed in 36 adolescents with IBD via interviews, pill counts, and biological assays.<sup>101</sup> Nonadherence to 6-mercaptopurine/azathioprine was related to poorer self-reported physical health QOL. Conversely, greater adherence to a 5-aminosalicylate was related to poorer psychological health QOL, especially social functioning, on the Pediatric Quality of Life Inventory. These results may be related to the child's percep-

tion that taking multiple pills is related to poorer QOL, particularly in social realms. Given the link between emotional fragility and poor QOL, one may hypothesize that medication nonadherence is related to a worse self-reported QOL.

### LIMITATIONS

There are several limitations in integrating factors that influence HRQOL as well as assessing strategies to improve QOL with chronic illness. Depending on how HRQOL is measured, different outcomes are possible. Study design (e.g., retrospective versus prospective) can also influence associations. In addition to being aware of what realms are being probed, it is important to take into account psychometric as well as contextual variables. For example, obtaining HRQOL data in a clinic setting in the context of where medical care occurs has the potential of artificially increasing the child's attention on illness-related aspects of their life.<sup>102</sup> The cognitive level and language used in questions can be problematic for younger teens that may not have the metacognitive skills necessary to understand the meaning of the question. Finally, different informants may have different perspectives on the adolescent's HRQOL.

For psychosocial intervention studies, differences in therapy methods, inclusion criteria, sample size, and outcome measures make it difficult to compare results across studies. Many existing HRQOL measures based on adult concepts do not take into effect developmental changes, language, and cognitive levels, or young people's construction of health and illness.<sup>14</sup> Despite these limitations, there is much valuable information to be gained by assessing HRQOL and providing support for areas of concern.

### FUTURE RESEARCH

There are several aspects of HRQOL in adolescents with IBD that require additional research. At this time, there has been limited study of parental QOL, and the role that ethnicity, life stressors, and genetic vulnerabilities play in HRQOL. Further research is needed to evaluate how medication adherence affects QOL, as studies are limited. As a medical community, we may also benefit from continuing to examine the current tools used to measure HRQOL, and how they might be improved. For example, there is no brief HRQOL assessment measure for children and adolescents with IBD that would be feasible and practical to use in busy medical clinics. Nicholas et al<sup>35</sup> raise excellent questions regarding a family's capacity to communicate, and how physicians can facilitate effective communication. In their study concerning adolescents with ostomies, Nicholas et al<sup>39</sup> note that finding ways to increase public awareness concerning pediatric IBD and life with an ostomy, promote adaptation, and reduce personal stigma are all goals that will promote HRQOL.

## CONCLUSION

Adolescents with IBD are at risk for psychosocial distress, which can impair HRQOL. HRQOL has become a major outcome measure in recent research, with well-validated tools with which to assess it. HRQOL may be impacted by a variety of factors, especially by disease activity and psychological disorders. Coping styles need to be assessed so that psychological intervention may target maladaptive behaviors. HRQOL needs are important to assess, particularly for those patients with active disease, so that affected individuals may be identified and quickly referred for appropriate services. As Nicholas et al<sup>35</sup> suggest, gender, age, and developmental stage should be taken into account, as these factors may help anticipate typical concerns that may be intensified by IBD. Family communication skills should be assessed, as some may benefit from education in the form of family meetings, psycho-educational materials or workshops, and supportive family interaction.

Adolescents with chronic illness experience well-being when they are allowed to prepare for living a normal life integrated into society. Self-management should be addressed as a way of creating order in their lives.<sup>103</sup> This may be accomplished through reconstructing self-identity by exploring their personal limitations, boundaries, and/or experience of transition. Adolescents who have the best adjustment to chronic illness have developed coping strategies to: 1) accept illness/disability as a natural part of life; 2) feel supported; and 3) experience the feeling of personal growth.<sup>104</sup>

IBD is a lifelong illness that can impact daily lives as well as attitudes, fears, and beliefs. Effective medical and surgical treatments, coupled with targeted social and psychological intervention for at-risk adolescents, can significantly improve HRQOL. Careful attention to the adolescent's illness perception and a strong doctor-patient alliance to address fears about unanticipated flares, need for surgery, fatigue, school functioning, and medication side effects are essential. In high-pressure medical clinics, however, probing the many facets of HRQOL adequately is not always feasible. Therefore, better HRQOL tools that rapidly identify the aspects that are central to a given patient are necessary. More active participation of adolescents in treatment decisions, addressing family distress, and encouraging an active lifestyle that is not defined by sick role behavior ("I have IBD" instead of "IBD has me") will have the best chance of ushering adolescents through the transition to adulthood. Finally, growing models of multidisciplinary teams and transitional clinics will continue to be of paramount importance for the adolescent IBD population. This will help to improve compliance with therapy, effective planning of long-range life goals, independent living skills, and ultimately improve HRQOL not just for the short-term, but for a lifetime.<sup>5,105</sup>

## REFERENCES

- Baldassano RN, Piccoli DA. Inflammatory bowel disease in pediatric and adolescent patients. *Gastroenterol Clin North Am.* 1999;28:445-458.
- Katon W, Korff M v, Liu F, et al. A randomised trial of psychiatric consultation with distressed high utilizers. *Gen Hosp Psychiatry.* 1992; 14:86-98.
- Verhoef M, Sutherland L. Outpatient health care utilization of patients with inflammatory bowel disease. *Dig Dis.* 1995;11:1124-1128.
- Bousvaros A, Sylvester F, Kugathasan S, et al. Challenges in Pediatric Inflammatory Bowel Disease. *Inflamm Bowel Dis.* 2006;12:885-913.
- Mamula P, Markowitz JE, Baldassano RN. Inflammatory bowel disease in early childhood and adolescence: special considerations. *Gastroenterol Clin North Am.* 2003;32:967-995, viii.
- Engstrom I. Parental distress and social interaction in families with children with inflammatory bowel disease. *J Am Acad Child Adolesc Psychiatry.* 1991;30:904-912.
- Engstrom I. Inflammatory bowel disease in children and adolescents: Mental health and family functioning. *J Pediatr Gastroenterol Nutr.* 1999;28:S28-S33.
- Tojek TM, Lumley MA, Corlis M, et al. Maternal correlates of health status in adolescents with inflammatory bowel disease. *J Psychosom Res.* 2002;52:173-179.
- Maunder R, Esplen MJ. Facilitating adjustment to inflammatory bowel disease: A model of psychosocial intervention in non-psychiatric patients. *Psychother Psychosom.* 1999;68:230-240.
- De Boer M, Grootenhuys M, Derkx B, et al. Health-related quality of life and psychosocial functioning of adolescents with inflammatory bowel disease. *Inflamm Bowel Dis.* 2005;11:400-406.
- Moody G, Eaden JA, Mayberry JF. Social Implications of childhood CD. *J Pediatr Gastroenterol Nutr.* 1999;28:S43-S45.
- Irvine EJ. Quality of life issues in patients with inflammatory bowel disease. *Am J Gastroenterol.* 1997;92(12 Suppl):18S-24S.
- Sainsbury A, Heatley RV. Review article: psychosocial factors in the quality of life of patients with inflammatory bowel disease. *Aliment Pharmacol Ther.* 2005;21:499-508.
- Taylor RM, Gibson F, Franck LS. A concept analysis of health-related quality of life in young people with chronic illness. *J Clin Nurs.* 2008;17:1823-1833.
- Griffiths AM, Otley AR, Hyams J, et al. A review of activity indices and end points for clinical trials in children with Crohn's disease. *Inflamm Bowel Dis.* 2005;11:185-196.
- Patrick L, Deyo RA. Generic and disease-specific measures in assessing health status and quality of life. *Med Care.* 1989;27:S217-S232.
- Boye B, Jahnsen J, Mogleby K, et al. The INSPIRE study: are different personality traits related to disease-specific quality of life (IBDQ) in distressed patient with ulcerative colitis and Crohn's disease? *Inflamm Bowel Dis.* 2008;14:680-686.
- Pace F, Molteni P, Bollani S, et al. Inflammatory bowel disease versus irritable bowel syndrome: a hospital-based, case-control study of disease impact on quality of life. *Scand J Gastroenterol.* 2003;38: 1031-1038.
- Landgraf JM, Abetz L, Ware JE. Child Health Questionnaire (CHQ): A User's Manual. Boston: The Health Institute, New England Medical Center, 2006.
- Szigethy E, Levy-Warren A, Whitton S, et al. Depressive symptoms and inflammatory bowel disease in children and adolescents: a cross-sectional study. *J Pediatr Gastroenterol Nutr.* 2004;39:395-403.
- Guyatt G, Mitchell A, Irvine EJ, et al. A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology.* 1989;96:804-810.
- Irvine EJ. Development and subsequent refinement of the Inflammatory Bowel Disease Questionnaire: a quality-of-life instrument for adult patients with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr.* 1999;28:S23-S27.
- Otley A. Measurement of quality of life in pediatric inflammatory bowel disease. In: Mamula P, Baldassano RN, Markowitz JE, eds. *Pediatric Inflammatory Bowel Disease.* 1st ed. New York: Springer; 2008:565-576.
- Perrin JM, Kuhlthau K, Chughtai A, et al. Measuring quality of life in

- pediatric patients with inflammatory bowel disease: psychometric and clinical characteristics. *J Pediatr Gastroenterol Nutr.* 2008;46:164–171.
25. Wolfe BJ, Sirois FM. Beyond standard quality of life measures: the subjective experiences of living with inflammatory bowel disease. *Qual Life Res.* 2008;17:877–886.
  26. Larsson K, Löf L, Rönnblom A, et al. Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. *J Psychosom Res.* 2008;64:139–148.
  27. Nordin K, Pählman L, Larsson K, et al. Health-related quality of life and psychological distress in a population-based sample of Swedish patients with inflammatory bowel disease. *Scand J Gastroenterol.* 2002;37:450–457.
  28. Casellas F, Arenas JJ, Baudet JS, et al. Impairment of health-related quality of life in patients with inflammatory bowel disease: a Spanish multi-center study. *Inflamm Bowel Dis.* 2005;11:488–496.
  29. Bernklev T, Jahnsen J, Schulz T, et al. Course of disease, drug treatment and health-related quality of life in patients with inflammatory bowel disease 5 years after initial diagnosis. *Eur J Gastroenterol Hepatol.* 2005;17:1037–1045.
  30. Simren M, Axelsson J, Gillberg R, et al. Quality of life in inflammatory bowel disease in remission: the impact of IBS-like symptoms and associated factors. *Am J Gastroenterol.* 2002;97:389–396.
  31. Graff LA, Walker JR, Lix L, et al. The relationship of inflammatory bowel disease type and activity to psychological functioning and quality of life. *Clin Gastroenterol Hepatol.* 2006;4:1491–1501.
  32. Ansari R, Attari F, Razjyouan H, et al. Ulcerative colitis and irritable bowel syndrome: relationships with quality of life. *Eur J Gastroenterol Hepatol.* 2008;20:46–50.
  33. Lix LM, Graff LA, Walker JR, et al. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflamm Bowel Dis.* 2008;14:1575–1584.
  34. Drossman DA, Patrick DL, Mitchell CM, et al. Health-related quality of life in inflammatory bowel disease. Functional status and patient worries and concerns. *Dig Dis Sci.* 1989;34:1379–1386.
  35. Nicholas DB, Otley A, Smith C, et al. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health Qual Life Outcomes.* 2007;5:28.
  36. Otley AR, Griffiths AM, Hale S, et al. Health-related quality of life in the first year after diagnosis of pediatric inflammatory bowel disease. *Inflamm Bowel Dis.* 2006;12:684–691.
  37. Griffiths AM, Nicholas D, Smith C, et al. Development of a quality-of-life index for pediatric inflammatory bowel disease: dealing with differences related to age and IBD type. *J Pediatr Gastroenterol Nutr.* 1999;28:S46–52.
  38. Adler J, Raju S, Beveridge AS, et al. College adjustment in University of Michigan students with Crohn's and colitis. *Inflamm Bowel Dis.* 2008;14:1281–1286.
  39. Nicholas DB, Swan SR, Gerstle TJ, et al. Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy. *Health Qual Life Outcomes.* 2008;6:114.
  40. Minderhoud IM, Oldenburg B, Wismeijer JA, et al. IBS-like symptoms in patients with inflammatory bowel disease in remission; relationships with quality of life and coping behavior. *Dig Dis Sci.* 2004;49:469–474.
  41. Farokhyar F, Marshall JK, Easterbrook B, et al. Functional gastrointestinal disorders and mood disorders in patients with inactive inflammatory bowel disease: prevalence and impact on health. *Inflamm Bowel Dis.* 2006;12:38–46.
  42. Faure C, Giguère L. Functional gastrointestinal disorders and visceral hypersensitivity in children and adolescents suffering from Crohn's disease. *Inflamm Bowel Dis.* 2008;14:1569–1574.
  43. Loonen HJ, Grootenhuis MA, Last BF, et al. Quality of life in pediatric inflammatory bowel disease measured by a generic and a disease-specific questionnaire. *Acta Paediatr.* 2002;91:348–354.
  44. Mussell M, Böcker U, Nagel N, et al. Predictors of disease-related concerns and other aspects of health-related quality of life in outpatients with inflammatory bowel disease. *Eur J Gastroenterol Hepatol.* 2004;16:1273–1280.
  45. van der Zaag-Loonen HJ, Grootenhuis MA, Last BF, et al. Coping strategies and quality of life of adolescents with inflammatory bowel disease. *Qual Life Res.* 2004;13:1011–1019.
  46. Richardson G, Griffiths AM, Miller V, et al. Quality of life in inflammatory bowel disease: a cross-cultural comparison of English and Canadian children. *J Pediatr Gastroenterol Nutr.* 2001;32:573–578.
  47. Straus W, Eisen G, Sandler R, et al. Crohn's disease: does race matter? *Am J Gastroenterol.* 2000;95:479–483.
  48. Hjortswang H, Almer S, Ström M, et al. The network: a strategy to describe the relationship between quality of life and disease activity. The case of inflammatory bowel disease. *Eur J Gastroenterol Hepatol.* 1999;11:1099–1104.
  49. Akobeng AK, Suresh-Babu MV, Firth D, et al. Quality of life in children with Crohn's disease: a pilot study. *J Pediatr Gastroenterol Nutr.* 1999;28:S37–39.
  50. Rabbett H, Elbadri A, Thwaites R, et al. Quality of life in children with Crohn's disease. *J Pediatr Gastroenterol Nutr.* 1996;23:528–533.
  51. Lavigne JV, Faier-Routman-J. Psychological adjustment to pediatric physical disorders: a meta-analytic review. *J Pediatr Psychol.* 1992;17:133–157.
  52. Mackner LM, Crandall WV, Szigethy EM. Psychosocial functioning in pediatric inflammatory bowel disease. *Inflamm Bowel Dis.* 2006;12:239–244.
  53. Mackner LM, Crandall WV. Long-term psychosocial outcomes reported by children and adolescents with inflammatory bowel disease. *Am J Gastroenterol.* 2005;100:1386–1392.
  54. Turnbull GK, Vallis TM. Quality of life in inflammatory bowel disease: the interaction of disease activity with psychosocial function. *Am J Gastroenterol.* 1995;90:1450–1454.
  55. Guthrie E, Jackson J, Shaffer J, et al. Psychological disorder and severity of inflammatory bowel disease predict health-related quality of life in UC and CD. *Am J Gastroenterol.* 2002;97:1994–1999.
  56. Mittermaier C, Dejaco C, Waldhoer T, et al. Impact of depressive mood on relapse in patients with inflammatory bowel disease: a prospective 18-month follow-up study. *Psychosom Med.* 2004;66:79–84.
  57. Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel disease: a comparison with children having other chronic illnesses and with healthy children. *J Child Psychol Psychiatry.* 1992;33:563–582.
  58. Burke P, Meyer V, Kocoshis S, et al. Depression and anxiety in pediatric inflammatory bowel disease and cystic fibrosis. *J Am Acad Child Adolesc Psychiatry.* 1989;28:948–951.
  59. Burke P, Kocoshis SA, Chandra R, et al. Determinants of depression in recent onset pediatric inflammatory bowel disease. *J Am Acad Child Adolesc Psychiatry.* 1990;29:608–610.
  60. Raymer D, Weininger O, Hamilton JR. Psychological problems in children with abdominal pain. *Lancet.* 1984;1:439–440.
  61. Ranjbaran Z, Keefer L, Farhadi A, et al. Impact of sleep disturbances in inflammatory bowel disease. *J Gastroenterol Hepatol.* 2007;22:1748–1753.
  62. Boye B, Jahnsen J, Mokleby K, et al. The INSPIRE study: are different personality traits related to disease-specific quality of life (IBDQ) in distressed patient with ulcerative colitis and Crohn's disease? *Inflamm Bowel Dis.* 2008;14:680–686.
  63. Weinryb RM, Gustavsson JP, Barber JP. Personality traits predicting long-term adjustment after surgery for ulcerative colitis. *J Clin Psychol.* 2003;59:1015–1029.
  64. Moreno-Jimenez B, Lopez Blanco B, Rodriguez-Munoz A, et al. The influence of personality factors on health-related quality of life of patients with inflammatory bowel disease. *J Psychosom Res.* 2007;62:39–46.
  65. Barrett SM, Standen PJ, Lee AS, et al. Personality, smoking and inflammatory bowel disease. *Eur J Gastroenterol Hepatol.* 1996;8:651–655.
  66. Lazarus RS, Folkman S. *Stress, Appraisal and Coping.* New York: Springer; 1984.
  67. Moskowitz DN, Maunder RG, Cohen Z, et al. Coping behavior and social support contribute independently to quality of life after surgery for inflammatory bowel disease. *Dis Colon Rectum.* 2000;43:517–521.
  68. Jones MP, Wessinger S, Crowell MD. Coping strategies and interpersonal support in patients with irritable bowel syndrome and inflammatory bowel disease. *Clin Gastroenterol Hepatol.* 2006;4:474–481.

69. Gitlin K, et al. Stress mediators in children with inflammatory bowel disease. In: Johnson JH, Johnson SB, eds. *Advances in Child Health Psychology*. Gainesville: University of Florida Press, 1991:54–62.
70. Dorrian A, Dempster M, Adair P. Adjustment to inflammatory bowel disease: the relative influence of illness perceptions and coping. *Inflamm Bowel Dis*. 2009;15:47–55.
71. Han SW, McColl E, Barton JR, et al. Predictors of quality of life in ulcerative colitis: the importance of symptoms and illness representations. *Inflamm Bowel Dis*. 2005;11:24–34.
72. Reichenberg K, Lindfred H, Saalman R. Adolescents with inflammatory bowel disease feel ambivalent towards their parents' concern for them. *Scand J Caring Sci*. 2007;21:476–481.
73. Lynch T, Spence D. A qualitative study of youth living with Crohn disease. *Gastroenterol Nurs*. 2008;31:224–230.
74. Greenley RN, Cunningham C. Parent quality of life in the context of pediatric inflammatory bowel disease. *J Pediatr Psychol*. 2008 (in press).
75. Bitton A, Sewitch MJ, Peppercorn MA, et al. Psychosocial determinants of relapse in ulcerative colitis: a longitudinal study. *Am J Gastroenterol*. 2003;98:2203–2208.
76. Casellas F, Fontanet G, Borrueal N, et al. The opinion of patients with inflammatory bowel disease on healthcare received. *Rev Esp Enferm Dig*. 2004;96:174–184.
77. Moser G, Tillinger W, Sachs G, et al. Disease-related worries and concerns: a study on out-patients with inflammatory bowel disease. *Eur J Gastroenterol Hepatol*. 1995;7:853–858.
78. Waters BM, Jensen L, Fedorak RN. Effects of formal education for patients with inflammatory bowel disease: a randomized controlled trial. *Can J Gastroenterol*. 2005;19:235–244.
79. Kennedy AP, Nelson E, Reeves D, et al. A randomised controlled trial to assess the effectiveness and cost of a patient orientated self management approach to chronic inflammatory bowel disease. *Gut*. 2004;53:1639–1645.
80. Garcia-Vega E, Fernandez-Rodriguez C. A stress management program for Crohn's disease. *Behav Res Ther*. 2004;42:367–383.
81. Oxelmark L, Magnusson A, Löfberg R, et al. Group-based intervention program in inflammatory bowel disease patients: effects on quality of life. *Inflamm Bowel Dis*. 2007;13:182–190.
82. Langhorst J, Anthonisen IB, Steder-Neukamm U, et al. Patterns of complementary and alternative medicine (CAM) use in patients with inflammatory bowel disease: perceived stress is a potential indicator for CAM use. *Complement Ther Med*. 2007;15:30–37.
83. Whittemore R, Dixon J. Chronic illness: the process of integration. *J Clin Nurs*. 2008;17:177–187.
84. Narula N, Fedorak RN. Exercise and inflammatory bowel disease. *Can J Gastroenterol*. 2008;22:497–504.
85. Ng V, Millard W, Lebrun C, et al. Low-intensity exercise improves quality of life in patients with Crohn's disease. *Clin J Sport Med*. 2007;17:384–388.
86. von Wietersheim J, Kessler H. Psychotherapy with chronic inflammatory bowel disease patients: a review. *Inflamm Bowel Dis*. 2006;12:1175–1184.
87. Jantschek G, Zeitz M, Pritsch M, et al. Effect of psychotherapy on the course of CD. Results of the German prospective multicenter psychotherapy treatment study on Crohn's disease. German Study Group on Psychosocial Intervention in Crohn's Disease. *Scand J Gastroenterol*. 1998;33:1289–1296.
88. Mussell M, Böcker U, Nagel N, et al. Reducing psychological distress in patients with inflammatory bowel disease by cognitive-behavioural treatment: exploratory study of effectiveness. *Scand J Gastroenterol*. 2003;38:755–762.
89. Diaz Sibaja MA, Comeche Moreno MI, Mas Hesse B. Protocolized cognitive-behavioural group therapy for inflammatory bowel disease. *Rev Esp Enferm Dig*. 2007;99:593–598.
90. Milne B, Joachim G, Niedhardt J. A stress management programme for inflammatory bowel disease patients. *J Adv Nurs*. 1986;11:561–567.
91. Deter HC, Keller W, von Wietersheim J, et al. Psychological treatment may reduce the need for healthcare in patients with CD. *Inflamm Bowel Dis*. 2007;13:745–752.
92. Szigethy E, Kenney E, Carpenter J, et al. Cognitive-behavioral therapy for adolescents with inflammatory bowel disease and subsyndromal depression. *J Am Acad Child Adolesc Psychiatry*. 2007;46:1290–1298.
93. Weisz JR, McCabe MA, Dennig MD. Primary and secondary control among children undergoing medical procedures: adjustment as a function of coping style. *J Consult Clin Psychol*. 1994;62:324–332.
94. Caprilli R, Gassull MA, Escher JC, et al. European evidence based consensus on the diagnosis and management of CD: special situations. *Gut*. 2006;55(Suppl 1):i36–i58.
95. Miller V, Whorwell PJ. Treatment of inflammatory bowel disease: a role for hypnotherapy? *Int J Clin Exp Hypn*. 2008;56:306–317.
96. Mawdsley JE, Jenkins DG, Macey MG, et al. The effect of hypnosis on systemic and rectal mucosal measures of inflammation in ulcerative colitis. *Am J Gastroenterol*. 2008;103:1460–1469.
97. Shepanski MA, Hurd LB, Culton K, et al. Health-related quality of life improves in children and adolescents with inflammatory bowel disease after a camp sponsored by the Crohn's and Colitis Foundation of America. *Inflamm Bowel Dis*. 2005;11:164–170.
98. Szigethy E, Hardy D, Craig A, et al. Letter to the editor. Girls connect: effects of a support group for teenage girls with inflammatory bowel disease and their mothers. *Inflamm Bowel Dis*. 2008 (in press).
99. Kane SV. Systematic review: adherence issues in the treatment of ulcerative colitis. *Aliment Pharmacol Ther*. 2006;23:577–585.
100. Mackner LM, Crandall WV. Oral medication adherence in pediatric inflammatory bowel disease. *Inflamm Bowel Dis*. 2005;11:1006–1012.
101. Hommel KA, Davis CM, Baldassano RN. Medication adherence and quality of life in pediatric inflammatory bowel disease. *J Pediatr Psychol*. 2008;33:864–874.
102. Noll RB, Fairclough D. Health-related quality of life: developmental and psychometric issues. *J Pediatr*. 2004;145:8–9.
103. Kralik D, Koch T, Price K, et al. Chronic illness self-management: taking action to create order. *J Clin Nurs*. 2004;13:259–267.
104. Berntsson L, Berg M, Brydolf M, Hellström AL. Adolescents' experiences of well-being when living with a long-term illness or disability. *Scand J Caring Sci*. 2007;21:419–425.
105. Baldassano R, Ferry G, Griffiths A, et al. Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*. 2002;34:245–248.