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Skills-Based Group Intervention for Adolescent Girls With Inflammatory Bowel Disease

Lisa G. Hayutin,1 Ronald L. Blount,2 Jeffery D. Lewis,3,4 Laura E. Simons,5 and Megan L. McCormick2

Abstract
In this study we describe the responses of six adolescent girls with inflammatory bowel disease and their parents to a 10-session, manualized intervention program focusing on decreasing pain and functional disability in adolescents with a chronic illness, and increasing coping and sense of competency for their parents. Measures of adolescent physical symptoms and parenting sense of competence and coping were collected at pretreatment, post-treatment, and 6-month follow-up. Improvements were observed post-treatment and at 6 month follow-up on measures of adolescents’ pain and functional disability, as well as parents’ sense of competency and use of adaptive coping strategies. The potential effectiveness of this type of program and implications for its use are discussed.

Keywords
pediatric, inflammatory bowel disease, skills training, coping, parents, treatment, adolescents

I Theoretical and Research Basis
Ulcerative colitis (UC) and Crohn’s disease (CD), often grouped together and referred to as inflammatory bowel disease (IBD), are serious disorders of the gastrointestinal tract. They are chronic, unpredictable, and often embarrassing conditions frequently causing abdominal pain, diarrhea, weight loss, growth delay, and intestinal bleeding. Up to 30% of cases are diagnosed prior to 20 years of age (Mendeloff & Calkins, 1988). Around 31% to 50% of these children and adolescents reported functional limitations in life activities, such as decreased school attendance and fewer extramural or social activities, due to IBD (Moody, Eaden, & Mayberry, 1999).

There have been very few psychologically based treatments developed for adolescents with IBD. Schwarz and Blanchard (1991) implemented a multicomponent behavioral intervention for

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adults with IBD consisting of education, relaxation, biofeedback, and coping skills. Results indicated increased patient coping with IBD and less stress related to their disease, as compared to participants in a symptom-monitoring control condition. Success of adult treatment programs supports development of similar programs for children and adolescents.

For pediatric patients with IBD who were also depressed, Szigethy et al. (2004) utilized a cognitive behavioral therapy (CBT) intervention to reduce depression and other disease-related difficulties. This intervention resulted in 10 of 11 adolescents no longer meeting criteria for depression. Participants also reported improvements in perceptions of physical health, feelings of helplessness, and increased control in social situations. A follow-up assessment (Szigethy et al., 2006) and a controlled group investigation (Szigethy et al., 2007) yielded similar findings.

In addition to a paucity of research focused on reducing pain and functional disability in adolescents with IBD, a small number of CBT studies that have been conducted with patients with the functional disorder of recurrent abdominal pain (RAP). RAP and IBD are both associated with abdominal pain and psychosocial stress (American Academy of Pediatrics’ Subcommittee on Chronic Abdominal Pain, 2005). Sanders et al. (1989) evaluated an 8-week CBT family intervention for children with RAP, finding that pain was reduced more quickly for the eight treated families as compared to controls. Similar findings were obtained in a second study, and these improvements were maintained at 6- and 12-month follow-up (Sanders, Shepherd, Cleghorn, & Woolford, 1994). Functional disability also decreased (Sanders et al., 1994).

The primary goals of this treatment intervention were to reduce pain and functional disability in adolescents with IBD. Adolescent girls and their parents participated. Literature has shown that overly attentive parental behavior correlates with their adolescents with chronic abdominal pain experiencing more severe stomach aches and missing more school days (Levy et al., 2004). In addition, we have observed in clinical settings that parents often feel unsure about how to set appropriate expectations and limits with their adolescents who have IBD. Thus, the parental component was designed to improve parents’ coping and competence in their parental role, as well as decrease their daughters’ pain and disability.

2 Case Introduction

Six adolescent girls with a diagnosis of CD or UC were recruited through a pediatric gastroenterology practice for participation in the skills-based group. There were three 13-year-olds, two 14-year-olds, and one 17-year-old. Five were White and one was Indian-American. Gross family income ranged from US$13,000 to US$250,000 per year ($M = 102,600, SD = 89.68$). Five girls were accompanied by their mothers and one was accompanied by a father. Requirements for participation were that the child and parent spoke English and that neither had significant developmental delay that would impede participation. Prior to participation, parental consent and adolescents’ assent were obtained. The girls and their parents then completed assessment measures. The study was approved by the participating university Institutional Review Board. A waiver of authorization for protected health information was received from the participants.

3 Presenting Complaints

Adolescent patients were referred for participation by their gastroenterologists who were part of a large pediatric gastroenterology group practice. All patients reported pretreatment difficulties with abdominal pain and/or functional disability related to their disease (e.g., missing school, not participating in sports), and these reports were confirmed by five of six parents. One parent reported no pain for her daughter; however, the family was still allowed to participate given the daughter’s report of abdominal pain, history of pain episodes, and the possibility for learning
useful skills for managing future pain-related difficulties. Four of six parents reported an above average sense of incompetence in their role as a parent.

4 History

Review of medical records revealed that two of the girls had UC and four had CD. One girl with CD also had diagnoses of endometreosis and migraine headaches. One girl with UC also had diagnoses of recurrent pancreatitis and irritable bowel syndrome. These adolescents had been diagnosed with IBD for 4, 9, 18, 32, 34, or 36 months prior to beginning the intervention.

5 Assessment

Self-report and parent-report questionnaires were completed by participants on three separate occasions: prior to starting the intervention program (pretreatment), at the conclusion of the 10-week training (post-treatment), and again at 6-month follow-up (follow-up). Both parent and adolescent reports were used to measure adolescents’ abdominal pain and functional disability. Parents also reported on their sense of inadequacy as a parent and their coping strategies. Participants received gift certificates for return of their assessment packets.

Background Information Form

Parents completed a brief questionnaire and provided information about family demographic variables (i.e., gender, ethnicity, members of family, etc.), diagnosis (CD or UC), and family history of disease.

Adolescent Outcome Measures

Abdominal Pain Index (API; Walker, Smith, Garber, & Van Slyke, 1997). This 8-item questionnaire assesses abdominal pain in the past 2 weeks. The API has been shown to differentiate children with chronic abdominal pain from pain-free peers (Walker et al., 1997). Frequency of pain is reported on a 6-point scale ranging from 0 (not at all) to 5 (everyday), and the typical duration of pain episodes is on a 5-point scale ranging from 1 (less than 1 hour) to 5 (all day). Parent-report and self-report versions of the API were administered.

Functional Disability Inventory (FDI; Walker & Greene, 1991). This is a 15-item measure of the degree to which illness impairs one’s ability to participate in daily activities in the past 2 weeks. A list of activities is provided, and respondents report their level of impairment on a 5-point scale that ranges from no trouble to impossible to do. Parent-report and self-report versions of this instrument were used. Cronbach’s alphas were .90 to .94 for the child and parent-report version. Test–retest reliability coefficients for children and mothers were .85 and .95, respectively. The FDI correlated significantly with measures of somatization, anxiety, depression, and internalizing behavior (Walker & Greene, 1991).

Parent Outcome Measures

Stress index for parents of adolescents (SIPA; Sheras, Abidin, & Konold, 1998). This parent-completed questionnaire consists of 112-items that assess areas of stress in parent–adolescent interactions. For this investigation, the subscale Incompetence (measuring sense of incompetence as a parent) was used to evaluate changes in parents’ view of their own competence as a parent of an adolescent with IBD. Internal consistency for this subscale was .82 and test–retest reliability was .83 (Sheras et al., 1998). T-scores will be presented.
Coping-Health Inventory for parents (CHIP; McCubbin, McCubbin, Nevin, & Cauble, 1983). This 45-item measure assesses coping behaviors that parents of ill children might employ in the management of family life. Each item details a coping strategy (e.g., “Encouraging children with medical conditions to be more independent”), and the respondent rates the degree to which the strategy is helpful on a 4-point scale (3 = extremely helpful, 0 = not helpful). The CHIP yields one total coping score, and three subscale scores. The total score was used in this investigation. Higher scores indicate more effective coping. The CHIP has internal consistency alphas that range from .71 to .79.

6 Case Conceptualization

We conceptualized these patients’ abdominal pain as possibly being exacerbated by one or more of several biopsychosocial factors. We viewed such factors as interacting within a 4-point model in which pain could potentially result from or be made worse by maladaptive cognitions, negative emotions, physiological stress, and/or unproductive behaviors. These four factors were seen as interacting in a mutually reciprocal fashion, thereby influencing each other. Examples of maladaptive cognitions might include catastrophic thinking about pain (i.e., “The pain is bad and will get worse”) as well as thoughts that would be likely to produce anxious or depressed emotions, including those unrelated to pain (e.g., “I’ll never get better” or “My parent treats me unfairly”). Consistent with the approach used in manualized treatments for anxiety, such as the Coping Cat by Phil Kendall (1990), anxious or other negative emotions were conceived of as not directly modifiable, but rather as signaling the need to assess for maladaptive thoughts that may be promoting those emotions. Melzack and Wall (1965) indicated in their seminal Gate Control Theory of Pain that negative emotions can lead to greater pain experience. Heightened physiological stress was also viewed as potentially increasing the probability or severity of pain experience (Cunningham & Banez, 2006). Unproductive behavioral repertoires, such as inadequate problem solving or communication skills, might lead to stressful reactions to daily challenges and thereby increase pain. Also, none of the adolescents had been formally trained in the use of behavioral pain coping strategies. Just as these parts of the 4-point model could contribute to more pain and disability, training in these areas might result in pain reduction and resumption of more normal, fulfilling daily activities.

Family factors were included in our conceptualization in two ways. First, pain reactions and associated disability can be heightened by social influences, including those present in the family. Parents may unintentionally direct children’s and adolescents’ attention to their pain and provide social consequences contingent on pain, as well as remove unpleasant behavioral expectations of the adolescent contingent on the presence of pain (Blount et al., 2009; Levy et al., 2004). Anecdotally, many parents report that they feel guilty about their child’s disease, and that they tend to indulge their children more than they would otherwise. They may reduce normal expectations parents have for their adolescents’ behavior, and inadvertently promote functional disability. Second, there are many challenges involved in parenting a child with a chronic illness. These may include time off work, need for additional child care, negotiations with schools over assignments, and the need to communicate well with one’s spouse and with their adolescent. Stresses in these areas may have direct or indirect effects within the family system as a whole. Therefore, deficits in parents’ problem solving, behavior management skills, their own coping behaviors, and stress within the family system were seen as possible contributors to their adolescents’ pain and disability.

7 Course of Treatment and Assessment of Progress

Treatment protocol. Treatment was designed to address possible deficits noted in our conceptualization above. The treatment was administered in two separate cohorts, with groups of four and two parent–adolescent dyads. All of the participants attended at least 80% of the sessions.
Groups were led by doctoral students in clinical and counseling psychology under the supervision of a licensed clinical psychologist. The manual created for this intervention included skill components that were selected based on a review of the literature, our knowledge of evidence-based interventions for other pediatric conditions, and input from a pediatric gastroenterologist (J.L.) and families of adolescent girls with IBD. Manuals were piloted with two families and subsequently revised prior to beginning this treatment intervention. Each session included the following format: review of written homework; didactic presentations on the topic for the day; discussion, problem solving and practice of the new skill; plans for application during the week; and assignment of homework related to the skills.

A total of 10 sessions was used to teach a variety of skills and practice the use of skills in session. During the initial session, a 4-point cognitive–behavioral conceptual model was reviewed, with an emphasis on the interaction between cognitions, emotions, physiology, and behavior and how these interactions can be beneficial or detrimental. This model acted as a framework for teaching and applying the coping skills. Table 1 provides a general overview of each session and the specific skills taught. Adolescent and parent groups generally met separately to facilitate camaraderie among peers and confidentiality. Exceptions to this were the relaxation session and conflict resolution communication sessions, during which parent and adolescent groups met together. A special module was included for parents only that focused on issues specific to parenting an adolescent daughter with IBD (e.g., limit setting, avoiding unintentional reinforcement of their daughters’ pain behavior or functional disability, encouraging normal development). This special parent module was designed to improve parents’ competence and ability to effectively cope with the challenges that are inherent in caring for an adolescent with a chronic medical condition. The parenting module was presented on the same day that the parents were presented an abbreviated version of the distraction based pain coping skills module that the adolescents received.

**Treatment progress presentation overview.** Data for the pretreatment, post-treatment, and follow-up evaluations are presented in Table 2 for each participant across pretreatment, post-treatment, and follow-up assessments. Directional arrows are included to assist the reader in recognizing increases or decreases from baseline for each of the variables. To further increase ease of understanding the results, mean data per phase are presented in Figures 1a, 1b, 2a, and 2b. Below the number of participants who responded in the therapeutic direction for each measure at each evaluation will be indicated. To further examine the magnitude of benefit for the participants considered as a whole, the ranges for effect sizes will be provided.

**Adolescent progress.** Figure 1a and b display decreases in mean scores from pretreatment to post-treatment assessments for both parent and adolescent reports of abdominal pain and functional disability. Also, 7 of the 12 total parent-reported and adolescent-reported outcome measurements of abdominal pain revealed decreases from pretreatment to post-treatment. Each participant had at least one decrease in pain from pre- to postintervention, as reported by the adolescent, parent, or both. One parent reported a score of zero at baseline for their adolescent; thus, no decreases could be found. For functional disability, 9 of 12 total outcome measures revealed decreases, and five of the six adolescents showed at least one decrease from pretreatment to post-treatment, as reported by the adolescent, parent, or both.

**Parent progress.** Figure 2a and b display improvements in mean scores from pretreatment to post-treatment for parent reports of their sense of inadequacy as a parent and in their utilization of coping strategies. Five of the six parents reported decreases in sense of incompetence from pre- to post-treatment. One parent who did not have any decreases reported exceptionally low pretreatment levels of parenting sense of incompetence (scale score = 16), making it unrealistic to expect further reductions following treatment. Also, five of six parents reported increases in their use of adaptive coping strategies.
Table 1. Intervention Components by Session

1. Overview of treatment, and introduction of 4-point cognitive model
   Session included introductions and presentation of the treatment model (cognitions, behaviors, emotions, physiology)

2. Problem solving
   Participants learned to define problem, break it down into component parts, generate solutions, choose best solution, and evaluate outcomes

3. Cognitive restructuring
   This session focused on thoughts and emotions, and how to distinguish the two. Presented how to identify cognitive distortions and change them

4. Progressive muscle relaxation with imagery
   Participants taught how to recognize muscle tension and use relaxation and imagery to control it. Practiced in session

5. Distraction-based pain coping strategies/Limit setting
   Adolescents and parents learned effective and ineffective pain coping strategies. Whole session for adolescents. Parents received brief pain coping presentation, plus discussion and training in limit setting and setting reasonable behavioral expectations, particularly in their reactions to adolescents’ pain/activity limitation

6. Communication skills
   Use of “I” statements, paraphrasing, taking turns, body language

7. Review and integration of all skills
   Discussed how to use the skills in concert, and how their use can reduce pain and improve overall functioning

8. Applying skills in session: negotiating ongoing family conflict
9. Applying skills in session: second session on negotiating ongoing family conflict
10. Final review and feedback
    Trouble shooting specific problem areas was provided. Inquiries were made about what sorts of skills they used most at home. Planned with participants on how they could most likely continue to use skills. A graduation certificate was provided. All handouts for each session were kept in workbooks the participants kept

To further evaluate the effect of the intervention, effect size r’s were calculated. Effect sizes may range from 0 (no effect) to ±1.0 (perfect effect). Generally accepted guidelines indicate that .30-.49 is a medium effect and .50 or greater are a large effect (Cohen, 1988). For all the adolescent and parent outcome measures, pretreatment to post-treatment effect sizes ranged from \( r = .49 \) to \( .70 \), indicating medium to mostly large effect sizes for the intervention.

8 Complicating Factors

Several challenges were present when implementing this intervention and measuring its effects. First, the episodic nature of IBD presents the possibility that a child could experience more or less symptoms due mainly to biological factors that were unrelated to coping skills development. Second, the intervention is a multicomponent package that involved both adolescents and parents. In turn, we are unable to identify which components were effective and cannot isolate the mechanisms of action which contributed to the observed desirable effects. An informal post-treatment assessment of patients’ perceptions of the usefulness of the different components was not helpful, as participants gave each component the highest rating. In addition, because treatment was presented using an AB design, it is not possible to strictly attribute benefit to the treatment per se. The results of this intervention are encouraging for conducting larger scale...
Table 2. Change in Scores on Adolescent and Parent Outcomes for Individual Participants

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Part. = participant number; API–P = Abdominal Pain Index, parent report; API–A = Abdominal Pain Index, adolescent report; FDI–P = Functional Disability Inventory, parent report; FDI–A = Functional Disability Inventory, adolescent report; CHIP–T = Coping Health Inventory for Parents, total score; SIPA–Inc = Stress Index for parents of adolescents, incompetence subscale; Pre = assessment period immediately prior to treatment; Post = assessment period immediately following treatment; FU = 6-month follow-up assessment. Decreases in scores indicate improvement on all measures except the CHIP.

controlled investigations. Finally, many patients live great distances from specialists and would be unable to participate in multisession, face-to-face treatments such as this one. In the future, developing methodologies for distance learning could prove to be advantageous.

9 Managed Care Considerations

Although not measured for this particular study, this intervention offers the possibility of being a cost-effective method for providing needed care to patients. It is possible that providing patients with strategies for making pain more bearable would preclude the need for some physician and ED visits, thus reducing unneeded spending for insurance providers. In addition, the group setting allows for efficiency in providing care and may prevent exacerbations of psychosocial and pain-management difficulties that may later require individual psychotherapy.

10 Follow-up

Six months following the completion of treatment, assessment packets were mailed to the participants to complete and return. Results of these evaluations are described below.
As seen in Figure 1a and b, improvement in mean scores from pre- to post-treatment continued at similar or better levels at the 6 month follow-up assessment for both parents’ and adolescents’ reports of abdominal pain and functional disability. Eight of 12 measures revealed reductions in abdominal pain from pretreatment to follow-up. Five of the six participants had at least one decrease in pain from pretreatment to follow-up, as reported by adolescents, parents, or both. As was true at post-treatment, one parent reported a score of zero at baseline for their adolescent; thus, no decreases could be found. For functional disability, 9 of 12 outcome measurements revealed decreases from pretreatment to follow-up, and five of the six adolescents showed a decrease in functional disability at this time.

Maintenance of adolescents’ gains. As seen in Figure 1a and b, improvement in mean scores from pre- to post-treatment continued at similar or better levels at the 6 month follow-up assessment for both parents’ and adolescents’ reports of abdominal pain and functional disability. Eight of 12 measures revealed reductions in abdominal pain from pretreatment to follow-up. Five of the six participants had at least one decrease in pain from pretreatment to follow-up, as reported by adolescents, parents, or both. As was true at post-treatment, one parent reported a score of zero at baseline for their adolescent; thus, no decreases could be found. For functional disability, 9 of 12 outcome measurements revealed decreases from pretreatment to follow-up, and five of the six adolescents showed a decrease in functional disability at this time.

Maintenance of parents’ progress. Figure 2a and b indicate that improvements in mean scores on parent measures at post-treatment tended to maintain during the 6 month follow-up interval. Four of the six parents indicated reductions from pretreatment to follow-up in their sense of incompetence as a parent. As noted earlier when discussing parents’ progress, one parent had extremely low pretreatment scores and no improvement was expected. Five of the six parents had increases in their use of adaptive coping from the pretreatment to follow-up.
Figure 2. (a) Mean of Parents’ Reports of Feelings of Incompetence in Parental Role. (b) Mean of Parents’ Report of Coping.

Note: SIPA Incompetence = Stress Index for Parents of Adolescents, Incompetence subscale T-score; CHIP Total = Coping Health Inventory for parents, total coping score. This measures sense of incompetence as a parent. Measures were taken at pretreatment, post-treatment, and 6 month follow-up.

For all the adolescent or parent outcome measures, pretreatment to 6 month follow-up effect sizes ranged from $r = .44$ to .62, indicating medium to large effect sizes (Cohen, 1988).

### Treatment Implications of the Case

These results lend credence to use of cognitive behavioral group interventions in pediatric patients with IBD for reducing their pain and the functional limitations that may be associated with their disease. Pain and functional disability were targeted by teaching the adolescents pain management skills, as well as skills to change their cognitions, physical tension, and other behavioral repertoires (problem solving, communication). Improvements in parents’ reports of their own coping and in their view of their competence as parents were seen as important outcomes in their own right, as well as means to augment the intervention that was provided to the adolescents. The communication and limit setting components of the intervention influence the parent–daughter relationship in a direct way. In addition, the cognitive restructuring and problem solving skills help parents to cope with the demands of parenting a child with IBD. Thus, parents were provided with additional skills to meet their own coping needs as well as to interact in a more therapeutic way with their adolescents, possibly resulting in indirect benefits for the adolescents. Parents anecdotally indicated throughout this treatment program that they were able to coach their daughters in the skills they learned.
In terms of individual responses, Participants 1, 2, and 6 responded positively to the treatment on almost all measures. Even though Participants 4 and 5 reported low initial levels of pain, functional disability, or sense of inadequacy, they also responded in the therapeutic direction on most measures. Participant 3 was less responsive to the treatment, perhaps due to biological contributions to pain and functional disability, or to psychosocial factors outside the scope of this intervention. Overall, this intervention study contributes to an important but neglected area of pediatric health care and provides promising results for future work in this area.

12 Recommendations to Clinicians and Students

The coping skills training program described in this pilot study has implications for use in other pediatric gastroenterology clinics, for boys diagnosed with IBD, and for patients who experience abdominal pain due to other conditions, such as RAP. Clinicians should consider the relationship between adolescents’ pain and functional disability, their biopsychosocial functioning, and parental influences. As noted in the case conceptualization, pain and accompanying functional disability may be increased by multiple factors in addition to disease activity. These factors include maladaptive cognitions, negative emotions, physiological stress, and unproductive behaviors. Just as difficulties in these areas might lead to more pain, more adaptive skills in these areas could lead to less pain. Teaching effective pain management skills may increase these patients’ sense of mastery when they might otherwise feel helpless when confronted with painful IBD symptoms. Although not assessed in this study, enhanced coping skills and a greater sense of mastery might lead to improvements in these patients’ quality of life and less health care utilization. Attempts should be made to equip parents to encourage their adolescents’ application of the coping skills and also to improve their own competency in meeting the challenges associated with having a child who has IBD.

Declaration of Conflicting Interests

The authors declare that they do not have any conflict of interest.

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References


**Bios**

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