

Dyadic Confirmatory Factor Analysis of the Inflammatory Bowel Disease Family Responsibility Questionnaire

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Objectives Evaluate the factor structure of youth and maternal involvement ratings on the Inflammatory Bowel Disease Family Responsibility Questionnaire, a measure of family allocation of condition management responsibilities in pediatric inflammatory bowel disease. **Methods** Participants included 251 youth aged 11–18 years with inflammatory bowel disease and their mothers. Item-level descriptive analyses, subscale internal consistency estimates, and confirmatory factor analyses of youth and maternal involvement were conducted using a dyadic data-analytic approach. **Results** Results supported the validity of 4 conceptually derived subscales including general health maintenance, social aspects, condition management tasks, and nutrition domains. Additionally, results indicated adequate support for the factor structure of a 21-item youth involvement measure and strong support for a 16-item maternal involvement measure. **Conclusions** Additional empirical support for the validity of the Inflammatory Bowel Disease Family Responsibility Questionnaire was provided. Future research to replicate current findings and to examine the measure's clinical utility is warranted.

Key words adolescents; chronic illness; family functioning; gastroenterology; inflammatory bowel disease.

Inflammatory bowel disease (IBD), consisting of Crohn's disease, ulcerative colitis, or indeterminate colitis, is a chronic immune-mediated disease of the gastrointestinal tract affecting ~71 of 100,000 youth in the United States (Kappelman et al., 2007), with documented rising rates of incidence (Malaty, Fan, Opekun, Thibodeaux, & Ferry, 2010). Estimates that 20–30% of patients have onset of IBD symptoms before the age of 18 years (Malaty et al., 2010) point to the need for family-based research to help guide treatment for youth with IBD and their families. Symptoms can include abdominal pain, diarrhea, rectal bleeding, weight loss, growth and pubertal delay, fever, fatigue, and arthritis (Mackner, Sisson, & Crandall, 2004). Managing IBD requires youth and families to navigate

complicated medication regimens, frequent medical appointments, disease symptoms, nutritional modifications or supplementation, school absences, and disease- and symptom-related questions from friends and relatives (Fishman, Barendse, Hait, Burdick, & Arnold, 2010). For pediatric patients diagnosed with chronic illnesses such as IBD that require daily attention, successful disease management depends on involvement from adult caregivers.

The multiple demands placed on youth with chronic illness and their families have led to investigations on how condition management responsibilities are allocated between youth and their caregivers. As would be expected, research has consistently demonstrated increases in youth involvement and decreases in parental involvement as

youth age (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Walders, Drotar, & Kerckmar, 2000). These shifts in allocation of responsibilities may have serious consequences for disease and developmental outcomes. On the positive side, among youth with asthma, greater youth involvement in condition management has been associated with greater general independence and disease management self-efficacy (McQuaid et al., 2001). Also, across multiple chronic condition groups, greater levels of both adolescent and parental involvement in condition management have been associated with improved adherence, health-related quality of life, and disease outcomes (Greenley, Josie, & Drotar, 2006; Modi, Marciel, Slater, Drotar, & Quittner, 2008; Wysocki & Gavin, 2006). In contrast, caregiver overestimation of adolescents' actual condition management responsibility has been shown to predict higher health care utilization, disease severity, and disease symptoms (Greenley et al., 2006). Adolescents are at particularly high risk for nonadherence to prescribed medical regimens (DiMatteo, 2004), and this could be owing to less parental involvement. Extant literature highlights the need to assess both youth and parent report of the allocation of treatment responsibility to gain an accurate assessment, identify discrepancies in perceptions, and identify potential gaps in responsibility.

Given the important outcomes associated with the allocation of condition management responsibilities, a better understanding of how families allocate responsibilities specific to IBD health care is needed. Because IBD is oftentimes diagnosed in adolescence, as opposed to early childhood when many chronic illnesses are diagnosed (Sandler & Eisen, 2000), families may experience particular difficulty in deciding how to allocate responsibilities. Although adolescence is a time of increasing responsibility, the diagnosis of a chronic illness carries unique challenges that adolescents may not be able to anticipate or manage without caregivers' guidance. To our knowledge, the only measure of family involvement in IBD management with preliminary reliability and validity data available is the Inflammatory Bowel Disease Family Responsibility Questionnaire (IBD-FRQ; Greenley, Doughty, Stephens, & Kugathasan, 2010). The IBD-FRQ includes parallel youth- and caregiver-report versions to assess the allocation of condition management responsibility. Development of the 26 items describing tasks involved in IBD management on the IBD-FRQ included: (1) review of the pediatric IBD literature and other illness-specific family involvement scales; (2) consultation with pediatric gastroenterology physicians, nurses, and psychologists; and (3) patient and parent focus groups. Preliminary analyses have provided support for the internal consistencies of total

scores measuring youth (Cronbach $\alpha = .93-.96$), maternal ($\alpha = .88-.89$), and paternal ($\alpha = .95-.96$) involvement (Please see Greenley et al., 2010 for further information on measure development and psychometric properties). Correlations across youth and parental reports of involvement were moderate to high, providing preliminary support for the validity of the measure. In addition, greater maternal involvement as measured using the IBD-FRQ has been linked to higher medication adherence (Reed-Knight, Lewis, & Blount, 2010). Similar to findings with other disease groups, greater youth age was related to higher levels of youth involvement in condition management and lower levels of maternal and paternal involvement (Greenley et al., 2010).

The current study aimed to build on existing preliminary evidence for the reliability and validity of the IBD-FRQ based on youth and maternal report of the allocation of condition management responsibility in a large multisite sample of youth with IBD. Our previous work was conducted with a relatively small sample size ($N = 58$ youth) and presented psychometric data specific to the internal consistency and validity of the IBD-FRQ total score. The factor structure of the measure was not tested previously. The current manuscript offers a confirmatory factor analysis (CFA) of the IBD-FRQ using a dyadic data-analytic approach with a large multisite sample. Specifically, we sought to evaluate the theoretically derived factor structure of the measure by conducting a CFA of both youth and maternal reports of youth and maternal involvement in IBD management. Based on the theoretical underpinnings used to develop the IBD-FRQ and the face validity of the items, we expected to find support for a model that included latent constructs representing a total score and four subscale domains measuring components of condition management responsibility: General Health Maintenance, Social Aspects of Condition Management, Condition Management Regimen Tasks, and Nutritional Aspects of Condition Management. These hypothesized subscale domains represent broad areas of condition management responsibility for youth with IBD based on our review of pediatric IBD literature and other measures of condition management developed for different pediatric populations (Anderson et al., 1990; McQuaid et al., 2001). Moreover, the subscale domains are consistent with current conceptualizations of pediatric self-management, which posit that condition management consists of a variety of illness-specific behaviors occurring within individual, family, community, and health care system realms (Modi et al., 2012). To account for nonindependence between youth and maternal report, reports by both youth and their mothers were modeled simultaneously for analysis of youth involvement

and maternal involvement. Modeling youth and maternal reports simultaneously allowed for a more psychometrically and theoretically sound analysis of how both members of the dyad view the division of condition management responsibility (Kenny, 2011; Kenny, Kashy, & Cook, 2006).

Methods

Procedure

Data included in the current investigation were obtained from four studies conducted at three different sites. Procedures for all four studies were approved by the institutional review boards at the participating institutions, and all participants were compensated. See Table I for information about participating samples from each study, study-specific inclusion/exclusion criteria, and data collection procedures for each study.

Participants

Participants included 251 youth–mother dyads. Mean age of participating youth was 14.77 years ($SD = 2.10$ years). Slightly more males (53%; $n = 134$) than females (47%; $n = 117$) participated. The majority of participants were Caucasian (90%; $n = 227$), with fewer African American

(4%; $n = 11$), Hispanic (2%; $n = 4$), Asian (1%; $n = 2$), or youth of other ethnicities (2%; $n = 6$) participating. One participant (0.4%) did not report his/her ethnicity. The majority of youth were diagnosed with Crohn's disease (79%; $n = 198$), whereas fewer had ulcerative colitis (20%; $n = 50$) or indeterminate colitis (1%; $n = 3$). Forty-five percent of families had an annual income of <\$100,000. The majority of participating maternal caregivers were biological mothers (98%; $n = 246$).

Measures

Demographic Information

Demographic information including youth age, youth gender, youth ethnicity, maternal caregiver relationship to child, and annual family income was obtained in all studies using a questionnaire created for the given study. As different metrics were used to assess annual family income across studies, a dichotomous variable was computed to reflect income <\$100,000 annually or income \geq \$100,000 annually.

Medical Information

Type of IBD (i.e., Crohn's disease, ulcerative colitis, or indeterminate colitis) was reported by mothers. Maternal report was corroborated by medical record review.

Table I. Description of Individual Study Inclusion/Exclusion Criteria and Study Procedures for Each Subsample

Study Characteristics	Study 1	Study 2	Study 3	Study 4
Study location	Children's hospital outpatient IBD clinic in Midwest	Two children's hospital outpatient IBD clinics in Midwest	Children's hospital outpatient IBD clinic in Midwest	Private pediatric gastroenterology practice in the southeastern U.S.
N	66	37	72	76
Participant age range	11–18 years	11–18 years	11–18 years	11–18 years
Inclusion criteria	<ul style="list-style-type: none"> English speaking Medically confirmed IBD diagnosis Parent/guardian willing to participate 	<ul style="list-style-type: none"> English speaking Medically confirmed IBD diagnosis Parent/guardian willing to participate Prescribed daily oral IBD maintenance medication 	<ul style="list-style-type: none"> English speaking Medically confirmed IBD diagnosis Parent/guardian willing to participate Prescribed daily oral IBD maintenance medication 	<ul style="list-style-type: none"> English speaking Medically confirmed IBD diagnosis Parent/guardian willing to participate
Exclusion criteria	<ul style="list-style-type: none"> Developmental delay Presence of comorbid chronic medical condition requiring daily medication 	<ul style="list-style-type: none"> Developmental delay Presence of comorbid chronic medical condition requiring daily medication 	<ul style="list-style-type: none"> Developmental delay Presence of comorbid chronic medical condition requiring daily medication 	<ul style="list-style-type: none"> Developmental delay
Data collection procedure	Questionnaires completed either in-person at time of enrollment or at home and returned through mail	Questionnaires completed in-person	Questionnaires completed either in-person at time of enrollment or at home and returned through mail	Questionnaires completed in-person

IBD Family Responsibility Questionnaire

The IBD-FRQ (Greenley et al., 2010) is a 26-item measure of the extent to which family members are involved in various condition management tasks. Parallel parent- and youth-report versions exist. Respondents first indicate if there is a female caregiver, male caregiver, and/or other caregiver who assists with IBD management within the family and then specify who that caregiver is (i.e., biological mother, stepmother, etc). Subsequently, respondents rate the level of involvement of the youth and each caregiver in each condition management task using a 4-point Likert scale. Involvement ratings range from 0 (“not involved at all”) to 3 (“involved almost all of the time”), with higher scores reflecting greater perceived involvement. Total involvement scores are computed for the youth and each caregiver by averaging ratings across the 26 items. Items on the original scale were organized into four conceptually derived subscales including General Health Maintenance, Social Aspects of Condition Management, Condition Management Regimen Tasks, and Nutritional Aspects of Condition Management. In the present investigation, only youth and maternal reports of youth and maternal involvement in condition management were used, as mothers were the most common participating caregiver.

Analytic Plan

Analyses proceeded in a series of stages, following the approach of Lietz et al., (2011). First, preliminary analyses assessed scale- and item-level descriptive information. Items with high levels of missing data owing to being rated as “not applicable” by a substantial subset of the sample (i.e., >10%) were dropped at this stage. Second, internal consistency analyses were conducted to determine how well items correlated with other items on their intended scales. Reliability estimates were evaluated for total and subscale scores for mother and child reports of both mother and child involvement. Items were dropped if their deletion would result in a higher alpha.

The final stage involved testing two separate measurement models using CFA: (1) child involvement, including both child and mother reports on the four subscales; and (2) maternal involvement, including both child and mother reports on the four subscales. Each model included eight latent factors representing child reports for each scale and mother reports for each scale. As recommended for CFA with dyadic data, factor loadings for corresponding child and mother report items were constrained to be equal (Kenny et al., 2006). Covariances among the latent variables and residual (error) covariances between corresponding child- and mother-report items were estimated. Parameters were estimated with a maximum likelihood

estimator that is robust to non-normality and nonindependence of observations (MLR), equivalent to the Yuan–Bentler T2* test statistic (Muthen & Muthen, 2007). Missing data were handled with full-information maximum likelihood estimation, a method that uses all data available for each case and thus avoids biases and loss of power associated with traditional approaches to missing data (Allison, 2003; Schlomer, Bauman, & Card, 2010).

We evaluated multiple indices of overall model fit. A chi-square statistic (χ^2) reflects the difference between the observed model relationships and estimated relationships based on the specified model. A low χ^2 and nonsignificance ($p > .05$) are desirable, and a χ^2 to degrees of freedom (df) ratio of <3 is considered adequate (Bollen, 1989). A comparative fit index (CFI) and Tucker–Lewis index (TLI) of .90 or higher indicate good fit. Root mean square error of approximation (RMSEA) of <.05 is considered a close fit, and standardized root-mean-square residual (SRMR) of <.10 indicates a good fit. Current recommendations support consideration of both the χ^2 test and other indices of model fit (Barrett, 2007), as χ^2 can be overly sensitive to discrepancies between observed and expected relationships. Individual factor loadings were equivalent to standardized linear regression coefficients. Statistical significance was assessed with z -scores, and R^2 indicated the amount of variance in each latent variable explained by the model.

Results

Child Involvement Model

Descriptive Statistics

Mean, range, and standard deviation of items are presented in Tables II and III. Two items (“knowing infusion schedule” and “cleaning up after bowel accident”) were removed owing to a high proportion of missing data in child and mother reports of both child and mother involvement (i.e., 40–73% of respondents indicated these tasks were not applicable).

Internal Consistency

Internal consistencies for the subscales were >.76 for all youth and maternal involvement subscales, with three exceptions: youth and mother reports for the maternal involvement Social Aspects of Condition Management subscale (α s = .62 and .64, respectively) and maternal report for the maternal involvement General Health Maintenance subscale (α = .57). Item-to-total correlations were examined, and no items were dropped at this stage because item removal would not have improved subscale internal consistency estimates.

Table II. Descriptive Statistics for IBD-FRQ Child Involvement Items

Item	Reporter	Item description	Missing or not applicable <i>n</i> (%)	Rating of not involved at all "0" <i>n</i> (%)	Rating of a little involved "1" <i>n</i> (%)	Rating of somewhat involved "2" <i>n</i> (%)	Rating of involved almost all the time "3" <i>n</i> (%)
General health maintenance							
1	Youth	Making appointments	1 (.4%)	82 (33%)	69 (28%)	55 (22%)	44 (18%)
	Mother		3 (1%)	132 (53%)	65 (26%)	26 (10%)	25 (10%)
2 ^a	Youth	Attending appointments	1 (.4%)	25 (10%)	53 (21%)	68 (27%)	104 (41%)
	Mother		4 (2%)	54 (22%)	63 (25%)	56 (22%)	74 (30%)
3 ^a	Youth	Noticing changes in health	0 (0%)	4 (2%)	12 (5%)	41 (16%)	194 (77%)
	Mother		3 (1%)	13 (5%)	18 (7%)	49 (20%)	168 (67%)
4 ^a	Youth	Seeking medical attention when needed	3 (1%)	12 (5%)	31 (12%)	83 (33%)	122 (49%)
	Mother		4 (2%)	20 (8%)	41 (16%)	78 (31%)	108 (44%)
5 ^a	Youth	Getting prescription filled	7 (3%)	59 (24%)	55 (22%)	67 (27%)	63 (25%)
	Mother		7 (3%)	94 (38%)	59 (24%)	41 (16%)	50 (20%)
6 ^a	Youth	Talking to doctor	2 (1%)	15 (6%)	29 (11%)	84 (34%)	121 (48%)
	Mother		5 (2%)	34 (14%)	44 (18%)	73 (29%)	95 (38%)
7 ^a	Youth	Adjusting activity as needed	9 (4%)	8 (3%)	21 (8%)	48 (19%)	165 (66%)
	Mother		7 (3%)	12 (5%)	22 (9%)	57 (23%)	153 (61%)
8 ^a	Youth	Getting rest	2 (1%)	7 (3%)	21 (8%)	67 (27%)	154 (61%)
	Mother		4 (2%)	17 (7%)	28 (11%)	82 (33%)	120 (48%)
Social aspects							
9 ^a	Youth	Talking to teachers	9 (4%)	47 (19%)	56 (22%)	63 (25%)	76 (30%)
	Mother		10 (4%)	49 (20%)	62 (25%)	53 (21%)	77 (31%)
10 ^a	Youth	Talking to relatives	3 (1%)	42 (17%)	61 (24%)	62 (25%)	83 (33%)
	Mother		4 (2%)	53 (21%)	54 (22%)	65 (26%)	75 (30%)
11 ^a	Youth	Talking to friends	5 (2%)	39 (16%)	47 (19%)	42 (17%)	118 (47%)
	Mother		7 (3%)	50 (20%)	51 (20%)	48 (19%)	95 (38%)
12 ^a	Youth	Explaining absences to school	11 (4%)	27 (11%)	38 (15%)	64 (26%)	111 (44%)
	Mother		16 (6%)	51 (20%)	40 (16%)	69 (28%)	75 (30%)
Condition management regimen							
13 ^a	Youth	Remembering when daily medication to be taken	5 (2%)	6 (2%)	9 (4%)	42 (17%)	189 (75%)
	Mother		5 (2%)	10 (4%)	14 (6%)	44 (18%)	178 (71%)
14 ^a	Youth	Administering daily medication	12 (5%)	3 (1%)	16 (6%)	38 (15%)	182 (73%)
	Mother		12 (5%)	10 (5%)	15 (6%)	36 (14%)	178 (71%)
15 ^a	Youth	Getting medication when away from home	10 (4%)	4 (2%)	19 (8%)	64 (26%)	154 (61%)
	Mother		11 (4%)	19 (8%)	35 (14%)	48 (19%)	138 (55%)
16 ^a	Youth	Taking as needed medication	22 (9%)	11 (4%)	24 (10%)	49 (20%)	145 (58%)
	Mother		26 (10%)	17 (7%)	17 (7%)	63 (25%)	128 (51%)
17 ^a	Youth	Knowing medication names/doses	3 (1%)	22 (9%)	19 (8%)	78 (31%)	129 (51%)
	Mother		2 (1%)	16 (6%)	30 (12%)	77 (31%)	126 (50%)
18	Youth	Knowing medication side effects	3 (1%)	31 (12%)	39 (16%)	71 (28%)	107 (43%)
	Mother		4 (2%)	29 (11%)	61 (24%)	85 (34%)	73 (29%)
19	Youth	Using thermometer to check for fever	17 (7%)	36 (14%)	33 (13%)	53 (21%)	112 (45%)
	Mother		23 (9%)	31 (12%)	45 (18%)	54 (22%)	98 (39%)
20	Youth	Knowing infusion schedule	142 (57%)	16 (6%)	22 (9%)	28 (11%)	43 (17%)
	Mother		185 (74%)	15 (6%)	10 (4%)	18 (7%)	23 (9%)
21	Youth	Cleaning up after bowel accident	104 (41%)	35 (14%)	15 (6%)	24 (10%)	73 (29%)
	Mother		115 (46%)	18 (7%)	23 (9%)	15 (6%)	80 (32%)
Nutrition							
22 ^a	Youth	Getting adequate calories	24 (10%)	22 (9%)	34 (14%)	55 (22%)	116 (46%)
	Mother		20 (8%)	17 (7%)	22 (9%)	87 (35%)	105 (42%)
23 ^a	Youth	Getting adequate fluid intake	7 (3%)	7 (3%)	23 (9%)	66 (26%)	147 (59%)
	Mother		4 (2%)	16 (6%)	16 (6%)	74 (30%)	141 (56%)
24 ^a	Youth	Administering daily vitamin or mineral supplements	23 (9%)	19 (8%)	41 (16%)	62 (25%)	106 (42%)
	Mother		27 (11%)	20 (8%)	35 (14%)	53 (21%)	116 (46%)
25 ^a	Youth	Avoiding foods that cause discomfort during flares	20 (8%)	17 (7%)	24 (10%)	52 (21%)	138 (55%)
	Mother		26 (10%)	13 (5%)	17 (7%)	63 (25%)	132 (53%)
26 ^a	Youth	Eating a balanced diet	7 (3%)	12 (5%)	38 (15%)	83 (33%)	111 (44%)
	Mother		5 (2%)	16 (6%)	32 (13%)	89 (36%)	109 (43%)

^aDenotes item that was retained in the final 21-item scale.

Table III. Descriptive Statistics for IBD-FRQ Maternal Involvement Items

Item	Reporter	Item description	Missing or not applicable n (%)	Rating of not involved at all "0" n (%)	Rating of a little involved "1" n (%)	Rating of somewhat involved "2" n (%)	Rating of involved almost all the time "3" n (%)
General health maintenance							
1	Youth	Making appointments	0 (0%)	0 (0%)	3 (1%)	8 (3%)	240 (96%)
	Mother		2 (1%)	0 (0%)	3 (1%)	3 (1%)	243 (97%)
2	Youth	Attending appointments	0 (0%)	1 (.4%)	3 (1%)	8 (3%)	239 (95%)
	Mother		3 (1%)	1 (.4%)	1 (.4%)	3 (1%)	243 (97%)
3 ^a	Youth	Noticing changes in health	0 (0%)	2 (1%)	14 (6%)	76 (30%)	159 (63%)
	Mother		2 (1%)	2 (1%)	0 (0%)	16 (6%)	231 (92%)
4	Youth	Seeking medical attention when needed	3 (1%)	1 (.4%)	1 (.4%)	39 (16%)	207 (83%)
	Mother		4 (2%)	0 (0%)	0 (0%)	5 (2%)	243 (98%)
5	Youth	Getting prescriptions filled	9 (4%)	4 (2%)	4 (2%)	21 (8%)	213 (85%)
	Mother		5 (2%)	3 (1%)	3 (1%)	11 (4%)	229 (91%)
6	Youth	Talking to doctor	1 (.4%)	1 (.4%)	5 (2%)	23 (9%)	221 (88%)
	Mother		2 (1%)	2 (1%)	0 (0%)	5 (2%)	242 (96%)
7 ^a	Youth	Adjusting activity as needed	9 (4%)	14 (6%)	42 (17%)	56 (22%)	130 (52%)
	Mother		6 (2%)	3 (1%)	6 (2%)	33 (13%)	203 (83%)
8 ^a	Youth	Getting rest	2 (1%)	13 (5%)	25 (10%)	62 (25%)	149 (59%)
	Mother		4 (2%)	2 (1%)	6 (2%)	33 (13%)	206 (82%)
Social aspects							
9 ^a	Youth	Talking to teachers	9 (4%)	25 (10%)	34 (14%)	41 (16%)	142 (57%)
	Mother		9 (4%)	7 (3%)	13 (5%)	20 (8%)	202 (81%)
10 ^a	Youth	Talking to relatives	3 (1%)	4 (2%)	18 (7%)	53 (21%)	173 (69%)
	Mother		3 (1%)	1 (.4%)	8 (3%)	24 (10%)	215 (86%)
11 ^a	Youth	Talking to friends	5 (2%)	97 (39%)	52 (21%)	49 (20%)	48 (19%)
	Mother		6 (2%)	13 (5%)	23 (9%)	50 (20%)	159 (63%)
12 ^a	Youth	Explaining absences to school	11 (4%)	11 (4%)	16 (6%)	33 (13%)	180 (72%)
	Mother		15 (6%)	3 (1%)	4 (2%)	6 (2%)	222 (88%)
Condition management regimen							
13 ^a	Youth	Remembering when daily medication to be taken	5 (2%)	13 (5%)	33 (13%)	41 (16%)	159 (69%)
	Mother		4 (2%)	5 (2%)	22 (9%)	34 (14%)	186 (74%)
14 ^a	Youth	Administration of daily medication	12 (5%)	14 (6%)	27 (11%)	37 (15%)	161 (64%)
	Mother		11 (4%)	6 (2%)	18 (7%)	39 (16%)	177 (71%)
15 ^a	Youth	Getting medication when away from home	10 (4%)	6 (3%)	13 (5%)	39 (16%)	183 (73%)
	Mother		10 (4%)	2 (1%)	9 (4%)	21 (8%)	209 (83%)
16 ^a	Youth	Taking as needed medication	22 (9%)	12 (5%)	27 (11%)	60 (24%)	130 (52%)
	Mother		27 (11%)	1 (.4%)	7 (3%)	28 (11%)	188 (75%)
17	Youth	Knowing medication names/doses	3 (1%)	2 (1%)	12 (5%)	31 (12%)	203 (81%)
	Mother		2 (1%)	2 (1%)	1 (.4%)	16 (6%)	230 (92%)
18	Youth	Knowing medication side effects	3 (1%)	4 (2%)	16 (6%)	45 (18%)	183 (73%)
	Mother		3 (1%)	2 (1%)	5 (2%)	20 (8%)	221 (88%)
19	Youth	Using thermometer to check for fever	17 (7%)	14 (6%)	29 (12%)	45 (18%)	146 (58%)
	Mother		23 (9%)	5 (2%)	8 (3%)	27 (11%)	188 (75%)
20	Youth	Knowing infusion schedule	142 (57%)	11 (4%)	3 (1%)	8 (3%)	87 (35%)
	Mother		185 (74%)	4 (2%)	0 (0%)	0 (0%)	62 (25%)
21	Youth	Cleaning up after bowel accident	103 (41%)	42 (17%)	15 (6%)	18 (7%)	73 (29%)
	Mother		115 (46%)	19 (8%)	19 (8%)	12 (5%)	85 (34%)
Nutrition							
22 ^a	Youth	Getting adequate calories	23 (9%)	32 (13%)	32 (13%)	55 (22%)	109 (43%)
	Mother		19 (8%)	6 (2%)	7 (3%)	41 (16%)	178 (71%)
23 ^a	Youth	Getting adequate fluid intake	7 (3%)	26 (10%)	44 (18%)	63 (25%)	111 (44%)
	Mother		4 (2%)	10 (4%)	19 (8%)	72 (29%)	146 (58%)
24 ^a	Youth	Administering daily vitamin or mineral supplements	23 (9%)	14 (6%)	31 (12%)	53 (21%)	130 (52%)
	Mother		27 (11%)	5 (2%)	15 (6%)	40 (16%)	164 (65%)
25 ^a	Youth	Avoiding foods that cause discomfort during flares	21 (8%)	17 (7%)	26 (10%)	59 (24%)	128 (51%)
	Mother		26 (10%)	4 (2%)	15 (6%)	40 (16%)	167 (67%)
26 ^a	Youth	Eating a balanced diet	7 (3%)	9 (4%)	23 (9%)	64 (26%)	148 (59%)
	Mother		4 (2%)	2 (1%)	6 (2.4%)	51 (20%)	188 (75%)

^aDenotes item that was retained in the final 16-item scale.

Confirmatory Factor Analysis

The child involvement model was examined first. For the initial 24-item model, fit indices overall diverged slightly from desirable levels ($\chi^2 = 1,892.24$, $df = 1,063$, $p < .05$; CFI = .84; TLI = .83; RMSEA = .06; SRMR = .09). Additionally, factor loadings for two items were $< .40$ (“making appointments” and “using thermometer to check for fever”), and thus both child and mother reports of these items were dropped. In the trimmed 22-item model, an additional variable loaded at $< .40$ (“knowing medication side effects”), and child and mother reports on this item were also dropped from the model. The resulting 21-item model provided an adequate, although not ideal, fit ($\chi^2 = 1,378$, $df = 802$, $p < .05$; CFI = .87; TLI = .86; RMSEA = .05; SRMR = .08), and all factors loadings were within the acceptable range. Allowing all factors loadings to be estimated (rather than constraining child and mother report items to be equal) did not improve model fit ($\chi^2 = 1,321$, $df = 785$, $p < .05$; CFI = .88; TLI = .87; RMSEA = .05; SRMR = .08). Given that a number of items cross-correlated with other subscales, we tested an alternate model with two latent variables representing total scores for mother and child reports, without the subscale factors. However, fit was less strong for this model ($\chi^2 = 1,892.24$, $df = 1,063$, $p < .05$; CFI = .84; TLI = .83; RMSEA = .06; SRMR = .09). Thus, the model with most support for measuring child involvement is the eight-factor 21-item model (Figure 1).

For the mother involvement model, we began by testing the fit of the 21-item model supported for child involvement to evaluate parallel forms of the IBD-FRQ. This model did not provide a good fit for mother involvement ($\chi^2 = 1,413.30$, $df = 802$, $p < .05$; CFI = .79; TLI = .77; RMSEA = .06; SRMR = .09). Five additional items were eliminated from the model because of factor loadings $< .40$ (“attending appointments,” “seeking medical attention when needed,” “getting prescriptions filled,” “talking to doctor,” and “knowing medication names and doses”). It is notable that the vast majority of children and mothers (81–98%, respectively) rated mothers’ involvement on these eliminated items as “almost all the time.” As such, little variability in participant responses likely contributed to their low factor loadings. The residual variance of the latent variable for child report of the General Health Maintenance subscale was set to zero to address a negative estimated residual variance (as negative variance is not actually possible). This final model yielded a good fit to the data ($\chi^2(447) = 655.47$, $df = 447$, $p < .05$; CFI = .91; TLI = .90; RMSEA = .04; SRMR = .08). A model with freely estimated factor loadings did not improve overall fit ($\chi^2 = 647.91$, $df = 435$, $p < .05$; CFI = .91; TLI = .89;

RMSEA = .04; SRMR = .07). Fit indices were not as strong for an alternate two-factor model representing only the total scores for child and mother reports ($\chi^2 = 1,903.68$, $df = 1,063$, $p < .05$; CFI = .74; TLI = .73; RMSEA = .06; SRMR = .09). Similar to findings for child involvement, the eight-factor model provided the strongest fit, but a smaller set of 16 items was supported for measuring maternal involvement (Figure 2).

Discussion

Patterns of family involvement in disease management have been established as important influences on youth’s health-related outcomes (e.g., disease symptoms, health care utilization), adherence, and psychosocial adjustment (e.g., health-related quality of life, general independence, self-efficacy) in various pediatric illness groups (Greenley et al., 2006; McQuaid et al., 2001; Modi et al., 2008; Wysocki & Gavin, 2006). However, the role of different family patterns of allocating condition management responsibilities in promoting adaptive disease and psychosocial adjustment in pediatric IBD has not been well studied. In particular, as IBD is a condition that is often diagnosed during adolescence, attention to how families allocate condition management responsibilities may be particularly relevant for this group of youth. Developmental shifts during adolescence lead to greater youth autonomy and reduced parent involvement in nondisease management domains (Holmbeck, 2002). However, these normative developmental changes may be at odds with the patterns of youth and caregiver involvement that are optimal for youth disease functioning (i.e., high levels of both youth and caregiver involvement). As such, families of youth with IBD may face unique challenges in effectively allocating condition management responsibilities during adolescence.

One barrier to studying condition management allocation in pediatric IBD has been the lack of a validated measure to assess this construct. In 2010, Greenley and colleagues provided preliminary psychometric data to support the reliability of the IBD-FRQ as a disease-specific measure of parent and youth involvement in managing pediatric IBD. Although informative, this study was only the first step in the measure’s validation, and the authors called for additional research on the psychometric characteristics to build the evidence base for this instrument. The current study sought to expand the findings of (Greenley et al., 2010) by systematically examining the factor structure of youth and maternal report forms of the IBD-FRQ, using a novel approach to data analysis that took advantage of the dyadic nature of the data (Kenny 2011; Kenny et al., 2006).

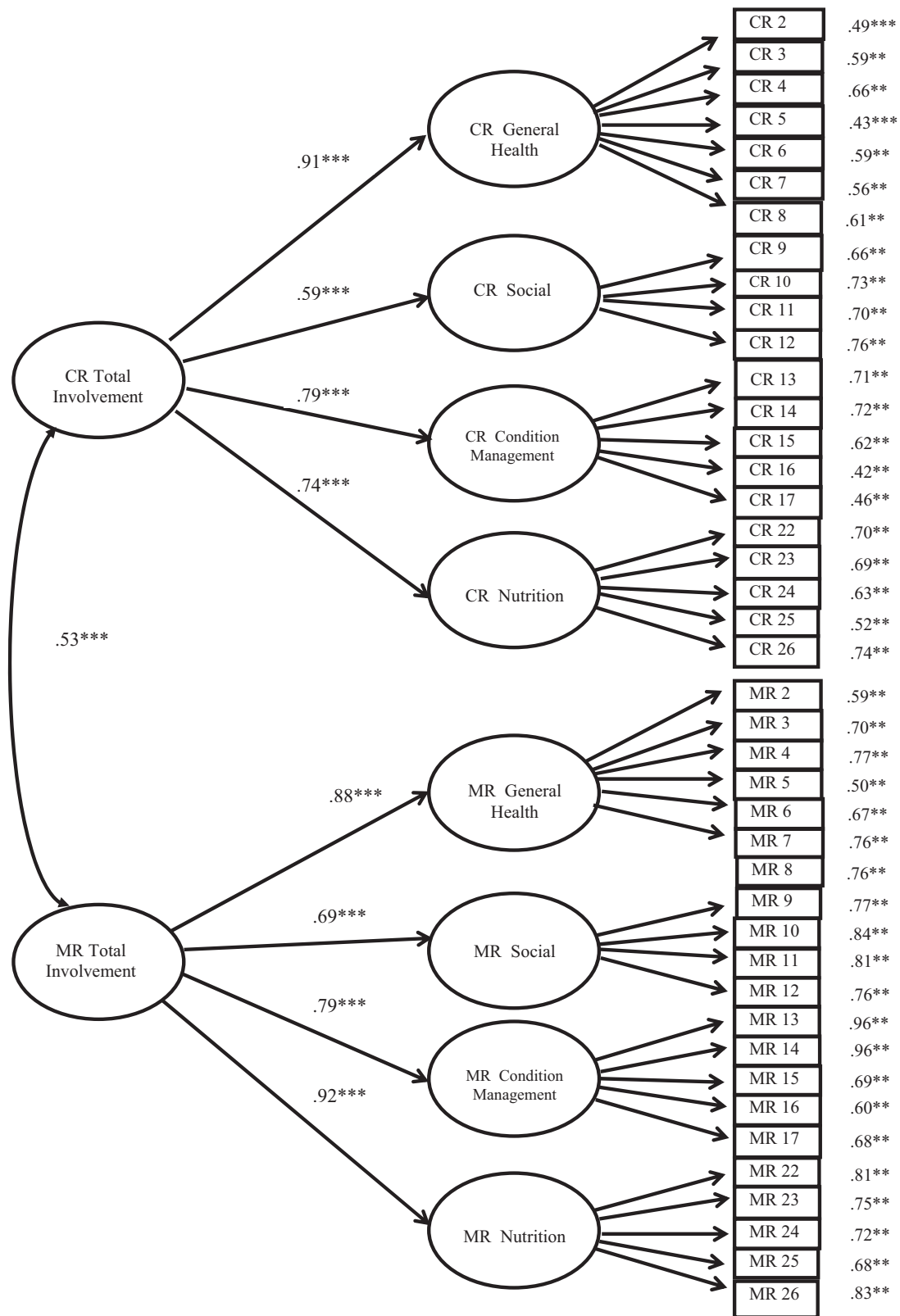


Figure 1. Dyadic confirmatory factor analysis final model for child involvement with factor loadings. Ovals represent latent constructs, and rectangles represent measured variables. Straight lines with arrows represent factor loadings, and the curved line with double arrows reflects covariance. Values for the loadings of measured variables on subscales are reported to the right of the measured variables, and values for the loadings of subscales on total scales are reported above the lines. Covariances between each of child-report subscales and the corresponding mother-report subscales were included in the model but are not reported in the figure. CR = child report. MR = mother report.

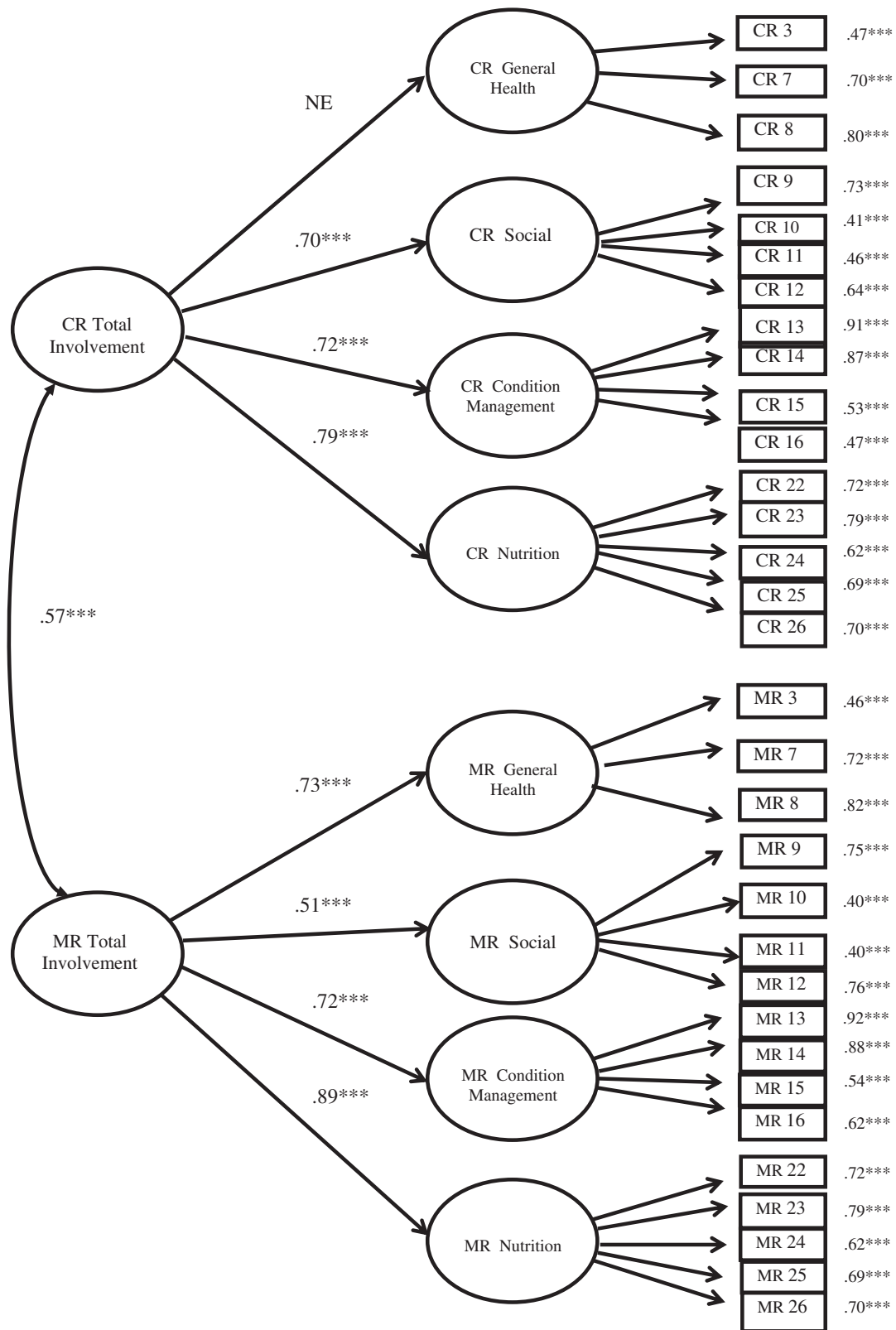


Figure 2. Dyadic confirmatory factor analysis final model for maternal involvement with factor loadings. Ovals represent latent constructs, and rectangles represent measured variables. Straight lines with arrows represent factor loadings, and the curved line with double arrows reflects covariance. Values for the loadings of measured variables on subscales are reported to the right of the measured variables, and values for the loadings of subscales on total scales are reported above the lines. Covariances between each of child-report subscales and the corresponding mother-report subscales were included in the model but are not reported in the figure. NE = factor loading was not estimated because the variance of the subscale construct was fixed at zero owing to a negative estimated variance. CR = child report. MR = mother report.

Findings of the current study provide additional support for the utility of the youth- and maternal-report forms of the IBD-FRQ in several ways. First, current findings extend those of (Greenley et al., 2010) in establishing support for the validity of four conceptually derived subscales. Specifically, CFA supported General Health Maintenance, Social Aspects of Condition Management, Condition Management Regimen Tasks, and Nutritional Aspects of Condition Management subscales across both youth and maternal involvement domains. These domains are similar to those that have been documented as relevant in assessing condition management responsibilities in other pediatric chronic illness groups. For example, measure of responsibility allocation in pediatric diabetes and pediatric cystic fibrosis includes subscales assessing general health maintenance, regimen tasks, and social aspects of condition management (Anderson et al., 1990; Drotar & Ievers, 1994). However, the specific items that loaded on each of these subscales varied depending on whether youth or maternal involvement models were evaluated. Second, findings corroborate the (Greenley et al., 2010) conceptualization of condition management allocation, as CFA results support the overall youth and maternal involvement latent constructs.

Results of the preliminary item-level analyses elucidated several items that were not highly relevant to a large sample of youth with IBD, thus providing an empirical basis for measure refinement through the elimination of low-frequency items. Thus, current analyses suggest that revised scales with 21 items to assess youth involvement and 16 items to assess maternal involvement are more parsimonious than the original 26-item scale. The reduced set of items for maternal involvement reflects the finding that almost all mothers were highly involved in certain disease management activities. Although these activities represent critical aspects of condition management (“attending appointments,” “seeking medical attention when needed,” “getting prescriptions filled,” “talking to doctor,” and “knowing medication names and doses”), it may be that evaluating mother involvement in these areas is not as useful for identifying relative strengths and weaknesses in family involvement. On the other hand, families in which parents are not highly involved in these activities could be at higher risk. Moreover, our sample consisted of primarily Caucasian middle to upper middle class families. Thus, it is possible that maternal involvement in the aforementioned domains may be more variable in families from lower socioeconomic backgrounds, who have fewer resources and experience more stress than those families represented here.

Despite the contributions of the present study with respect to item refinement and factor structure analysis of the IBD-FRQ, as outlined by Holmbeck & Devine (2009), measure development is a multiphase process. Thus, additional research on this measure is needed to replicate and extend the current findings. First, as the fit of the child involvement model was adequate but not ideal, cross-validation of this model in another sample would be of value. In addition, future research that focuses on the convergent and discriminant validity of the IBD-FRQ would be of benefit. In addition, evaluation of the clinical utility of the measure, especially with respect to identifying youth who are at risk for negative disease, adherence, and psychosocial outcomes is needed.

Several limitations of the current study exist, each of which has the potential to be addressed in future research. First, this study focused on youth and maternal reports only and did not examine paternal involvement or include paternal reports of youth and maternal involvement. As many families rely on paternal or other supplemental caregivers in condition management, attention to involvement of these family members in future research may be beneficial. Second, the sample used in the present investigation, although large and obtained from two different geographic regions in the United States, was limited with respect to sociodemographic diversity. Thus, future research examining the psychometric characteristics and factor structure of the IBD-FRQ in more culturally, racially, and economically diverse groups would be of value.

Psychometrically sound and developmentally appropriate methods are needed to assess allocation of condition management responsibilities in families affected by pediatric IBD. Availability of such measures is critical to understanding the role of family dynamics in influencing disease and psychosocial outcomes. To this end, the current findings improve our ability to assess maternal and youth involvement in IBD condition management by providing empirical support for the factor structure of the IBD-FRQ youth- and maternal-report forms.

Furthermore, use of the IBD-FRQ to understand patterns of youth–parent allocation of IBD management responsibilities in General Health Maintenance, Social Aspects of Condition Management, Condition Management Regimen Tasks, and Nutritional Aspects of Condition Management domains may aid in the development of family-based interventions and the provision of targeted clinical care. Availability of well-validated multi-informant assessment instruments is essential to delivering evidence-based treatments with youth (Kazdin and Weisz, 2003). Our results support evaluation of specific domains of condition management to determine families’

unique treatment needs. Rather than broadly addressing disease management or regimen adherence, this measure could be used to develop an individualized treatment plan that targets the specific domains in most need of intervention. For example, use of the IBD-FRQ would allow for identification of tasks for which no one is taking primary responsibility, patterns of developmentally inappropriate allocation of responsibility, and areas in which parents incorrectly believe that adolescents are assuming responsibility. In summary, findings from this study support the use of this new measure to assess allocation of IBD management activities within families and thus provide a tool that can potentially benefit research and clinical intervention in this area.

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