Brief Report: Development of the Inflammatory Bowel Disease Family Responsibility Questionnaire

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Objective To present psychometric data on youth and parent versions of the Inflammatory Bowel Disease-Family Responsibility Questionnaire (IBD-FRQ), a measure of family involvement in IBD management.

Methods Fifty-eight adolescents with inflammatory bowel disease (IBD), along with 55 mothers and 26 fathers completed the IBD-FRQ, a demographics questionnaire, and a measure of family involvement in decision making in non-IBD domains. Medical information was obtained via chart review. Results Support for the internal consistency of the IBD-FRQ was obtained. Evidence of validity was documented via moderate to high intercorrelations among reporters. Youth involvement increased with youth age, while maternal and paternal involvement decreased with youth age. Across all reporters, maternal involvement was higher than paternal involvement. Conclusions Preliminary analyses offer support for the measure’s reliability and validity. The measure shows promise as a means of assessing family involvement in IBD condition management; however, further validation studies are needed.

Key words chronic illness; family functioning; gastroenterology; inflammatory bowel disease.
involvement in condition management has been associated with better adherence and disease control (Greenley, Josie, & Drotar, 2006; Wysocki & Gavin, 2006). In contrast, low levels of family involvement or caregiver overestimation of adolescent involvement predict poorer adherence, worse disease control, greater healthcare utilization, and problematic family functioning (Greenley et al., 2006; Walders et al., 2000).

Assessment of family involvement in condition management is critical in pediatric IBD. Since most research has focused on examining this process in conditions diagnosed before adolescence, the extent to which these findings generalize to IBD, which is often diagnosed during adolescence, is unknown. Additionally, youth with IBD are at risk for impairments in individual and family functioning (Mackner, Sisson, & Crandall, 2004). Such impairments may interfere with adaptive sharing of condition management responsibilities in pediatric IBD. In contrast, involvement in condition management may enhance youth psychosocial functioning, as has been documented with other populations (McQuaid et al., 2001; Wade et al., 1999). Given the importance of this construct, we developed a measure of family involvement in condition management, the Inflammatory Bowel Disease Family Responsibility Questionnaire (IBD-FRQ). Our aim was to document adequate internal consistency and validity of the measure. We also sought to describe levels of youth, mother, and father involvement, and to examine associations of involvement with youth age and time since diagnosis. We expected older age and greater time since diagnosis to be associated with higher youth but lower parent involvement. We also expected maternal involvement to be higher than paternal involvement, given that mothers often take on the primary role in condition management in the context of a chronic medical condition.

Method

Participants

Participants were recruited from an outpatient pediatric gastroenterology clinic at a tertiary care children’s hospital. Eligibility criteria included age 11–18 years, diagnosis of IBD, and prescribed oral IBD medication. Youth with another chronic condition requiring daily medication or a history of cognitive delay were excluded. Fifty-eight of 80 families (73%) invited to participate completed the study. Ten families declined participation and 12 consented to participate but did not return questionnaires. No differences in youth age (t(78) = .06, p = .95) or sex (χ² = 1.19, p = .28) existed between participants and nonparticipants. Participants were primarily Caucasian (n = 56, 97%) and female (n = 31, 53%), with a mean age of 15.17 years (SD = 2.21). Mean time since diagnosis was 33.47 months (SD = 24.44) and 85% had CD. Seventy percent had inactive disease, 6% had mild, 13% had moderate, and 3% had severe symptoms. Fifty-five mothers and 26 fathers participated. Caregivers were primarily Caucasian (n = 52, 95% mothers; n = 23, 89% fathers) and 88% of families were intact. Median family income was $100,000–$119,999. Fifty-four percent of parents (n = 44) held a college degree.

Procedure

This study was approved by the local Institutional Review Board. Participants were recruited during clinic appointments between June 2007 and December 2007. Upon providing consent or assent, families completed study questionnaires. Questionnaire packets were sent home for completion by secondary caregivers not in attendance.

Measures

Demographics

Parents provided information on youth and caregiver age, ethnicity, and sex, as well as caregiver marital status, education, and family income.

Medical Data

Time since diagnosis and physician global assessment of disease activity (Hyams et al., 1991) were obtained via chart review.

IBD-FRQ

The IBD-FRQ was developed in a multistep fashion. Reviews of the pediatric IBD literature and published family involvement scales developed for other populations (e.g., Diabetes Family Responsibility Questionnaire; Anderson et al., 1990; Asthma Responsibility Questionnaire; McQuaid et al., 2001) were conducted to identify 26 tasks relevant to IBD management. Next, 19 pediatric gastroenterology physicians, nurses, and psychologists reviewed the items, as did eight parents and eight youth during two separate 90-min focus groups. No additional items were generated through these efforts, and all 26 items were rated as relevant by the majority of individuals. Finally, the measure was administered to the current sample, and three items that were rated as “not applicable” by the majority of participants were eliminated.

The resulting measure consisted of 23 items and included parallel youth report (YR), maternal report (MR), and paternal report (PR) versions (see JPEPSY Online for a full list of items). For each item, respondents rated family members’ involvement on a 4-point Likert...
scale. Higher scores reflected greater involvement of the family member. Total involvement scores were computed separately for youth, female caregiver (subsequently labeled mother), male caregiver (subsequently labeled father), and an “other” family member specified by the respondent (e.g., sibling or grandparent) by averaging ratings across the 23 items.

Decision-Making Questionnaire
The Decision Making Questionnaire (DMQ; Prinz, Foster, Kent, & O’Leary, 1979) is a 15-item measure of adolescent and parent decision making involvement in non-illness contexts such as completing homework, household responsibilities, and social activities. Families rate the balance of decision-making responsibility as follows: 1 = parents decide independently, 2 = parents and youth discuss but parents have final say, 3 = parents and youth discuss but youth has final say, and 4 = youth decides independently. A total score is computed by averaging ratings across all items. The DMQ evidenced adequate reliability in a previous study of youth with pediatric chronic conditions (αs = .66 to .90; Coakley, Holmbeck, & Bryant, 2006) and in the current study (αs = .85 YR, .88 MR, .91 PR).

Analysis Plan
Internal consistency reliabilities were calculated for youth, maternal, and paternal involvement scores. Validity analyses examined intercorrelations among YR, MR, and PR on the IBD-FRQ, and correlations between IBD-FRQ total scores and DMQ total scores. Descriptive analyses summarized levels of family involvement, correlations tested associations between family involvement and youth age and time since diagnosis, and paired t-tests examined differences in maternal and paternal involvement. Bonferroni corrections were used for t-test analyses (n = 3), resulting in a p-value of 0.0167 (.05/3) denoting significance.

Results
Psychometric Properties of the IBD-FRQ
Internal Consistency
IBD-FRQ total scores for YR, MR, and PR forms demonstrated high internal consistency as evidenced by αs > .80 in all domains (Table 1).

Convergent Validity
YR IBD-FRQ youth involvement scores were significantly correlated with both MR and PR youth involvement scores (rs = .72, .66; ps < .001, respectively). MR and PR of youth involvement were also highly correlated (r = .87, p < .001). YR maternal involvement ratings were correlated with both MR and PR maternal involvement ratings (rs = .50, .43; ps < .001, = .03, respectively). Similarly, MR and PR of maternal involvement were highly correlated (r = .90, p < .001). Finally, YR of paternal involvement was significantly correlated with both MR and PR of paternal involvement (rs = .81, .72; ps < .001, respectively). MR and PR of paternal involvement were also correlated (r = .79, p < .001).

Correlations between IBD-FRQ involvement scores and DMQ involvement scores were also examined. Contrary to prediction, YR IBD-FRQ youth involvement scores and YR DMQ scores were not significantly correlated (r = .15, p = .26). In contrast, MR IBD-FRQ maternal involvement and MR DMQ scores (r = −.43, p < .001) were significantly correlated. Finally, PR IBD-FRQ paternal involvement scores and PR DMQ scores were significantly correlated (r = −.39, p = .05). As expected, greater parental involvement in IBD management was associated with greater parental involvement in decision making in non-IBD-related domains.

Involvement of Family Members
Total maternal involvement was significantly higher than total paternal involvement [MR: t(51) = 10.84, p < .001; PR: t(25) = 5.41, p < .001, and YR: t(55) = 9.10, p < .001].

Associations between Family Involvement and Youth Age and Time since Diagnosis
As predicted, older youth age was associated with greater youth involvement in IBD management in all analyses and negatively associated with both maternal and paternal involvement.
involvement in four of six analyses (Table II). Contrary to prediction, time since diagnosis was not associated with youth involvement or maternal involvement based on YR or PR. Time since diagnosis was moderately and positively correlated with maternal involvement based on MR, but negatively associated with YR and MR of paternal involvement. No relationships between family involvement and youth sex, family income, or disease activity were documented.

### Discussion

Findings provide preliminary support for the internal consistency and validity of the IBD-FRQ. Internal consistency reliabilities were high across all reporters. Intercorrelations among reporters concerning youth, maternal, and paternal involvement were also high. Finally, correlations between maternal and paternal involvement on the IBD-FRQ and maternal and paternal involvement in decision making in non-IBD-related domains were significant.

In addition to documenting preliminary support for the psychometric properties of the IBD-FRQ, findings revealed that developmental differences in family involvement are present in the context of pediatric IBD. Consistent with developmental theory and data from other pediatric conditions (Anderson et al., 1990; Wade et al., 1999), positive associations between youth age and youth involvement in condition management were documented. Although one might expect youth involvement in condition management to increase as a function of time since diagnosis, our findings did not support this hypothesis. It may be that youth involvement in their IBD management is more a function of normative developmental processes (i.e., age-related increases in levels of autonomy) than some disease-specific process.

Our findings also suggested maternal and paternal involvement decrease as a function of youth age. Although time since diagnosis did not consistently relate to levels of maternal involvement, paternal involvement (based on MR and YR) decreased as a function of time since diagnosis. The lack of association between PR of their own involvement and youth age or time since diagnosis was likely due to the small sample of fathers (Type 2 error). It appears as though different processes may contribute to maternal versus paternal changes in levels of involvement in this population. Paternal involvement seems to be influenced both by youth age and length of diagnosis, whereas maternal involvement is influenced solely by youth age. Additionally, as has been documented in past research (Wysocki & Gavin, 2004), maternal involvement was higher than paternal involvement across all reporters. However, examining the “quantity” of involvement provides insight into only one aspect of family responsibility allocation. As illustrated by Wysocki & Gavin (2004), the “quality” of the involvement (e.g., perceived helpfulness) may be another important consideration when examining the roles of mothers and fathers. Future research to document the domains in which fathers are most involved and how these compare to the activities in which mothers are most involved would be of value. Additional research on youth perceptions of the helpfulness of maternal and paternal involvement is also an important next step. Given differences in levels of maternal and paternal involvement and different correlates of maternal versus paternal involvement, our findings underscore the importance of examining mothers and fathers separately (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005).

Results should be interpreted within the context of several limitations. First, this study utilized a small cross-sectional sample which precluded the use of factor analysis or examination of test–retest reliability. Research with larger longitudinal samples is an important next step in the validation of the IBD-FRQ. Second, our sample was primarily Caucasian, well educated, and of high socioeconomic status (SES). Although participants were representative of the clinic population, future studies should employ purposive sampling to recruit larger numbers of ethnic minority and socioeconomically disadvantaged families. This is particularly important given that patterns of family involvement may vary as a function of these factors. Third, given that our findings documented differences in maternal and paternal levels of involvement; future research should incorporate larger samples of

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*p < .05, **p < .01, ***p < .001
fathers to better understand their unique role. Finally, future research should examine how patterns of family involvement in condition management relate to adherence, as documentation of such relationships would enhance the measure’s validity and clinical utility.

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Conflicts of interest: None declared.

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References


Hait, E., Arnold, J., & Fishman, L. (2006). Educate, communicate, anticipate—practical recommendations for transitioning adolescents with IBD to adult health care. Inflammatory Bowel Disease, 12, 70–73.


