

Partner Burden in Irritable Bowel Syndrome

REUBEN K. WONG,^{*,†} DOUGLAS A. DROSSMAN,^{*} STEPHAN R. WEINLAND,^{*} CAROLYN B. MORRIS,^{*} JANE LESERMAN,^{*} YUMING HU,^{*} RENUKA KELAPURE,^{*} and SHRIKANT I. BANGDIWALA^{*,§}

^{*}Center for Functional GI and Motility Disorders, and [§]Department of Biostatistics, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina; and [†]Department of Gastroenterology and Hepatology, University Medical Cluster, National University Health System, Singapore

See editorial on page 156.

BACKGROUND & AIMS: Studies have described the burden experienced by caregivers and next of kin to patients with diseases such as cancer. However, the burden of functional gastrointestinal disorders on partners of patients has not been determined. We aimed to quantify the degree of burden to partners of patients with irritable bowel syndrome (IBS), to describe the factors that affect the burden perceived, and to identify the areas of relationship that are affected. **METHODS:** We surveyed 152 patients diagnosed with IBS at a tertiary gastrointestinal clinic, on the basis of Rome III criteria, and their partners. Their partners completed questionnaires including the Zarit Burden Interview (ZBI), Relationship Satisfaction Scale, and questions on sexual relationships. Patients with IBS were rated for disease severity by using the Functional Bowel Disease Severity Index. We compared findings with those from 39 partners of healthy individuals (controls). **RESULTS:** There were no significant demographic differences between the partners of patients with IBS and controls; demographics had no effect on burden. Burden was significantly higher among partners of IBS patients (mean ZBI score, 22.1) than controls (mean ZBI score, 11.5) ($P = .0002$). The degree of burden was directly related to IBS severity ($P < .0001$). There were inverse relationships between partners' rating of burden (ZBI) and relationship quality ($R = -0.60$; $P < .001$) and sexual satisfaction ($R = -0.56$; $P < .0001$). There was no difference in the Relationship Satisfaction Scale scores (4.25 vs 4.19; $P = .78$) or sexual relationship (6.47 vs 6.21; $P = .64$) between partners of IBS patients and controls, respectively. **CONCLUSIONS: Partners of patients with IBS have a significant burden (on the basis of ZBI score), compared with partners of healthy individuals. Perceived burden increases with IBS severity and poorer sexual and relationship satisfaction.**

Keywords: FBDSI; Psychology; Spouse; Chronic Illness.

The concept of caregiver burden has been well recognized for many years. Initial studies in the cognitively impaired elderly established not only a physical and economic strain but also suggested an emotional burden in their caregivers.¹ Subsequent studies done in dementia and other chronic illness such as rheumatoid arthritis and, more recently, fibromyalgia have reaffirmed the concept of caregiver burden.²⁻⁴

Clinical experience and feedback from patients suggest that the symptoms experienced from irritable bowel syndrome (IBS) affect their social life and daily functioning and hence have a sizable impact on their partners or next of kin, that is, whom ever the individual relies on with respect to IBS. There are

multiple studies looking at the socioeconomic and psychological burden of IBS on patients themselves, but none have addressed the burden on partners of IBS patients.⁵⁻⁷

Partner burden in IBS may have similarities to other chronic illnesses of organic origin. However, because it is a functional gastrointestinal (GI) disorder with no structural disease elements, it may be difficult to consider the degree of burden or to recognize its validity for the partner. For the patient with demonstrable organic diseases such as cancer or Crohn's disease, the burden seems more obvious. From our experience, we propose that there will be similar effects in the partners of IBS patients as in partners of patients with structural disease. However, because of varying attitudes relating to the legitimacy of the functional GI disorders, it may be necessary to also consider caregiver attitudes toward IBS in addition to the patient-caregiver relationship.

The aims of our study were 3-fold. The first aim was to quantify the burden experienced by the partners of IBS patients by using a validated measure. The primary aim would be to describe the degree of burden in the partners of IBS patients of varying severity. We used the Zarit Burden Interview (ZBI), an established instrument developed by Steven H. Zarit in 1983, which allows us to quantify caregiver burden and distress.¹ Reviewing current studies, Ankri et al⁸ used the ZBI in reviewing burden among caregivers of dementia patients and described a mean score of 32.9. In a study on the caregivers of terminal cancer patients, Higginson and Gao⁹ reported a score of 18.5. By using these data, we will also compare the scores from caregivers of IBS patients with those from caregivers of patients with other conditions.

For the second aim we evaluated the factors that affected the degree of caregiver burden, including whether there is a direct correlation between IBS disease severity and the degree of burden. We also studied whether there is an association between partner and relationship characteristics and the degree of burden reported by using a 7-point relationship scale (RS).¹⁰ In doing so, we sought to describe how burden relates to the relationship both as perceived by the partner as well as by the patient. Finally, we looked at any difference in the RS between the patient vs partner and how a significant difference might potentially correlate with a poor burden score or sexual relationship indexes.

Abbreviations used in this paper: FBDSI, Functional Bowel Disease Severity Index; GI, gastrointestinal; IBS, irritable bowel syndrome; RS, Relationship Scale; UNC, University of North Carolina; ZBI, Zarit Burden Interview.

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The third aim was to explore the potential effects of IBS on the physical relationship. In the case where there exists a conjugal relationship, we explored the impact the patient's IBS symptoms have had on sexual life, including sexual satisfaction in the light of the partner's IBS, perception of how the patient uses his/her IBS symptoms to avoid sex, and any change in the frequency of sex.

Methods

Study Population

This cross-sectional, case-control study was conducted between 2008 and 2010 at the University of North Carolina (UNC), Chapel Hill. Patients who fulfilled the Rome III criteria for IBS and had a "partner" were invited to participate. The definition of "partner" in the context of this study would be a live-in significant other, usually a spouse or partner who spent significant amounts of time with the subject.

Patients were identified through the functional gastroenterology clinic at UNC, and if they were agreeable, their partners were also contacted to establish their interest in participating in the study. Healthy individuals and their partners with no functional GI diseases were recruited through campus advertisements and served as a control group.

Ethics Approval

The study was approved by the Institutional Review Boards for the protection of Human Subjects at UNC Chapel Hill, North Carolina. Subjects were required to sign informed consent and allow their partners to be contacted by the study team. Partners who agreed to participate were also required to provide informed, signed consent. The responses of the patients and partners were kept strictly confidential, and because of the sensitive nature of the questions, they were specifically instructed not to share their answers with one another. Questionnaires were kept anonymous, and respondents were identified by a study code. Data were stored on a secure password-protected database.

Survey Methodology Questionnaires

The study was a 2-step process, with both the patients (or controls) and their partners being surveyed. IBS patients were required to fill out a 3-paged paper survey form that collected data on their (1) demographics, (2) the IBS module of the Rome III criteria, (3) Functional Bowel Disease Severity Index (FBDSI), and (4) Relationship Scale The Rome III module was used to ensure that patients fulfilled the diagnostic criteria for IBS, and those who did not meet the criteria were excluded from the study.¹¹ The FBDSI is a 5-question instrument that scores the severity of the patient's IBS, allowing us to categorize them into 3 categories of mild, moderate and severe.¹² Finally, respondents were also required to complete the RS; this is a validated 7-question instrument that quantifies the strength of the relationship as perceived by the respondents.¹⁰

The second part of the survey involved the partners of the respondents. They had to complete a questionnaire that consisted of the following components: (1) demographics, (2) RS, (3) ZBI, (4) questions on sexual relations, and (5) attitudes and beliefs about IBS. The ZBI is an instrument used to quantify burden. It consists of 22 questions probing 5 aspects that would contribute to an overall burden score and has been

validated and used in multiple studies.¹ The questions on sexual relations consist of 5 questions that represent areas we believed would be most affected by IBS. Included were questions such as "Do you think your partner uses IBS as a reason to avoid sex?" The final section consisted of questions that probed the perception the partner had of the patient's IBS, including fields such as "Do you think IBS is a real medical condition?" If partners were present at the clinic visit, they were asked to complete the questionnaire on-site in a paper-and-pencil format. If they were not physically present but were willing to participate, they had the option of completing the survey and sending it back by mail or via a survey monkey by using a secure log-in identification.

Healthy volunteers completed a similar questionnaire consisting of sections (1), (2), and (3). The Rome III questionnaire was used to screen out any respondents with previously undiagnosed IBS, and these individuals were excluded from the analysis. Their partners completed the full partner survey instrument.

Data Analysis

Descriptive statistics were calculated for patient-partner dyads and control-partner dyads for all demographics. Means and standard deviations were calculated for continuous variables, and frequencies were determined for categorical variables. The relationships between variables were described; if between 2 continuous variables, Pearson correlation coefficients were calculated and tested for significance, and if the relationship compared a continuous and categorical variable, means and standard deviations were calculated for each category and compared by *t* tests and analysis of variance testing. A two-tailed *P* value <.05 was considered significant. Statistical analyses used SAS software (version 9.12 for Windows; SAS Inc, Cary, NC).

Results

A total of 152 IBS subjects and their partners were surveyed. The IBS respondents were mostly white (92.1%), with a predominance of women (77.6%), and the majority of them had been in a long-term (mean duration of 19.6 years) spousal relationship (82.9%) with their current partner. Thirty-nine healthy controls and their partners were also surveyed as the control group. There were no statistically significant differences on demographic variables between the partners of the IBS patients and the partners of the control group. A comparison of these characteristics is listed in Table 1.

Table 1. Respondent Characteristics of Partners of IBS Patients and Healthy Controls

	IBS partners	Healthy control partners
Age (y)	47.7 (15.6)	49.0 (11.6)
Sex (male) (%)	78.3	76.9
Race (white) (%)	90.1	79.5
Education/y in school	16.0 (2.8)	15.2 (2.9)
Relationship (spouse) (%)	83.3	79.5
No. of years together	19.6 (14.0)	18.8 (12.0)

NOTE. Standard deviation indicated in parentheses (in years).

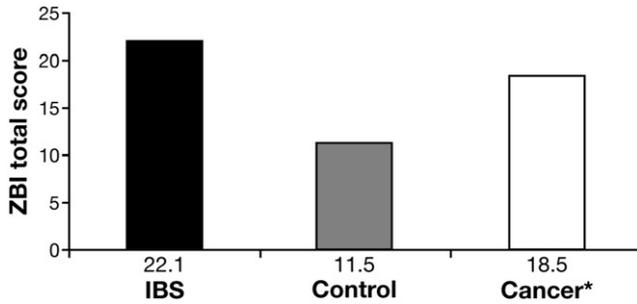


Figure 1. Partner burden for different types of patients (as measured by mean total ZBI scores). *Data from Higginson et al.⁹

Degree of Burden Experienced by Partners of Patients With Irritable Bowel Syndrome

Partners of patients with IBS reported a mean total ZBI score of 22.1 ± 15.4 , a personal strain subscale score of 11.9 ± 7.7 , and a role strain subscale score of 5.8 ± 4.9 . The partners of the control group reported an overall ZBI score of 11.5 ± 16.2 . There was a significant difference in the overall ZBI scores between the IBS partners and healthy control partners, with the former reporting markedly higher overall burden scores ($P = .0002$) (Figure 1). When subtyped by the patients' IBS phenotype, there were no appreciable differences in partner burden (mean ZBI scores: IBS with diarrhea 20.3, mixed IBS 22.0, and IBS with constipation 24.4; $P = .62$).

Correlation Between Disease Severity and Partner Burden

The severity of the patients' IBS was graded by using the FBDSI, which allowed us to classify the patients into 3 major categories of mild (score <37), moderate (score $37 \leq 110$), and severe (score ≥ 110). The subjects were uniformly spread in terms of disease severity, with 32.2% mild, 37.0% moderate, and

30.8% severe. The relationship between the ZBI score of the partner and the FBDSI of the patient was significant whether FBDSI severity was considered as a continuous variable (Pearson $r = 0.34$; $P < .001$) or as a discrete 3-category ordinal variable (mean ZBI scores for mild, 15.8; moderate, 21.5; severe, 27.8; analysis of variance, $P = .0002$). In contrast, the mean ZBI score of the partners for the healthy volunteers was 11.5, lower than the mean burden for partners of mild FBDSI patients.

Relationship Attributes and Partner Burden

Partners of IBS patients reported a mean RS score of 4.19. When we correlated the RS scores of IBS partners against the perceived burden (ZBI overall scores), there was a significant negative relationship between an increased ZBI score and a higher RS score ($r = -0.60$; $P < .001$). This suggests that the high burden in partners of patients with IBS is associated with a weaker partner relationship. Among healthy controls, a similar but markedly weaker association was found ($r = -0.31$; $P = .048$) (Figure 2). Notably, there was also no statistical difference in the RS score between IBS partners and healthy control partners (controls, 4.24 ± 0.71) (Table 2).

There was also a significant correlation between perceived burden and 2 specific relationship questions. When asked "How many problems are there in your relationship?," there was a significant association between having many problems and a worse ZBI score ($P < .001$). Similarly, when asked "How often do you wish you hadn't entered into the relationship?," there was a correlation between those who frequently entertained that thought and a worse ZBI score ($P < .001$).

Sexual Relationship Attributes and Partner Burden

A total of 146 respondents had a sexual relationship with their partners. These partners were asked to rate their satisfaction with their sexual relationship with their IBS patient on a 10-point Likert scale, returning a mean score of 6.21

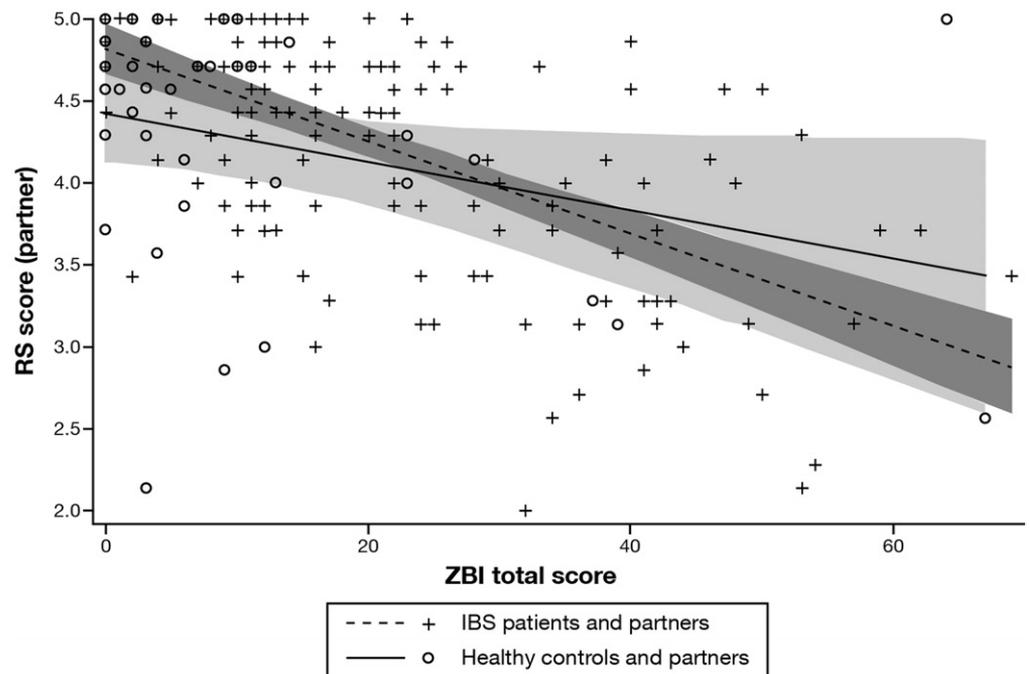


Figure 2. Linear regression plot of RS by patient burden (ZBI scores) showing partners of IBS patients and healthy controls.

Table 2. Comparisons in RS and Sexual Satisfaction Scores and Association With ZBI Scores Between Partners of IBS Patients and Partners of Healthy Controls

	Mean (SD)	Median (range)	Correlation With ZBI score
RS score			
IBS partners	4.19 (0.71)	4.43 (2–5)	$r = -0.60; P < .0001$
Healthy control partners	4.24 (0.74)	4.57 (2–5)	$r = -0.31; P = .048$
Sexual satisfaction score			
IBS partners	6.21 (2.73)	7 (1–10)	$r = -0.55; P < .0001$
Healthy control partners	6.47 (2.63)	7 (1–10)	$r = -0.28; P = .08$ (borderline)

(± 2.7). There was a negative correlation between the sexual satisfaction score and perceived burden ($r = -0.55; P < .001$). The partners of IBS patients were asked how often they perceived that IBS was interfering with their sexual relationship, and 31.3% believed that this was quite frequently or nearly always the case. There was a strong correlation ($r = 0.61; P < .0001$) between this perception and a concern that the patient was using IBS as an excuse to avoid sex. Among the control groups, their partners reported a sexual satisfaction score of 6.47 (± 2.63), with a weaker correlation score of $r = -0.28$ that was not statistically significant ($P = .08$) (Table 2).

Perceptions and Attitudes of the Partner Toward Irritable Bowel Syndrome as a Disease

Because patients with IBS may be stigmatized by others, partners were asked whether they believed IBS was a “real medical disorder,” with 88.6% responding positively (agree + strongly agree). There was a significant correlation between a positive disease perception and a willingness to attribute the patient’s symptoms and behavior to IBS ($r = 0.49; P < .001$). A similarly large proportion of partners (75.8%) agreed that the patient’s behavior and symptoms were related to their diagnosis of IBS. However, when disease burden was compared against the perception of the “realness” of IBS as a disease or their willingness to ascribe their partners’ symptoms to their diagnosis of IBS, there was no significant correlation between ZBI scores and either of these factors.

Multivariate Analysis

A multivariate logistic regression showed that the degree of burden (ZBI score) is significantly associated with the severity of IBS (as measured by the FBDSI score), the state of the relationship (RS score), the sexual relationship rating, and the perceived extent the patient’s IBS has affected the relationship. Burden increases with IBS severity, decreases with a better relationship, decreases with a better rating of the sexual relations, and increases when the partner has a greater perception that the IBS has adversely affected their relationship ($R^2 = 0.59$).

Discussion

The concept of caregiver burden articulates a recognized but often unaddressed phenomenon, where caregivers or spouses of patients also suffer as a result of the primary illness borne by the patient. Zarit et al¹ were the first to formally describe this burden in the caregivers of Alzheimer’s induced dementia patients, allowing for quantification of what was previously believed to be unmeasurable for the first time by

using the ZBI. Since then, caregiver burden has been described and documented in terminal illness such as cancer, as well as in chronic diseases such as fibromyalgia and osteoarthritis.^{2,3,5} The concept of studying caregiver burden in a GI disease is novel. Our research is also unique in the respect that burden has always been associated with organic diseases, and this study describes caregiver burden in a functional disorder. The aim would be to demonstrate in IBS, much like cancer and other chronic diseases, that the impact is not isolated to the individual alone but to the family (in this case the partner). Such care may be augmented when consideration is also given to the role of the partner and including them in decisions when the patient chooses to do so.

The overall partner burden from IBS (ZBI score 22.1) was comparable to other organic diseases such as dementia (ZBI score 32.9)⁸ and surprisingly exceeded that experienced by caregivers of terminal cancer patients (ZBI score 18.5).⁹ Possibly the lower score for caregivers of cancer patients may relate to a greater level of acceptance and support for the burden experienced by this partner than for the partner of a patient with IBS. This demonstrates that a functional disorder can pose at least comparable levels of burden on the caregivers/partners to that of organic diseases. It also validates what we anecdotally know from the spouses and partners of IBS patients; their lives are greatly affected, and quality of life is impacted. To confirm that our measurement of burden was not confounded by other factors in the patient-partner relationship, we compared the ZBI total and composite scores against an age- and gender-matched healthy control population and their partners. The partners of IBS patients had significantly higher burden scores, showing that the burden recorded was attributable to the symptoms arising from IBS. Further validating this observation was the finding that as the severity of the patient’s IBS increased, there was a corresponding significant increase in partner burden. Because the instruments used do not measure cause and effect, a possibility exists that the partner’s unhappiness or burden could have caused the patient’s IBS symptoms to worsen. We believe that the reverse causality is less likely, but this issue would need to be addressed in future studies.

We sought to identify what other factors could affect partner burden and found that the overall state of the relationship, the sexual relationship, and the perception by the partner of IBS were also significant contributors. Theoretically, the strength or weakness of the underlying relationship would have an effect on the perceived burden, but this had never been evaluated in this context. The significant correlation between a weak relationship (as measured by using the RS) and high burden indicates that the underlying strength of the relationship is inversely associated with

burden. However, a potential confounder of the association could be the presence of the illness itself; it might be argued that it is the illness that caused the burden and the deterioration in the quality of the relationship. We sought to clarify this by comparing the quality of relationships of IBS patients and the healthy controls. We found that, independent of illness, the relationship between burden (ZBI) and quality of relationship was retained for both the IBS and healthy control groups, although the slope of the curve was greater for the IBS group. This suggests that the association between the strength of the relationship and burden is not confounded by the illness, but having IBS amplifies this association. Therefore, efforts to improve the relationship could have dual effects on improving the burden as experienced by the partner.

The traditional concept of caregiver burden had hinged on assessing a caregiver who provided direct care and met the physical needs of a patient. In a functional GI disease such as IBS where there is no "caregiver" per se, our study focused on a "partner" who spends a significant amount of time with the patient, usually a spouse or a family member. In the spousal or partner relationship, there exists a conjugal dimension (96% of the respondents), and this allowed us to explore the effects that IBS was having on their sexual relations from the perspective of the spouse/partner. Although there was no significant difference in satisfaction with their sexual life between the partners of healthy controls and IBS patients, there was a significant correlation between a higher reported burden and a poorer sexual life, which was seen only in the IBS partners but not in the control group. This suggests that an unsatisfying sexual relationship could be a contributory cause to perceived burden by the spouse/partner. Probing further, nearly one-third of respondents believed that their partners' IBS symptoms frequently interfered with their sexual life, and this correlated strongly with a perception that they were using their symptoms as an excuse to avoid intercourse. This finding is important, because it highlights a possible disconnect between the reality of the patients' IBS symptoms affecting their sexual functioning and the perception that this was being misused to decline intercourse. We postulate that this could be an issue of validity, where there still exists a reluctance to fully acknowledge the impaired functioning arising from a nonorganic, functional disorder as being true.

Encouragingly, the majority of partners recognized that IBS was a bona fide medical disorder, with only 15% expressing reservations. Not unexpectedly, where there was acceptance that IBS was a "real disease," there was a greater willingness to ascribe the symptoms experienced by the patient to the disease. This underscores the importance of disease understanding and perception not only by the patient but also by their spouse, next of kin, and partner. Indeed, there have been great strides made toward patient education and empowerment but little or no efforts in ensuring the spouse or partner has a good grasp or understanding of IBS.

The traditional concept of disease burden had been centered on the patient, but our study highlights that the caregiver/spouse also experiences meaningful burden that had previously gone unrecognized. This suggests that intervention should also include the partner. Specifically, this could include recognition and supportive measures to help cope with burden and measures to address underlying contributory factors such as counseling to address any relationship issues. Education targeting the partner/spouse would also be advantageous to correct any misconception surrounding the etiopathogenesis of IBS, be-

cause this would have an effect on perceptions and acceptance of the symptoms arising from the disease.

Conclusions

This study has shown that the morbidity and burden in IBS rest not only on the patient but are also borne by the partner/spouse. The burden is mediated by factors such as the severity of the patient's IBS and strength of the underlying relationship. Where a conjugal relationship existed, partner burden had a major impact on sexual satisfaction. The ability to accept that IBS is a real disease predicted the willingness to attribute the patients' symptoms as being due to the disease.

References

- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–655.
- Jacobi CE, van den Berg B, Boshuizen HC, et al. Dimension specific burden of caregiving amongst partners of RA patients. *Rheumatology (Oxford)* 2003;42:1226–1233.
- Reich J, Olmsted EM, van Puymbroeck CM, et al. Illness uncertainty, partner caregiver burden and support and relationship satisfaction in fibromyalgia and OA patients. *Arthritis Rheum* 2006;55:86–93.
- McConaghy R, Caltabiano ML. Caring for a person with dementia: exploring relationships between perceived burden, depression, coping and well-being. *Nurs Health Sci* 2005;7:81–91.
- Drossman DA, Li Z, Andruzzi E, et al. U.S. householder survey of functional gastrointestinal disorders: prevalence, sociodemography and health impact. *Dig Dis Sci* 1993;38:1569–1580.
- Talley NJ, Gabriel SE, Harmsen WS, et al. Medical costs in community subjects with irritable bowel syndrome. *Gastroenterology* 1995;109:1736–1741.
- Whitehead WE, Burnett CK, Cook EW, et al. Impact of irritable bowel syndrome on quality of life. *Dig Dis Sci* 1996;41:2248–2253.
- Ankri J, Andrieu S, Beaufils B, et al. Beyond the global score of the ZBI: useful dimensions for clinicians. *Int J Geriatr Psychiatry* 2005;20:254–260.
- Higginson IJ, Gao W. Caregiver assessment of patients with advanced cancer: concordance with patients, effects of burden and positivity. *Health Qual Life Outcomes* 2008;6:42.
- Hendrick SS. A generic measure of relationship satisfaction. *J Marriage Fam* 1988;50:93–98.
- Drossman DA, Corazziari E, Delvaux M, et al. Rome III: the functional gastrointestinal disorders. McLean, VA: Degnon Associates, 2006.
- Drossman DA, Li Z, Toner BB, et al. Functional bowel disorders: a multicenter comparison of health status and development of illness severity index. *Dig Dis Sci* 1995;40:986–995.

Reprint requests

Address requests for reprints to: Reuben Wong, MBBS, Department of Gastroenterology & Hepatology, University Medical Cluster, National University Hospital, Level 10 NUHS Tower Block, Singapore 119228, Singapore. e-mail: reuben_wong@nuhs.edu.sg; fax: (65) 6775-1518.

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Conflicts of interest

The authors disclose no conflicts.

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