

# The Impact of Diagnostic Status on Quality of Life in Irritable Bowel Syndrome

Gillian Eleanor Cassar<sup>1</sup> , George Youssef J<sup>1,2</sup> , Simon R Knowles<sup>3,4,5,6</sup> , Richard Moulding<sup>1</sup> , David Austin<sup>1</sup> 

<sup>1</sup>School of Psychology, Deakin University, Geelong, Australia

<sup>2</sup>Centre for Adolescent Health, Murdoch Childrens Research Institute, Royal Children's Hospital, Parkville, Victoria, Australia

<sup>3</sup>Faculty Health, Arts, and Design, Department of Psychology, Swinburne University of Technology, Melbourne, Australia

<sup>4</sup>Department of Medicine, University of Melbourne, Melbourne, Australia

<sup>5</sup>Department of Psychiatry, St Vincent's Hospital, Melbourne, Australia

<sup>6</sup>Department of Gastroenterology and Hepatology, Royal Melbourne Hospital, Melbourne, Australia

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## ABSTRACT

**Background:** The aim of the study was to examine the impact of diagnostic status (i.e., having a clinical diagnosis of irritable bowel syndrome (IBS) or being symptomatic but undiagnosed on quality of life (QoL)). We also examined whether the relationships between QoL and variables such as symptom frequency, pain catastrophizing, visceral sensitivity, and psychological distress are moderated by diagnostic status.

**Methods:** The online sample comprised 404 participants ( $M_{age} = 33.59$ ,  $SD = 12.43$ ), of which 98 had been diagnosed with IBS and 306 were symptomatic but undiagnosed.

**Results:** The findings suggest that even after adjusting for symptom frequency, those diagnosed with IBS experience poorer QoL, relative to those without a diagnosis. Moreover, there was evidence that the relationship between specific QoL domains (namely, sex, food avoidance, and health worry) and psychological variables (namely, pain catastrophizing, and depression) was moderated by diagnostic status.

**Conclusion:** The results indicate that diagnostic status in relation to IBS has psychological implications for QoL outcomes distinct from symptom frequency, age, and gender. This highlights a substantial gap in our current understanding of how a diagnosis of IBS can impact the lives of those suffering from IBS symptomology and calls into question the intended purpose of diagnosis.

**Keywords:** Irritable bowel syndrome, pain catastrophizing, psychological distress, quality of life, visceral sensitivity

## INTRODUCTION

Irritable bowel syndrome (IBS) is a disorder of the gut–brain interaction.<sup>1</sup> Irritable bowel syndrome is a chronic condition, commonly associated with episodic symptoms, including altered bowel function and abdominal pain. Globally, IBS impacts up to 11% of the population<sup>2</sup> and lacks a detectable organic cause. As such, patient-reported symptoms are relied upon to diagnose and treat IBS.<sup>3</sup> The Rome criteria (presently the Rome IV) are the most widely accepted diagnostic system for IBS.<sup>4</sup>

Patients diagnosed with IBS tend to experience symptoms of greater duration, frequency, and severity than their undiagnosed peers, which drives increased help-seeking.<sup>5</sup> Those who experience milder symptoms are less likely to have sought medical care, and thus may not receive a formal diagnosis of IBS. Thus, it is possible that a

large portion of the community are experiencing gastrointestinal symptoms consistent with IBS in the absence of a formal diagnosis.<sup>6</sup> This may also be possible due to the delay between symptom onset and diagnosis.

Quality of life (QoL) is an important patient-reported outcome (PRO) encompassing one's experience across emotional, social, and physical functioning.<sup>7</sup> Although QoL is adversely impacted in both diagnosed and undiagnosed individuals, those with a formal IBS diagnosis have poorer QoL. Diagnosed individuals report disruption in daily activities due to their symptoms (e.g., avoidance of food consumption before events, avoidance of events with limited bathroom access, or pre-medicating).<sup>5</sup> Such studies, however, rarely controlled IBS symptom frequency, meaning the difference in QoL may be simply due to the fact that those with a diagnosis report more frequent

Corresponding author: Gillian Cassar, e-mail: [gill\\_cassar@hotmail.com](mailto:gill_cassar@hotmail.com)

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symptoms of IBS. As such, it remains unknown if having a formal diagnosis of IBS impacts QoL beyond the influence of symptom frequency.

In research that adjusted for symptom frequency, it is well established that pain catastrophizing (negative evaluation of one's pain experience), and visceral sensitivity (gastrointestinal-specific anxiety), contribute to poor QoL in both formally diagnosed<sup>8</sup> and undiagnosed IBS cohorts.<sup>9</sup> Research has established strong bidirectional associations between these variables, as well as psychological distress (anxiety, depression, and stress), and QoL in IBS sufferers.<sup>10</sup> Nevertheless, the role of diagnostic status in these associations remains unknown.

Research on diagnostic status in IBS is limited, however, for some other chronic diseases such as fibromyalgia and hypertension, studies have highlighted the potential for the diagnosis itself to either positively influence health status or activate unhelpful illness behaviors.<sup>11</sup> Disease labeling has also been identified as the main factor related to differences in patient QoL and self-reported health status in hepatitis C and hyperthyroidism.<sup>12</sup> The diagnosis of a chronic illness usually entails psychosocial consequences.<sup>13</sup> For IBS, however, the extent to which underlying psychological variables are impacted by receiving or lacking a formal diagnosis, remains unknown.

Due to the scarcity of research on this issue in the field of IBS, it is unclear whether a diagnosis of IBS is advantageous or disadvantageous to its sufferers, and how an individual's diagnostic status interacts with the well-established relationships between psychological variables and QoL outcomes. Accordingly, the current paper aimed to examine whether those diagnosed with IBS relative to those with undiagnosed IBS have lower QoL across a range of domains (dysphoria, activity interference, body image, health worry, social reaction, sexual, and relationships), independent of symptom frequency. We also aimed to investigate whether the relationship between IBS symptom frequency, pain catastrophizing, visceral sensitivity, psychological distress (anxiety, depression, and stress), and QoL are moderated by diagnostic status.

## MATERIALS AND METHODS

### Participants

Of the 551 participants who responded to the survey, a total of 147 participants were excluded due to their not having experienced bowel symptoms in the last 6 months ( $n = 44$ ), reporting a gastrointestinal condition other than

IBS or comorbid with IBS ( $n = 43$ ), residing outside of Australia ( $n = 39$ ), or being aged under 18 years ( $n = 1$ ). Completion of all demographic questions, as well as those related to bowel symptom frequency, was a minimum requirement for participant inclusion. As a consequence, a small number of cases were removed ( $n = 19$ ). Finally, 1 participant who reported "other" gender was removed, given that we were unable to use a single observation when covarying for gender in the analysis. Of the 404 participants included in the study, 98 self-reported having been diagnosed with IBS, while the remaining 306 reported experiencing gastrointestinal symptoms without a diagnosis in the past 6 months. Of the sample, 366 participants were female, and 38 were male ( $M_{\text{age}} = 33.59$ ,  $SD = 12.43$ ). Further participant details are contained in Table 1.

### Measures

#### Diagnostic Status

To determine diagnostic status, participants were asked, "have you been formally diagnosed with a gastrointestinal condition?" and, "what form of gastrointestinal condition have you been formally diagnosed with?" Participants that indicated that a healthcare provider (either medical doctor, gastroenterologist, or other professional) had diagnosed them with IBS were classified as "diagnosed IBS." Participants were also asked, "have you recently experienced bowel symptoms?" Individuals that self-reported not having received a diagnosis of IBS, yet still experiencing gastrointestinal symptoms consistent with IBS in the last 6 months (such as abdominal pain, bloating, diarrhea, constipation, change in stool habit) were considered as "undiagnosed IBS." The term "undiagnosed IBS" is used throughout this study for ease of group categorization.

#### Bowel Symptom Severity Scale (BSSS)<sup>14</sup>

The frequency subscale of the BSSS was utilized to measure gastrointestinal symptom frequency for participants with and without an IBS diagnosis. An overall score is generated by summing items. Scores range from 8 to 40, with higher scores indicating greater symptom frequency.

#### Irritable Bowel Syndrome Quality of Life (IBS-QoL)<sup>15</sup>

This scale measures IBS-specific QoL across 8 domains: dysphoria, activity interference, body image, health worry, social reaction, sex, and relationships. Items are summed to provide individual subscale scores and to yield a total score. Scores (ranging from 0 to 100) were reversed so

**Table 1.** Participant Characteristics

	Diagnosed		Undiagnosed IBS (n = 306)		Difference Between Diagnosed and Undiagnosed IBS
	IBS (n = 98)				
	n	%	n	%	$\chi^2$
Gender					
Female	88	89.8	278	90.85	$\chi^2(1) = 0.10, P = .76$
Male	10	10.2	28	9.15	
Marital status					
Single	32	32.65	133	43.46	$\chi^2(2) = 5.43, P = .07$
Relationship	57	58.16	159	51.96	
Separated/divorced/widowed	9	9.18	14	4.58	
Living arrangements					
Alone	13	13.27	22	7.19	$\chi^2(4) = 6.96, P = .14$
Partner	36	36.73	93	30.39	
Parent/s	19	19.39	73	23.86	
Friend/s	7	7.14	39	12.75	
Family (partner & children)	23	23.47	79	25.82	
Living setting					
Metropolitan	73	74.49	227	74.18	$\chi^2(2) = 1.31, P = .52$
Regional	15	15.31	57	18.63	
Rural	10	10.2	22	7.19	
Highest level of education					
Primary			1	0.33	$\chi^2(3) = 0.89, P = .83$
Secondary	15	15.31	47	15.36	
Certificate	37	37.76	103	33.66	
Tertiary	46	46.94	155	50.65	
Employment status					
Employed	61	62.24	209	68.3	$\chi^2(1) = 1.23, P = .27$
Unemployed	37	37.76	97	31.7	
Source of IBS diagnosis					
Medical doctors	49	50			
Gastroenterologists	40	40.82			
Other professionals	9	9.18			
IBS subtype					
IBS-D	37	37.76			
IBS-C	10	10.2			
IBS-M	31	31.63			
IBS-U	20	20.41			

n, number of participants (out of total N = 404).

%, Percentage.

IBS, irritable bowel syndrome.

IBS-D, IBS diarrhea predominant; IBS-C, IBS constipation-predominant; IBS-M, IBS mixed; IBS-U, IBS unspecified.

that lower scores indicated poorer QoL. Due to a technical error, data for item 28 from the food avoidance subscale was not collected. To maintain consistency with the range of responses in the original scoring, a within-participant mean replacement for this item was used, based on the participant's scores on the remaining items from the subscale.

### **Depression Anxiety Stress Scales (DASS-21)<sup>16</sup>**

The DASS-21 short-form measures psychological distress across 3 subscales: anxiety, depression, and stress. Relevant items are summed and then doubled to provide a subscale score. The same is conducted for all items to yield an overall score from 0 to 126. Higher scores indicate greater psychological distress.

### **Coping Strategies Questionnaire (CSQ)<sup>17</sup>**

To assess the frequency of pain catastrophizing, the catastrophizing subscale of the CSQ was used. Scores are summed and ranged from 0 to 36. High scores indicate increased catastrophizing.

### **Visceral Sensitivity Index (VSI)<sup>18</sup>**

Gastrointestinal-specific anxiety was measured using the VSI. Scores are reversed and summed to yield a total score from 0 to 75, with higher scores indicative of increased visceral sensitivity.

### **Procedure**

An online questionnaire package was available to participants between June 2016 and September 2016. It was advertised via social media platforms, universities, gastroenterological clinics, and Australian organizations related to mental and gastrointestinal health. This study was approved from the university's human research ethics committee.

### **Statistical Analysis**

Data analysis was performed in Stata v13. The sample was defined according to diagnostic status (i.e., diagnosed IBS or undiagnosed) and this variable was used as the main exposure variable in all analyses. Differences in total QoL between the groups were examined using linear regression. However, to examine associations between diagnostic status and QoL across the different QoL subscales, we used mixed-effects linear regression with random intercepts, to account for the multilevel nature of the data (i.e., multiple QoL subscales nested within individuals).

The QoL subscales were Z-score standardized to allow for consistent scaling and ease of comparison across subscales.

To address the primary aims, a series of regression models were specified in which QoL scores were regressed onto a variable denoting QoL domain (for the mixed-effects models only), diagnostic status, symptom frequency, pain catastrophizing, visceral sensitivity, psychological distress; and their interactions with diagnostic status and QoL domain. Simple slopes analysis was used to explore interaction effects. For 3-way interactions, we presented results only if both the 3-way interaction effect was statistically significant (i.e.,  $P < .05$ ) and if at least one of the simple 2-way interactions, stratified by QoL diagnosis, was also statistically significant (i.e.,  $P < .05$ ).

All analyses are covaried for bowel symptom frequency where this was not being examined as a main variable of interest; due to the possibility that those with a diagnosis would likely experience greater symptom frequency. Gender and age were also used as covariates, due to IBS more commonly occurring in females and younger adults.<sup>19</sup> Multiple imputation was used to deal with missing data across the survey, which was found to be consistent with a monotone pattern of missingness (due to survey non-completion), to maximize the use of all available data. Missing data ranged from 1.49% to 9.40%. All analyses are based on pooled estimates across the 20 imputed data sets using Rubin's rules.<sup>20</sup>

## **RESULTS**

### **Difference Between Diagnosed and Undiagnosed Irritable Bowel Syndrome Across Study Variables**

Bivariate correlations between key study variables are presented in Table 2. Data examining whether differences exist between those with and without a diagnosis of IBS are found in Table 3. Adjusted results comprise the marginal means after covarying for symptom frequency, age, and gender.

Those diagnosed with IBS reported greater symptom frequency ( $M = 13.33$ ,  $SD = 8.66$ ) than did those without a diagnosis ( $M = 10.38$ ,  $SD = 5.35$ ). After adjustment, those with a diagnosis of IBS had poorer total QoL and poorer QoL in the domains of dysphoria, activity interference, food avoidance, and social reaction, as compared to those without an IBS diagnosis. The domains of body image, health worry, sex, and relationships were not significantly

**Table 2.** Pearson's Correlations Between Study Variables

	Age	SF	PCS	VSI	QoL Dys	QoL AI	QoL BI	QoL HW	QoL FA	QoL SR	QoL Sex	QoL Rship	QoL Total	Anxiety	Stress	Dep	PD Total
Age																	
SF	0.02																
PCS	-0.06	.54***															
VSI	-0.01	.60***	.62***														
QoL Dys	-0.08	-.58***	-.73***	-.75***													
QoL AI	-.16**	-.58***	-.64***	-.71***	.86**												
QoL BI	0.06	-.53***	-.49***	-.62***	.65***	.59***											
QoL HW	0.04	-.52***	-.58***	-.64***	.74***	.64***	.70**										
QoL FA	-.11*	-.45***	-.46***	-.63***	.64***	.64***	.50***	.55***									
QoL SR	0.02	-.55***	-.65***	-.68***	.84***	.80***	.68***	.74***	.59***								
QoL Sex	-0.05	-.45***	-.44***	-.52***	.61***	.60***	.65***	.57***	.48***	.64***							
QoL Rship	-0.04	-.49***	-.63***	-.63***	.78***	.76***	.61***	.66***	.55***	.77***	.65***						
QoL Total	-0.07	-.622***	-.71***	-.78***	.94***	.91***	.78***	.81***	.73***	.91***	.73***	.85***					
Anxiety	-.12*	.39***	.46***	.42***	-.39***	-.40***	-.51***	-.46***	-.22***	-.43***	-.47***	-.48***	-.48***				
Stress	-.15**	.41***	.48***	.47***	-.45***	-.42***	-.50***	-.49***	-.32***	-.45***	-.41***	-.48***	-.51***	.72***			
Dep	-0.03	.35***	.56***	.40***	-.48***	-.42***	-.45***	-.48***	-.22***	-.43***	-.38***	-.50***	-.50***	.66***	.70***		
PD Total	-.11*	.43***	.56***	.48***	-.49***	-.46***	-.54***	-.54***	-.29***	-.49***	-.47***	-.55***	-.56***	.88***	.90***	.89***	

\*P < .05; \*\*P < .01; \*\*\*P < .001. Small correlation  $r = 0.1$ , medium  $r = 0.3$ , large  $r = 0.5$  (32).

SF, symptom frequency; PCS, pain catastrophizing; VSI, visceral sensitivity; QoL, quality of life; Dys, dysphoria; AI, activity interference; BI, body image; HW, health worry; FA, food avoidance; SR, social reaction; Rship, relationships; Dep, depression; PD, psychological distress.

**Table 3.** Difference Between Diagnosed IBS and Undiagnosed Groups

	Unadjusted Results										Adjusted Results			
	Diagnosed IBS (n = 98)					Undiagnosed IBS (n = 306)					Difference in Diagnostic Status			
	M	SD	M	SD	Cohens d	M	SD	M	SD	Cohens d	Difference	95% CI	Difference	95% CI
Age	36.78	28.88	32.58	13.37	0.19	36.92	12.57	32.53	12.24	0.36	4.20**	1.39, 7.01	4.39**	1.49, 7.28
SF	13.33	8.66	10.38	5.35	0.41	13.36	4.65	10.37	4.55	0.49	2.95***	1.91, 3.99	2.99***	1.94, 4.04
PCS	12.28	17.55	9.26	9.69	0.21	10.28	7.52	9.9	7.35	0.04	3.03**	1.09, 4.97	0.39	-1.34, 2.11
VSI	47.48	31.84	35.11	22.24	0.45	42.61	15.84	36.67	15.57	0.29	12.37***	8.13, 16.60	5.94**	2.25, 9.62
Anxiety	12.27	18.85	13.3	12.29	-0.06	10.49	9.4	13.87	9.62	-0.27	-1.03	-3.37, 1.30	-3.38**	-5.59, -1.18
Stress	17.66	20.03	18.51	12.79	-0.05	15.82	9.9	19.1	9.97	-0.25	-0.85	-3.28, 1.58	-3.28**	-5.57, -0.98
Depression	12.16	19.69	13.88	13.62	-0.1	10.15	10.79	14.52	10.85	-0.31	-1.72	-4.25, .81	-4.37**	-6.86, -1.87
PD Total	42.09	51.9	45.7	34.46	-0.08	36.47	26.13	47.5	26.59	-0.32	-3.61	-10.10, 2.89	-11.03***	-17.11, -4.94
QoL Dys	26.45	17.71	32.02	9.88	-0.39	28.85	7.52	31.25	7.35	-0.24	-5.57***	-7.54, -3.60	-2.41**	-4.14, -0.68
QoL AI	22.39	15.09	27.88	8.22	-0.45	24.52	6.14	27.2	6.12	-0.33	-5.49***	-7.13, -3.85	-2.68***	-4.11, -1.26
QoL BI	12.58	8.46	14.51	4.87	-0.28	13.51	3.66	14.21	3.67	-0.14	-1.93***	-2.89, -0.98	-0.7	-1.56, .16
QoL HW	10.14	6.09	11.56	3.42	-0.29	10.8	2.67	11.35	2.62	-0.16	-1.42***	-2.09, -0.74	-0.55	-1.17, .07
QoL FA	7.8	5.67	10.65	4.02	-0.58	8.48	3.17	10.43	3.15	-0.47	-2.85***	-3.61, -2.09	-1.94***	-2.68, -1.21
QoL SR	13.16	9.26	15.6	5.01	-0.33	14.2	3.96	15.27	3.85	-0.21	-2.44***	-3.46, -1.43	-1.07*	-1.98, -0.16
QoL Sex	7.44	4.73	7.91	2.87	-0.12	7.99	2.28	7.73	2.27	0.09	-0.47	-1.02, .09	0.26	-27.78, 0.09
QoL Rship	11	6.36	12.1	3.44	-0.22	11.7	2.77	11.88	2.8	-0.05	-1.09**	-1.78, -0.40	-0.18	-82.46, -0.05
QoL Total	110.97	58.04	132.23	36.12	-0.44	120.05	25.74	129.32	25.36	-0.27	-21.27***	-28.29, -14.24	-9.27**	-15.23, -3.32

\*P < .05, \*\*P < .01, \*\*\*P < .001. Estimates are pooled across 20 imputed datasets. Adjusted results covaried for symptom frequency, age and gender.

SF, symptom frequency; PCS, pain catastrophizing; VSI, visceral sensitivity; PD, psychological distress; QoL, quality of life; Dys, dysphoria; AI, activity interference; BI, body image; HW, health worry; FA, food avoidance; SR, social reaction; Rship, relationships; SD, standard deviation; IBS, irritable bowel syndrome.



different depending on diagnostic status. Diagnosed IBS sufferers also reported higher symptom frequency and visceral sensitivity. Effect sizes ranged from small ( $d = 0.04$ ) to moderate ( $d = 0.49$ ). No difference was found between diagnosed and undiagnosed participants in relation to pain catastrophizing. Psychological distress was greater for those with undiagnosed IBS symptomatology. After adjustment for symptom frequency and age, no relationship was found between gender and IBS diagnosis,  $t = -0.35$ ,  $P = .724$ . Effect sizes decreased for total QoL, pain catastrophizing, and visceral sensitivity following adjustment while increasing for psychological distress.

### Interactions Between Psychological Variables and Diagnostic Status

#### Total Quality of Life

Diagnostic status was not found to be a moderator of the relationship between total QoL and symptom frequency,  $F(1.370.8) = 1.25$ ,  $P = .264$ ; pain catastrophizing,  $F(1.386.5) = 0.18$ ,  $P = .672$ ; visceral sensitivity,  $F(1.385.9) = 0.25$ ,  $P = .618$ ; psychological distress,  $F(1.385.7) = 0.37$ ,  $P = .546$ ; anxiety  $F(1.372.4) = 0.12$ ,  $P = .734$ ; depression,  $F(1.367.1) = 0.81$ ,  $P = .369$ ; or stress,  $F(1.370.8) = 0.01$ ,  $P = .934$  (all in separate analyses). Given the lack of evidence that the relationship between total QoL and symptom frequency, pain catastrophizing, visceral sensitivity, or psychological distress was moderated by diagnostic status, we examined whether the effects were specific to different domains of QoL.

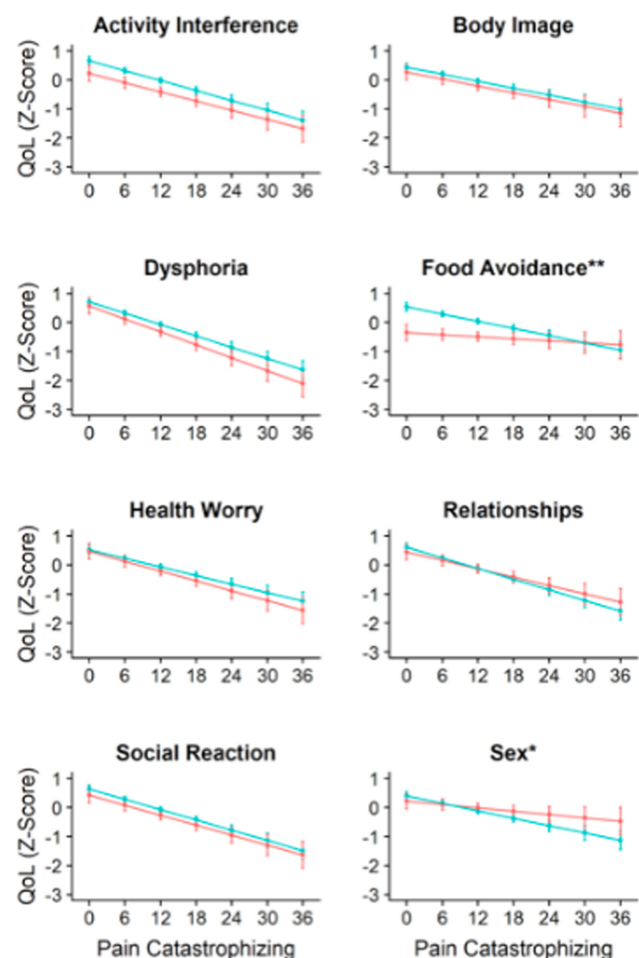
#### Quality of Life Domains

In a series of regression analyses, we explored whether the relationship between psychological variables and QoL domains was moderated by diagnostic status (i.e., 2-way interaction of diagnosis X psychological variable, averaged across all QoL domains), or whether this moderation effect differed depending on QoL domain (i.e., 3-way interaction of diagnosis X psychological variable X QoL domain). There was no evidence for any 2-way interactions involving any of the psychological variables. With respect to the 3-way interactions, there was little evidence to support a 3-way interaction involving psychological distress,  $F(7.730613.3) = 1.78$ ,  $P = .087$ , or stress,  $F(7.27344.1) = 0.75$ ,  $P = .627$ . While there were significant 3-way interaction effects involving the psychological variables of visceral sensitivity,  $F(7.127822.6) = 2.41$ ,  $P = .018$ , and weak evidence for anxiety,  $F(7.27322.0) = 2.01$ ,  $P = .050$ , simple slopes analysis found no significant psychological variable X diagnostic status moderations

for visceral sensitivity and anxiety when stratified by QoL domain. As such, no further examination of visceral sensitivity and anxiety analyses are presented. By contrast, there was evidence for 3-way interactions involving pain catastrophizing and depression, which are outlined below.

### Pain Catastrophizing

There was evidence of a diagnostic status X pain catastrophizing X QoL domain 3-way interaction,  $F(7.169243.6) = 3.16$ ,  $P = .002$ , which is presented in Figure 1. Simple slopes analysis found that the diagnostic status X pain catastrophizing interaction was only observed for the QoL domains of food avoidance ( $P = .006$ ) and sex ( $P = .027$ ). Specifically, a significant negative relationship was found between pain catastrophizing and food avoidance



**Figure 1.** Interaction between pain catastrophizing and diagnosis for each quality of life domain. Lines represent 95% confidence interval. Redlines = diagnosed IBS, blue lines = undiagnosed IBS; \* = interaction significant at  $< .05$ ; \*\* = interaction significant at  $< .01$ .

for those with no diagnosis of IBS ( $b = -.04$ ,  $SE = 0.006$ ,  $P < .001$ ) but not for those with a diagnosis ( $b = -.01$ ,  $SE = 0.009$ ,  $P = .219$ ). On inspection of Figure 1, it can be seen that at high levels of pain catastrophizing the difference between diagnostic status is relatively small, while at low levels of pain catastrophizing, diagnostic status is important, evident in a larger difference in food avoidance QoL for those with no diagnosis. Notably, due to the scaling of the measure, this result implies that those with no diagnosis and low pain catastrophizing had better food avoidance QoL. On the other hand, the relationship between pain catastrophizing and sex QoL was stronger for those with no diagnosis ( $b = -.04$ ,  $SE = 0.006$ ,  $P < .001$ ) relative to those with a diagnosis ( $b = -.02$ ,  $SE = 0.009$ ,  $P = .041$ ). From Figure 1, it can be seen that this effect is driven by a greater decrease in sex QoL at high levels of pain catastrophizing for those without a diagnosis.

### Depression

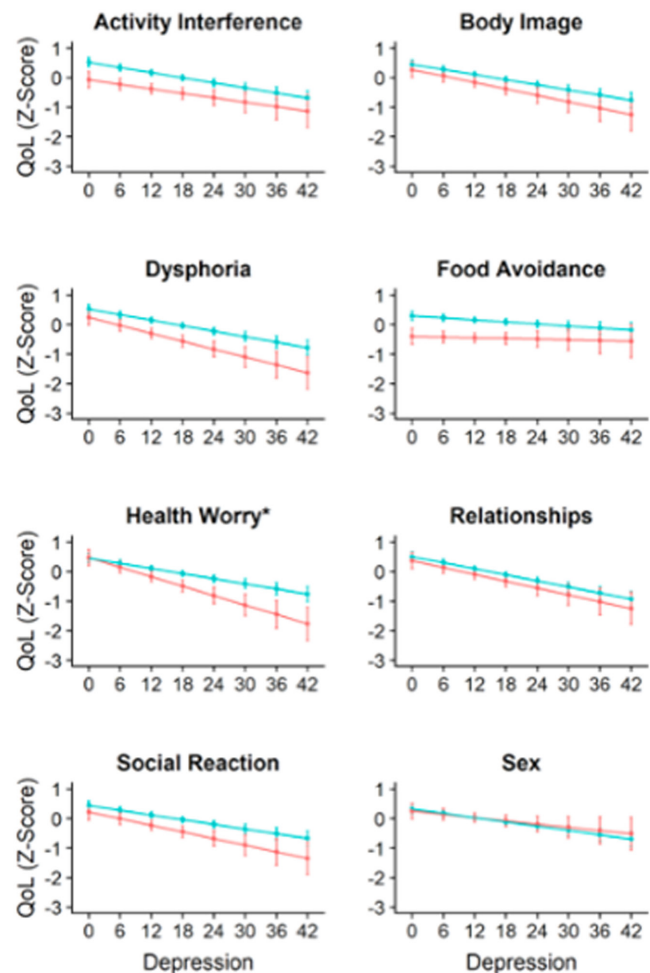
There was evidence of a three-way diagnostic status X depression X QoL domain interaction,  $F(7.23294.2) = 2.42$ ,  $P = .018$ . Figure 2 presents the simple slopes for the diagnostic status X depression interactions for each QoL domain. The diagnostic status X depression interaction was only observed for the QoL domain of health worry ( $P = .015$ ), whereby there was a stronger negative relationship between depression and health worry QoL for those with a diagnosis ( $b = -.05$ ,  $SE = .009$ ,  $P < .001$ ) compared to those without a diagnosis ( $b = -.03$ ,  $SE = .004$ ,  $P < .001$ ). As shown in Figure 2, at high levels of depression those with a diagnosis reported worse health worry QoL than those without a diagnosis.

## DISCUSSION

### Difference between Diagnosed and Undiagnosed Irritable Bowel Syndrome Across Study Variables

Limited research exists regarding diagnostic status in individuals suffering from IBS symptomology, and how diagnostic status interacts with psychological variables in influencing QoL outcomes. As such, the first aim of this paper was to examine whether QoL differs between participants with diagnosed and undiagnosed IBS symptoms across a range of domains, independent of symptom frequency.

As presented in the results, and consistent with past research,<sup>21</sup> those diagnosed with IBS were found to have lower total QoL. Extending on previous findings, this result was evident after adjusting for symptom



**Figure 2.** Interaction between depression and diagnosis for each quality of life domain. Lines represent 95% confidence interval.

Redlines = diagnosed IBS, blue lines = undiagnosed IBS;

\* = interaction significant at  $< .05$ ; \*\* = interaction significant at  $< .01$ .

frequency, gender, and age. Nevertheless, the magnitude of difference between groups was found to be attenuated after adjustment for symptom frequency. The diagnosis was also associated with worse QoL in the domains of dysphoria, activity interference, food avoidance, and social reaction, after adjusting for symptom frequency. The current findings highlight that having a diagnosis of IBS, independent of IBS symptom frequency, is important when considering the impact of IBS on QoL.

Various factors may explain these findings. Like other chronic diseases, receiving a diagnosis of IBS likely leads to the restructuring of one's identity.<sup>13</sup> This may translate into



altered daily activities which could contribute to changes in QoL. For others, diagnosis may trigger illness-related behaviors (e.g., preoccupation with disease, frequent physician visits) which serve to perpetuate the sick-role<sup>22</sup> and impact QoL. It is also possible that diagnosed individuals have a greater awareness of how their IBS influences their QoL in particular domains (e.g., food avoidance and social reaction). Accordingly, the use of a disease-specific QoL measured in the current study, which is more sensitive to IBS-related impairments, may have further aided in capturing these results. Further research is required to clarify the psychological implications of receiving a diagnosis of IBS for particular QoL domains.

### **Interactions Between Psychological Variables and Diagnostic Status**

The second aim of this paper was to investigate whether the relationship between IBS symptom frequency, pain catastrophizing, visceral sensitivity, psychological distress (anxiety, depression, and stress), and QoL, are moderated by diagnostic status. Diagnostic status did not influence the relationships between symptom frequency, pain catastrophizing, visceral sensitivity, psychological distress (anxiety, depression, and stress), and total QoL. This suggests that total QoL may not provide enough specificity to understand the complex interactions that exist between the study variables. Accordingly, diagnostic status was found to influence relationships between some psychological variables and particular domains of QoL, specifically, sex, food avoidance, and health worry. These findings are discussed below and organized according to the QoL domain for ease of interpretation.

### **Quality of Life-Sex**

In the current study, those with undiagnosed IBS and increased pain catastrophizing experience greater impairment in QoL related to sex. Increased pain sensitivity related to sex and interference in sexual functioning is a common experience for IBS sufferers. In the context of sex, where an individual with IBS might expect to experience abdominal pain,<sup>23</sup> pain catastrophizing may occur in an attempt to cope, leading to impairment in sex QoL through illness-behaviors (e.g., avoidance of sexual intercourse) or internal events (e.g., fear or anxious preoccupation with bodily sensations). It is possible that without a diagnosis, individuals find that their gastrointestinal symptoms interfere with sex to a greater extent because they are unexplained.<sup>23,24</sup> Thus, it is possible that the symptoms trigger further pain catastrophizing than those with a diagnosis.

### **Quality of Life-Food Avoidance**

Participants without an IBS diagnosis and low pain catastrophizing were found to experience better QoL related to food avoidance than those with a diagnosis. Although no specific food has been implicated in IBS, as true intolerances are rare, restriction and avoidance of "trigger" foods is a common coping strategy for IBS sufferers. Dietary modification is also usually recommended as part of the first phase of symptom management for IBS.<sup>25</sup> Despite the potential for symptom alleviation, dietary modification can be extremely demanding, with limited benefit, as it promotes interference in the type and amount of food consumed and sensitivity to certain foods.<sup>26</sup> The undiagnosed IBS sufferer, perhaps due to lack of awareness or lower hypervigilance regarding diet, is likely engaging in less, if any, attempts to modify food consumption. Together with low pain catastrophizing, this may reduce their vulnerability to impaired QoL related to food avoidance.

### **Quality of Life-Health Worry**

Participants with diagnosed IBS and increased depression were found to suffer poorer QoL in the domain of health worry. Depression is a common comorbidity in those with IBS, which can increase the perception of symptom severity, influence treatment-seeking and response, as well as IBS symptom persistence.<sup>3</sup> Depression may exacerbate anxiety about gastrointestinal symptoms, meaning that those with a diagnosis of IBS are more likely to perceive their symptoms as threatening, experience them as disruptive to daily life, and worry about developing a serious physical illness. Individual beliefs about vulnerability to illness and treatment efficacy (which is likely influenced by diagnostic status) may also play a role in this. It is possible that those without a diagnosis may be able to adaptively consider their IBS symptoms as being triggered by daily stressors, as such, not warranting further worry or attention and causing less impairment to QoL.

### **Limitations**

The present study has several limitations. Firstly, participant self-report was relied upon to determine IBS diagnosis and gastrointestinal symptoms. Although participants indicated the type of health professional that provided diagnosis, potential differences may exist between those diagnosed by a gastroenterologist as compared to a general medical practitioner. The inclusion of participants who indicated that their diagnosis was given by "other professional" may also be misrepresentative of true IBS

diagnosis. Moreover, the Rome IV diagnostic criteria were not utilized to verify diagnostic status. It is acknowledged that there may exist alternate explanations for symptoms in those classified as undiagnosed IBS, such as other undiagnosed gastrointestinal conditions. Other factors, such as body mass index (which was not measured in the current study) or socioeconomic status may also explain differences between the two groups.<sup>33</sup>

Although respondents with comorbid gastrointestinal conditions were excluded from the analysis to ensure homogenous groups, it is possible that participants experienced physical or psychiatric comorbidities (such as fibromyalgia or chronic fatigue syndrome) common in IBS which may influence QoL. We were also unable to obtain data on historical or current treatment, and as such, were unable to control for this in the analysis.

### Strengths

This study is one of very few that have considered diagnostic status in IBS,<sup>5</sup> and the first, to the authors' knowledge, to specifically investigate diagnostic status as a moderator of the relationships between symptom frequency, pain catastrophizing, visceral sensitivity, psychological distress, and QoL in IBS. Complex interactions between diagnostic status and psychological variables relevant to IBS were also examined. Empirical studies generally include groups of participants that are dichotomously classified as IBS affected or unaffected, when in fact, this precludes the investigation of diagnostic status. It is not uncommon for the "healthy" control group to consist of some individuals who experience gastrointestinal symptoms without a formal diagnosis of IBS,<sup>27</sup> yet who still suffer QoL impairments.

Another strength is the use of a disease-specific QoL measure (IBS-QoL).<sup>15</sup> Although generic or global measures are useful for comparison to other diseases, we were interested in implications that are particular to those experiencing symptoms of IBS. Moreover, we explored relationships between variables across the individual domains of QoL, rather than relying on total QoL as an overall indicator of functioning, subsequently providing a more detailed exploration of the construct.

### Implications and Future Directions

As highlighted in this paper, diagnostic status is an important variable to be investigated in future studies. The exclusion of potential IBS sufferers without a formal diagnosis introduces an unintended bias in the available

research.<sup>28</sup> This cohort should be clearly distinguished in future studies to expand the current knowledge beyond that which we have gained from clinically diagnosed IBS.

The presence of undiagnosed IBS in the community may be considered an unmet need as untreated IBS may lead to a cycle of impairment and lessened productivity, thus contributing to the economic burden imposed by IBS.<sup>29</sup> Alternatively, undiagnosed individuals may foster adaptive strategies that promote wellbeing and lessen the need to seek care or seek a diagnosis.

Research indicates that receiving an IBS diagnosis is beneficial in that it may lead to appropriate intervention and patients being better informed about IBS pathophysiology.<sup>30</sup> In contrast, the current results indicate that those with a diagnosis have poorer QoL. It is possible that while some find a diagnosis to be a relief, for others it contributes to worry about the presence of more serious underlying disease<sup>31</sup> and experience limited utility in receiving a diagnosis without a clear remedy.

### CONCLUSIONS

To our knowledge, this is the first Australian study to investigate interactions between diagnostic status, symptom frequency, pain catastrophizing, visceral sensitivity, and psychological distress, in relation to QoL domains in IBS. The findings indicate that independent of IBS symptom frequency, one's diagnostic status plays an important role in particular domains of QoL. This study highlights the need for continued research to further understand what it means to be diagnosed with IBS, how this interacts with individual difference variables and the associated psychosocial impact. Further research should seek to understand the impact of a diagnosis of IBS on an individual, the psychosocial process that may in turn help facilitate the management of IBS, and ultimately enhance QoL in those living with IBS.

**Ethics Committee Approval:** This study was approved by the Deakin University Human Research Ethics Committee.

**Informed Consent:** Participants provided informed consent to prior to participating in the study.

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