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Citation: Hulme, Katrin, Chilcot, Joseph and Smith, Michael Doctor-patient relationship and quality of life in Irritable Bowel Syndrome: an exploratory study of the potential mediating role of illness perceptions and acceptance. *Psychology, Health & Medicine*, 23 (6). pp. 674-684. ISSN 1354-8506

Published by: UNSPECIFIED

URL:

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Doctor-patient relationship and quality of life in Irritable Bowel Syndrome: an exploratory study of the potential mediating role of illness perceptions and acceptance.

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Word count (exc. figures/tables): 3,103

Acknowledgments: We are grateful to the IBS Network and its members for their help in conducting this research.

Keywords: Irritable Bowel Syndrome; Quality of Life; Doctor-patient relationship; Illness perceptions; Acceptance.

Funding: None.

Disclosure statement: No conflict of interest declared.

Doctor-patient relationship and quality of life in Irritable Bowel Syndrome: an exploratory study of the potential mediating role of illness perceptions and acceptance.

Abstract

Irritable Bowel Syndrome (IBS) is a functional gastrointestinal disorder characterised by unpredictable bowel symptoms. These can be difficult to manage, consequently impacting on sufferers' quality of life (QoL). In addition, a strained doctor-patient relationship is independently reported in the qualitative literature. Given that the doctor is often the first port-of-call for sufferers, a difficult relationship may influence IBS sufferers' subsequent management. Research suggests that illness perceptions are important in determining IBS outcomes in therapy; however, their association with doctor-patient relationship and QoL is yet to be investigated. This exploratory study aimed to investigate the association between doctor-patient relationship and QoL in IBS, as well as potential mediation of this relationship by illness perceptions. Online questionnaires measuring doctor-patient relationship, illness perceptions, acceptance and QoL, were completed by 167 participants (144 female, mean age=44.22 years, SD=15.91 years), who reported an IBS diagnosis from a doctor. Bootstrapped pathway analysis was used to model the relationship and mediation effects. There was a significant positive correlation between patient-doctor relationship and QoL, $r=.258, n=167, p=.001$. There was a significant indirect effect between doctor-patient relationship and QoL through illness coherence and acceptance (bootstrapped estimate=.058, 95%CI Lower-Upper=.02,.095, $p=.002$). No other indirect effects were observed in combination with good fit indices for the other illness perceptions. Findings suggest a doctor-patient relationship which fosters mutual understanding and helps patients make sense of symptoms, increases their ability to manage their IBS in a psychologically flexible manner, subsequently helping them maintain their QoL.

Introduction

Irritable Bowel Syndrome (IBS) is a functional gastrointestinal disorder with prevalence rates in Europe and North America estimated around 10-15%, affecting twice as many women as men (Quigley et al., 2009). The disorder is characterised by symptoms such as constipation and/or diarrhoea, bloating and abdominal pain, seemingly without an underlying pathophysiological cause (Mayer, 2008). Individuals may experience highly variable and unpredictable episodes regarding symptoms, duration and potential triggers. This can make coping with IBS on a day-to-day basis difficult, resulting in IBS having a considerable negative effect on peoples' lives (Dancey et al., 2009). Studies have shown that, although not a life-threatening illness, IBS sufferers report significantly impaired quality of life (QoL), not only in comparison to healthy controls (Amouretti et al., 2006), but also in comparison to other chronic disease sufferers, such as gastroesophageal reflux disease, asthma, migraines, diabetes and end-stage renal disease (Frank et al., 2002; Gralnek et al., 2000).

Applied research has demonstrated the association of illness perceptions (patients' illness beliefs) with IBS outcomes, highlighting their role as a mediator between Cognitive Behavioural Therapy (CBT) and subsequent improvements in symptom severity and social adjustment (Chilcot & Moss-Morris, 2013). Rutter & Rutter (2002) reported the association of low control, negative consequence and low coherence beliefs in predicting QoL, whilst demonstrating a possible mediation role of acceptance coping in this association. Similarly, de Gucht (2015) highlighted the role of illness perceptions, for example 'consequences' in mediating the relationship between severity and QoL. As such, it seems fostering positive illness perceptions is beneficial in IBS; however, the mechanistic pathways and best ways of achieving this have, as yet, not been ascertained.

Longitudinal research by Rutter & Rutter (2007) suggested that perceptions formed early in the illness trajectory may persist over time. Additionally, the Common Sense Model posits that individuals' illness perception formation occurs as a function of background factors such as their experiences and relationships. They then dictate the action/coping response and the appraisal of this while individuals try to make sense of symptoms (Leventhal, Diefenbach & Leventhal, 1992). Given that the doctor is often the first port-of-call for people with IBS, a difficult relationship may influence their illness beliefs, subsequent management and QoL.

Negative experiences surrounding the doctor-patient relationship are frequently described in the literature. Variable and individual symptoms mean that diagnosis is often one of exclusion after diagnostic testing and varying treatment approaches are employed by primary care practitioners (Hungin et al., 2014), which may not address the patient's exact combination of symptoms (Casiday et al., 2008; Lacy, Weiser & De Lee, 2009). Furthermore, patient and doctor may have different perceptions of the symptoms and severity of the IBS (Dalton et al. 2004). As a result, patients do not feel understood by the doctors who diagnose it and the adverse effect on their QoL is not acknowledged. Conversely, doctors struggle to provide successful treatment and adequate support because the exact aetiology of IBS is unidentified, leading to frustration for both parties in the patient-doctor dyad (Stenner, Dancey & Watts, 2000; Dhaliwal & Hunt, 2004; Di Palma & Herrera, 2012).

However, to our knowledge, these constructs have only been investigated independently. Considering the possible associations highlighted previously between doctor-patient relationship, illness perceptions, acceptance (as a coping mechanism) and QoL, this exploratory mediation study aimed to investigate these relationships further. Pathways tested were determined by initial univariate analyses. However, specifically, we hypothesise that a better doctor-patient relationship will increase patients' control and coherence beliefs, and

reduce their emotional distress beliefs, increasing their acceptance and resulting in improved QoL, as depicted in the model shown below (Figure 1).

Insert Fig 1 here.

Methods

Design & Procedure

This study employed an online survey tool to administer four self-report questionnaires. Participants were recruited via the website and monthly newsletter of an IBS patient support charity and an online patient forum. By following the web-link, interested respondents were directed to the information sheet and online survey. Respondents chose a unique and anonymous identifying code and gave their informed consent before proceeding through the demographics page and subsequent questionnaires by clicking 'next' to continue. Once 'next' had been clicked they were not able to return to that section, ensuring answers were not amended after further question topics had been seen. Finally, participants viewed a debrief page and were thanked for their time.

The study received approval from the Institution's Faculty of Health and Life Sciences Ethics Committee.

Materials

Demographic questions, including age, gender, country of residence, duration and severity of symptoms (Likert scale from 1 (none) to 5 (very severe)), were embedded in the first page of the survey, followed by the questionnaires.

Doctor-patient relationship was measured using the 'Patient-Doctor Relationship Questionnaire-9' (PDRQ-9) (Van der Feltz-Cornelis et al., 2004). This nine item measure focuses on patient's perspective of the relationship in primary care, with statements such as 'my PCP helps me' rated on a Likert scale from 1 (not at all appropriate) to 5 (totally appropriate). Total scores range from 9-45; the higher the score, the more positively the relationship is perceived. In order to avoid confusion 'PCP' (primary-care practitioner) was substituted with 'doctor' and it was made clear this referred to the primary medical setting. The validity and reliability of this instrument has been demonstrated (Cronbach's $\alpha = .94$; Van der Feltz-Cornelis et al., 2004).

Illness perceptions were assessed using the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002). For specificity, 'your illness' was replaced with 'your IBS.' Identity is assessed by participants choosing 'Yes' (=1) or 'No' (=0) in response to fourteen general and illness-related symptoms. The remaining 56 items are scored on a 5-point scale; 1(strongly disagree) to 5(strongly agree). High summed scores for identity, timeline and consequences dimensions represent strong beliefs regarding the number of symptoms attributable to the disorder, adverse consequences and the chronic or cyclical nature of the disorder. High scores on the control and coherence dimensions indicate positively perceived controllability and good levels of understanding. Causal items are not summed but used for grouping/factor analysis. The validity and reliability of the IPQ-R have been ascertained in previous research; Cronbach's $\alpha = .75$ for identity and $\alpha \geq .79$ all other subscales (Moss-Morris et al., 2002).

Acceptance was measured with the IBS-Acceptance & Action Questionnaire (IBSAAQ). The validity and reliability of this instrument has been demonstrated (Cronbach's $\alpha > .80$ for subscales and overall; Ferreira et al., 2013). A 7-point Likert scale ranging from 0(never true) to 6(always true) is used to rate twenty items; a higher summed score indicates

a higher level of acceptance. A two-factor structure exists; ‘Activities Engagement’ corresponds to the pursuit of valued activities despite IBS and ‘IBS Willingness’ reflects willingness to be in contact with difficult psychological and physical IBS experiences.

QoL was assessed using the IBS Quality of Life measure (IBS-QOL), an illness specific, validated, and reliable 34-item questionnaire (Cronbach’s $\alpha=.95$) (Patrick et al., 1998). Items such as ‘I feel my life is less enjoyable because of my bowel problems’, are responded to on a 5-point scale from 1(not at all) to 5(extremely), which is then reversed. Once summed, the total score is transformed to a 0-100 scale for ease of interpretation. The higher the score, the better the patient’s QoL.

Data Analysis

Statistical analysis was performed using the statistical packages SPSS and MPlus. Missing data was handled by case-wise mean substitution, e.g. where missing data was present, an individual’s average score from the corresponding subscale was imputed. This occurred in accordance with questionnaire instructions.

The bootstrapping technique was used to test direct and indirect effects between the constructs (two-tailed significance). Maximum likelihood estimation was used, and all models controlled for IBS severity and age. Five hundred bootstrap samples were generated for a 95% confidence interval effect. This procedure consists of non-parametric resampling with replacement, which is done many times and from which a new sampling distribution can be created, allowing the significance of the model pathway to be tested (Shrout & Bolger, 2002).

Model fit was evaluated using the following indices (cut-off values for good fit are indicated in the brackets, e.g. a CFI value of .95 or more indicates good fit): Chi-Squared ($p \geq .05$), Comparative Fit Index (CFI; $\geq .95$) and Root mean square error of approximation

(RMSEA; $\leq .05$) and Tucker–Lewis Index (TLI; $\geq .95$). These are commonly used criteria advocated in the literature for evaluating model fit (Hooper, Coughlan & Mullen, 2008). All models were adjusted for age and illness severity.

Results

Participants

In total 284 responses were logged. Forty-one of these were removed due to duplication or no responses (i.e. participants registering their consent, but not proceeding to answer any further questions). Nine participants were excluded because they had not received an IBS diagnosis from their doctor. Due to healthcare differences in non-UK countries, we excluded participants from any other country. The final sample consisted of 167 participants (144 female), see table 1 for sample characteristics.

Insert Table 1 here.

There was no significant difference between females and males on the outcome variable QoL, or any of the illness perception variables. This was with the exception of personal control, where females (mean=20.47, s.d.=5.08) scored higher than males (mean=18.09, s.d.=4.71), $F(1,165) = 4.461$, $p < .05$. However, this difference was not significant at the adjusted α -level ($p < .0056$).

In terms of IBS subtype, 64 participants reported having IBS-D (diarrhoea), 25 reported IBS-C (constipation), 73 reported IBS-A (alternating/mixed) and 5 did not know/did not respond. There was no significant association of subtype with any illness perception variables or QoL (all $p > .10$).

Correlation analyses

Initially, two-tailed correlations were calculated to assess the associations between all constructs. The correlations between each of the variables and, i) the predictor variable (doctor-patient relationship) and ii) the outcome variable (QoL) of interest, are shown in Table 2.

Of the illness perceptions, illness coherence and emotional representations in particular were significantly correlated with doctor-patient relationship. Regarding QoL, consequences and emotional representations were highly correlated, along with the control perceptions, illness coherence and also Acceptance.

Insert Table 2 here.

Accordingly, we conducted individual mediation analyses to investigate the direct and indirect effects of the pathway from doctor-patient relationship to QoL, via the variables which were shown to be significantly correlated with QoL: illness perceptions (consequences, personal control, treatment control, illness coherence, emotional representation) and Acceptance.

Correlation analyses were also used to check the associations between age, duration and severity, with the illness perception variables and QoL outcome. Age was not associated with any of these variables, except illness coherence, $r(165) = -.175$, $p < .05$. Duration was not associated with any of these variables, except personal control $r(158) = -.209$, $p < .01$ and treatment control $r(158) = -.168$, $p < .05$. Severity correlated significantly with identity $r(162) = .249$, $p < .01$, timeline (chronic) $r(162) = .286$, $p < .001$, consequences $r(162) = .519$, $p < .001$, treatment control $r(162) = -.216$, $p < .01$, emotional representations $r(162) = .337$, $p < .001$, and QoL $r(162) = -.392$, $p < .001$.

Mediation analyses

Doctor-patient relationship did not have a direct effect on QoL in any of the specified models, highlighting the importance mediating factors in determining effect on QoL. Mediating (i.e. indirect) effects are considered significant when the upper and lower bounds of the confidence interval do not contain the value zero and $p \leq .05$. Fit indices and indirect effects are shown in table 3 (all values given are standardised).

Insert Table 3 here.

Discussion

This exploratory study aimed to investigate the association between doctor-patient relationship and QoL in IBS, by testing mediating influences of illness perceptions and acceptance. Specifically, illness perceptions shown to be highly correlated with the QoL outcome, which were therefore included in the path analyses, were: consequences, personal control, treatment control, illness coherence and emotional representations.

Of these, illness coherence was the only perception that contributed to a model of good fit as well as demonstrating a significant mediating effect when combined with acceptance (see table 3), in line with our hypothesis. The association is summarised in the following model (Figure 2).

Insert Fig 2 here.

Given that the correlation between doctor-patient relationship and illness coherence was the strongest of all the variables, this finding is perhaps unsurprising. However, previous research suggested that the ‘consequences’ and ‘cure/control’ dimensions could also play an

important role (Rutter & Rutter, 2002). One difference must be highlighted; the current research utilised the IPQ-R whereas Rutter and Rutter (2002) used the Illness Perception Questionnaire (IPQ). The IPQ has since been amended to improve its measurement properties and include other important perception components, one of these being illness coherence. It could be argued that the use of the less comprehensive measure previously meant that illness coherence was not measured and so its predictive involvement could not have been reported. Indeed, this deduction is supported by research which demonstrated that ‘comprehensibility’ (understanding of the condition), along with consequences, was significantly associated with QoL impact (Ferreira et al., 2010).

Additionally, although no previous research has empirically linked doctor-patient relationship and illness perceptions in IBS, findings from doctor-patient relationship studies tend to centre around factors such as concordant (or discordant) views, shared knowledge and mutual understanding (Casiday et al., 2008; Dalton et al., 2004; Di Palma & Herrera, 2012; Bijkerk et al., 2003). Additionally, a disappointing experience of healthcare in the early stages together with a lack of a coherent illness narrative is common in many other “medically unexplained” conditions, whereby coherent ‘symptom stories’ are thought to help patients manage their condition better as the understanding or ‘sense-making’ can be seen as a transaction between the individual, healthcare professionals and a coherent illness narrative, which acts upon well-being (Kirmayer et al., 2004; Burton et al., 2015). Thus, it seems illness coherence may be the illness perception of particular importance when doctor-patient relationship is introduced into the equation.

The cross-sectional design employed here means that the directional causality remains speculative. However, the strong rationale which informed model specification suggests that using path analyses to confirm a directional relationship is not inappropriate (Pearl, 2012). Nonetheless, illness perceptions are activated on symptom presentation, and subsequently

dictate individuals' health behaviour: one such example being advice seeking (Diefenbach & Leventhal, 1996). Therefore, it may be more appropriate to view the doctor-patient relationship as an important influencing factor across the illness coherence trajectory, rather than a solely a preceding factor.

As Dhaliwal and Hunt (2004) point out, the local doctor is often a patient's first port-of-call. Additionally, as Rutter and Rutter (2007) found, illness perceptions for chronic conditions such as IBS will probably remain stable over time, unless challenged directly. Therefore, experiences are likely to be evaluated in light of beliefs formed, reinforced or modified in the early stages, placing substantial value on patients' positive early interactions with their GP. This means the early appointments are undoubtedly a valuable opportunity to influence IBS trajectory. As the present study shows, maximising illness coherence (essentially helping patients make sense of symptoms, treatment and management options) could result in improved QoL. Importantly, however, this must be done in such a way which minimises conflict and disparity in beliefs, to avoid the very issues that so many previous studies raise, such as discordance and patients feeling misunderstood. As Drossman (2013) describes when discussing the importance of good communication in healthcare, mutual understanding could, for example, be achieved by the doctor eliciting patients' beliefs and current understanding at the beginning of the consultation and then being mindful of these throughout. This sentiment is echoed in a recently published patient's perspective, whereby increasing understanding and providing clear explanations with patient relevance were important factors in successful self-management (Errico, 2017). Indeed, 'care in medically unexplained symptoms' leaflets advocate very similar strategies; for example, avoid mismatches in beliefs by explaining rather than just normalising symptoms (Chitnis et al., 2011). To further clarify the role of the doctor-patient relationship within this illness

coherence continuum and identify specific mechanisms underlying the association, a longitudinal or interventional approach in future research would be of great value.

A further valuable avenue for future research would be to investigate the role of acceptance in IBS, relative to both doctor-patient relationship and QoL. The correlations with both the primary predictor and outcome variables in the present study, along with its role as a necessary mediator in all models, suggest this could also be an important factor in determining IBS patient outcomes. Little research has investigated the role of acceptance in IBS, although it has been suggested as a therapeutic approach worth pursuing (Naliboff, Frese & Rapgay, 2008). One could hypothesise improving a patient's psychological flexibility and their ability to pursue valued action, enables them to uphold their QoL (see Naliboff et al., 2008; Ferreira et al., 2013; Hayes et al., 2006, for more detailed discussion of Acceptance and Commitment Therapy). However, further research is needed to explore the underlying mechanisms behind such tentative links.

It is imperative to stress that these conclusions are not aiming to blame doctors for the problematic outcomes IBS patients may experience. The variable and functional nature of the disorder makes successful care very difficult, especially in the pressured timeframe of medical appointments (Tsigas et al., 2013). Bearing this (and the advantages of a therapeutic, longer term care pathway for IBS) in mind, a solution could be to develop a care pathway focussing on factors such as illness coherence, mutual understanding and patient-led management, which could be delivered by other health professionals such as health psychologists. Gormley (2014) also considers this in his proposal for an integrated and inclusive healthcare framework for MUS patients when he highlights the need for 'a sensitive and valued service for this substantial client group' (pp. 89).

The present study has several strengths, including its theoretical and evidence based rationale and use of validated disease-specific measures (Ferreira et al., 2013; Patrick et al.,

1998). Additionally, to our knowledge it is a novel study and is the first to explore the association between doctor-patient relationship and QoL in IBS, using mediation analyses. While the data reported here are cross-sectional, they do shed an interesting new light on the interplay between the doctor-patient relationship, illness perceptions and QoL in IBS, which warrants further consideration to confirm the causal pathways. However, some limitations must also be considered. The female-to-male ratio of this sample (85% female) does not mirror epidemiological prevalence rates of IBS. Nevertheless, it is similar to ratios reported by similar previous research also using an IBS network to access participants (Rutter & Rutter, 2002; de Gucht, 2015). Additionally, it may be that individuals who experience negative QoL outcomes or are not satisfied with the support they receive, are more likely to visit IBS support websites, potentially biasing findings towards the adversely affected subsection of the IBS population. Future research should consider a large scale, community study to encompass a wide range of doctor-patient and QoL experiences, aiding model identification.

In summary, this novel, exploratory study aimed to investigate whether an association between doctor-patient relationship and QoL in IBS exists, and to model this association via possible mediators; illness perceptions and acceptance. Illness coherence was most strongly correlated with doctor-patient relationship and the only illness perception to yield a model of good fit, directly preceding acceptance and, indirectly, QoL. This illustrates, and explains, the importance of a relationship which fosters mutual understanding and reduces belief disparity; in turn influencing the patient's ability to make sense of their IBS which then, according to the model, positively influences their acceptance of the condition and subsequent QoL. Although further research is required to explore the mechanisms of this pathway fully, this preliminary research raises some early implications for the IBS care pathway. Medical

appointments could be seen as an ideal target point for IBS intervention strategies aimed at maximising patients' illness coherence and proximally influencing patients' QoL.

Table 1 Participant sample characteristics

	Mean (SD, range)
Age (years)	44.22 (15.91, 18-75)
Duration (years)	11.99 (10.82, 0.25-41)
Severity (scale: 0-5)	3.62 (.82, 2-5)

Table 2 Correlations of the primary independent and dependent variables, with the other variables

	Doctor-patient relationship	Quality of Life
	<i>r</i>	<i>r</i>
Doctor-patient relationship	-	.258***
Identity	-.222**	-.239**
Timeline (chronic)	.014	-.262***
Timeline (cyclical)	-.022	-.038
Consequences	-.160*	-.650***
Personal control	.230**	.303***
Treatment control	.197*	.369***
Illness coherence	.312***	.352***
Emotional representations	-.306**	-.696***
Acceptance	.228**	.712***
Quality of Life	.258***	-

* $p < .05$, ** $p < .005$, *** $p \leq .001$

Table 3 Summary of fit and indirect pathway significance for each of the illness perception models

Mediating illness perceptions	Model fit	Significant indirect pathways (bootstrapped point estimate, 95% CI)		
		Illness perceptions alone	Illness perceptions + Acceptance	Acceptance alone
		No	Yes	Yes
Consequences	Not good fit $X^2(5, N=167) = 60.220, p < .001,$ RMSEA=.257, CFI=.816, TLI=.557.	No (.040, 95% CI = -.009, .089; p=.106)	Yes (.050, 95% CI = .001, .099; p=.047)	Yes (.061, 95% CI = .001, .121; p=.045)
Personal control	Good fit $X^2(5, N=167) = 6.894, p = .2286,$ RMSEA=.048, CFI=.990, TLI=.975.	No (.015, 95% CI = -.009, .04; p=.224)	No (.025, 95% CI = -.001, .051; p=.063)	Yes (.107, 95% CI = .017, .198; p=.02)
Treatment control	Good fit $X^2(5, N=167) = 10.461, p = .0632,$ RMSEA=.081, CFI=.971, TLI=.930.	No (.028, 95% CI = -.003, .058; p=.076)	No (.023, 95% CI = -.003, .049; p=.089)	Yes (.107, 95% CI = .018, .196; p=.018)
Illness coherence	Good fit $X^2(5, N=167) = 9.371, p = .0952,$ RMSEA=.072, CFI=.979, TLI=.949.	No (.025, 95% CI = -.012, .062; p=.185)	Yes (.058, 95% CI = .02, .095; p=.002)	No (0.072, 95% CI = -.016, .159; p=.108)
Emotional representations	Not good fit $X^2(5, N=167) = 28.195, p < .001,$ RMSEA=.167, CFI=.925, TLI=.820	Yes (.130, 95% CI = .051, .208; p=.001)	Yes (.130, 95% CI = .024, .108; p=.002)	No (.016, 95% CI = -.029, 061, p=.481)

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