

Defence Styles, Alexithymia, Illness Perceptions, and HRQoL in IBD

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***Background/aims:** The role of psychological factors in the development and progression of Inflammatory Bowel Disease (IBD) is not completely understood. Several studies have suggested that defence styles, alexithymia and illness perceptions each individually influence the way a person experiences their disease, thereby impacting on health related quality of life (HRQoL). The study aimed to expand the knowledge base and assist in offering a better understanding of the variables by examining the extent of the relationship that defence styles, alexithymia and illness perceptions have with health related quality of life. **Methods:** The study employed a survey design and used opportunity sampling to recruit participants with IBD from a Regional Crohn's and Colitis support group and outpatient Gastroenterology clinics. Participants were given questionnaire packs containing measures and were asked to post them back to the researcher. **Results:** The study found that defence styles, alexithymia and illness perceptions were all correlated with HRQoL. However, multiple regression analysis revealed that the alexithymia subgroup, "difficulty identifying feelings" and the neurotic defence style were the only variables that had a significant relationship with HRQoL. It was also found that females and people that were recently diagnosed also had a worse HRQoL. **Conclusion:** These findings suggest that females who are recently diagnosed with IBD and have difficulty identifying feelings as well as a reliance on neurotic defence styles have a worse HRQoL. Therefore, screening of this population and the introduction of psychotherapy to assist with emotional care might be beneficial in improving HRQoL. **Practitioner Points:** + Gender, time since diagnosis, neurotic defence styles and difficulties identifying own emotional experiences found to potentially contribute to poorer HRQoL. + Therefore, therapy using emotional identification, especially when a person is just diagnosed, might be beneficial to people with IBD. - The study used a cross sectional design, therefore it is not possible to infer causation. Future research should use a prospective design.*

Introduction

Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) is an umbrella term used to describe a chronic inflammation of the digestive system, large intestine and the rectum. The most commonly diagnosed illnesses under the IBD umbrella are Ulcerative Colitis and Crohn's disease (Mawdsley and Rampton 2006). Approximately, three hundred

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thousand people in the UK and three million people in Europe are currently diagnosed with IBD (Burisch et al. 2013).

IBD symptoms can be both physical (e.g., bloody diarrhoea, joint pain, and fever) and psychological (e.g., stress, anxiety and depression) (Sajadinejad et al. 2012, Neuendorf et al. 2012). Due to both the physical and psychological symptoms, it is estimated that IBD costs society and the health care systems in Europe between 4.6 and 5.6 billion Euros per year (Burisch et al. 2013).

However, to date, emotional support for psychological symptoms has been limited, as psychoactive drugs are offered at a much higher rate than psychotherapy, despite psychotherapies, such as third wave therapy, being widely requested and shown to be effective for people with IBD (Tarricone et al. 2017). As such, recent research has focused on further understanding the psychological factors involved in managing the disease, with the hope of improving health related quality of life and reducing the economic burden. A recent systematic literature review of the psychological correlates in IBD found an association with neurotic defence styles, illness perceptions and alexithymia with negative adjustment outcomes, namely quality of life (Jordan et al. 2016).

Illness Perceptions

A person's illness perceptions are influenced by their personal experiences and the information they hold about the illness, such as personal identity, the cause, the consequence and the curability of the illness (Leventhal et al. 1984).

Previous studies have identified that illness perceptions can vary in people with IBD. Mussell et al. (2004) found that people with IBD tend to have illness perceptions that are either associated with responsibility for the outcome of the illness to themselves, others or fate. Other findings have identified that negative illness perceptions relating to social defamation and rejection, the social limits placed on a person due to the symptoms, and the concern of serious consequences, are related to poor HRQoL outcomes. As well as this, it was found that the perception of stigma felt by people with IBD can contribute to between 10 - 22% variance of their reported HRQoL (Kiebles et al. 2010, Taft et al. 2009, Faust et al. 2012).

It has also been found that being positive about the ability to manage and care for personal symptoms is related to an increase in HRQoL in people with IBD (Munson et al. 2009). This suggests that improving illness perceptions, can also improve HRQoL. However, to improve illness perceptions, a person's defence styles must also be able to cope with the impact of the illness.

Defence Styles

Studies on the role of defence styles in determining HRQoL within IBD populations have been limited; however, they suggest that certain defence profiles can have an impact. Hyphantis et al. (2009) found a significant positive correlation between IBD and immature defence profiles, namely maladaptive action (e.g., avoidance and withdrawal) and displacement (i.e., painful feelings associated with

one person are directed towards another person or thing). These defence styles are regarded as being socially undesirable, such as being passive aggressive, somatisation and retreating into fantasy. In particular, Hyphantis et al. (2005) demonstrated that Crohn's disease patients demonstrated higher levels of immature defence styles when compared to individuals with Ulcerative colitis.

Also, high rates of the immature defence style somatisation, which is a physical manifestation of emotional discomfort, is associated with a deprived HRQoL in people with IBD (Hyphantis et al. 2009). Whereas in contrast, IBD patients who adopted mature defence styles had lower relapse rates and surgical interventions. The mature defence styles, such as humility, mindfulness and forgiveness, are regarded as those that are displayed by emotionally healthy individuals.

Other studies have identified neurotic defence styles, which are regarded as being acceptable defences in the short term but not in the long term (e.g., repression, isolation and reaction formation), as being associated with poorer HRQoL of people with IBD (Moreno-Jimenez et al. 2007, Barbera et al. 2017). Interestingly, the neurotic defence style, reaction formation, which is to behave in a way that is the opposite of how a person wants or needs to behave, has been independently associated with a poor HRQoL in people with IBD (Hyphantis et al. 2009).

Therefore, it is potentially the case that people with IBD struggle to manage the negative illness perceptions and emotions associated with their illness, such as stigma, rejection and shame. As a result, unhealthy defence styles are adopted that offer protection from acknowledgment and resolution of these negative emotions (Vaillant 1992, Freud 1936, Freud 1936).

Alexithymia

A potential reason that some people with IBD struggle to manage their negative emotions, is because they have difficulty identifying and describing them.

Alexithymia can be translated from Greek, to mean "without words for emotions" (Sifneos 1996). It describes a person that is incapable of understanding or recognising their own feelings (Sifneos 1996). Nemiah and Sifneos (1970) described patients that they believed had alexithymia as "seemingly detached, unconcerned, and distant". Alexithymia has been found to be prevalent at a rate of between 5-13% in the general population (Taylor et al. 1997). However, it has been found to be prevalent at a higher rate in people with IBD (Iglesias-Rey et al. 2012, Moreno-Jimenez et al. 2007, Porcelli et al. 1999).

Recent research has identified that alexithymia, along with defence styles, are related to "severe physical conditions due to both CD and UC (i.e., low levels of physical health) in females with IBD (Barbera et al. 2017). This finding is supported by previous research which suggests that alexithymia, specifically the subgroups, "Difficulty identifying feelings" and "externally oriented thinking" are associated with a low HRQoL in people with IBD (Iglesias-Rey et al. 2012). It has also been found that having a greater difficulty describing feelings is linked to a poorer HRQoL (Moreno-Jimenez et al. 2007). As well as this, it has been suggested, that along with distress, alexithymia might have a significant effect on the symptomology of IBD (Filipovic & Filipovic 2014).

It has been argued that the association might be explained by the difficulty that people with alexithymia have in recognising and regulating their own emotions. This inability to resolve the discomfort then manifests itself physically, which may be attributed to the IBD symptomology, and further contributes to a reduced HRQoL (Serrano et al. 1996, Porcelli et al. 1995, Porcelli et al. 1996, Verissimo et al. 1998).

Rationale

Recent research has found that defence styles, specifically the neurotic defence style, alexithymia subgroups, and illness perceptions are related to HRQoL in the IBD population regardless of disease activity. However, to date no studies have collectively looked at the variables to identify the extent of their relationship with HRQoL and which of these psychological variables is most strongly related to HRQoL in this context.

The findings will expand the knowledge base and assist in offering a better understanding of the variables that influence the HRQoL of people with IBD. The practical clinical benefit of the study is that it will assist in producing empirical evidence that will inform future psychological interventions by assisting in identifying key variables.

Research Question

What is the extent of the relationship between the independent variables, defence styles, illness perceptions and alexithymia subgroups, with the dependent variable, HRQoL?

Method

Participants

The study used opportunity sampling to recruit participants from an IBD charity and outpatient Gastroenterology clinic.

Inclusion criteria included both male and female participants from the age of 18 years old who had the ability to give consent and had sufficient English language comprehension to understand and complete the questionnaires. The participants had a diagnosis of Inflammatory Bowel Disease. The diagnosis and type of IBD was identified by participants on the demographic self-report form.

Materials

Demographic Self-Report Form

The self-report form consisted of demographic and illness related information. It asked about gender, age, diagnosis, years since diagnosis and co-morbidity. The form attempted to capture any potential confounding variables. Confidentiality of data was ensured as personal details had not been requested from the participants.

Toronto Alexithymia Scale - TAS-20 (Bagby et al. 1994, Taylor et al. 1997)

The TAS - 20 is a 20 item self-report questionnaire of alexithymia. The measure consists of 3 sub-scales which include: difficulty identifying feelings, difficulty describing feelings, and an externally orientated thinking style. A score from 51 to 61 on the measure identifies “possible alexithymia”, where as a score above 61 suggests that a person has alexithymia. The TAS 20 has both a high test-retest reliability and internal reliability (Bagby et al. 1994, Bagby et al.1994).

The Brief Illness Perceptions Questionnaire - BIPQ (Moss-Morris et al. 2002, Broadbent et al. 2006)

The BIPQ is an eight item scale measure of illness perception that measures cognitive and emotional representation of illness perceptions. There is also a ninth item that allows for a qualitative response to be given.

The measure consists of an 11 point likert scale (0-10). It is designed to be prompt, valid and effective in large scale studies. The questionnaire can either produce a total overall score or it can produce sub scale scores (Karataş et al. 2017). However, there is no standardised way of identifying the sub scale groups. The measure has good test-retest reliability and validity with relevant measures (Broadbent et al. 2006).

BIPQ Subscales

Subscales have been suggested for the BIPQ, but the psychometric properties of these subscales have not been evidenced. Therefore, principal components analysis was conducted to determine whether any subscales are likely to exist within this sample. The analysis identified two components of the BIPQ; these were named “consequence focused” (i.e. questions 1-4) and “illness focused” (i.e., questions 5-8).

Questions in the “consequence focused” component (e.g., “How much does your illness affect your life?”) were closely related to the IBDQ outcome questions (e.g., “How often in the past 2 weeks have you had to delay or cancel a social engagement/ felt generally unwell/ tired and worn out/ unable to attend school or work/?”) and were therefore removed from analysis due to overlap. The “illness focused” component questioned a person’s perception of their illness (e.g., “How concerned are you about your illness?”) and was included in the analysis. Therefore, from here on all analysis excluded the “consequence focused” component of the BIPQ. A higher score on the illness focused sub-scale represents a more threatening perception of the illness.

Defense Style Questionnaire – DSQ-28 (Andrews et al. 1993)

The Defense Style Questionnaire (DSQ-28) is a shortened version of the DSQ-40. The DSQ-40 was lacking in face validity and internal consistency on several items, so these items were removed and the DSQ-28 was created. It is a 28 item questionnaire with a 9 point likert scale ranging from “disagree strongly” to “strongly agree”. It assesses mature, neurotic and immature defence styles. With the removal of the items from DSQ-40, the measure was found to have improved discriminant and criterion validity (Saint Martin et al. 2013).

Inflammatory Bowel Disease Questionnaire - IBDQ (Irvine et al. 1996)

The IBDQ is a 32 item self-administered or interview administered measure of the health related quality of life (HRQOL) of people with IBD. The measure consists of four differing domains which include; bowel symptoms, emotional health, systemic systems and social function. The questionnaire produces scores on a range between 1-7, with 1 representing a poor HRQOL and 7 representing a good HRQOL. The IBDQ is a widely used instrument that has demonstrated its reliability and validity cross-culturally (Han et al. 1998, Pallis et al. 2004).

Design and Statistical Analysis

The study employed a cross-sectional survey design. Exploratory analysis of the data identified that the variables met the required assumptions of normality and linearity for statistical analysis. Pearson product-moment correlation coefficient (r) was conducted to identify the strength of the relationship between the independent variables (defence styles, alexithymia and illness perceptions), and the dependent variable; health related quality of life.

Also, a multiple regression analysis was conducted to determine the amount of variance in HRQoL that is explained by the independent variables.

Procedure

Information and invitation sheets were displayed on the IBD charity website and in the newsletter. Questionnaire packs were then posted out to members of the IBD charity by the charity organisers to ensure confidentiality. Posters were also put up in the outpatient Gastroenterology clinic and a nurse gave out the application packs when requested by interested potential participants.

The questionnaire pack which contained the information sheet, one demographic self-report form and four questionnaires were returned by post, using the stamped addressed envelope, to the University, Psychology Department.

520 questionnaire packs were given out to participants, 420 through the IBD charity and 100 through the Gastroenterology clinic. 145 questionnaire packs were returned and 139 were eligible and used in the study.

The study was granted ethical approval by the NHS Research Ethics Committee (REC) and the local trust health board.

Results

Demographics

One hundred and thirty-nine participant questionnaire packs were included in the study. The majority of participants were female, with 73.5% of responses compared to 26.5% of males. Participants were most commonly aged between 30 and 49 years old and most people identified that they were diagnosed with the disease between the ages of 20 and 29. Crohn's Disease was the most common type of IBD identified, and 57% stated that they also had another medical condition. Most participants (60.4%) felt that stress and worry was the cause of their IBD (see Table 1).

Table 1. *Descriptive Data for Demographic Information*

Demographic information (total sample size – 139 participants)	N	Percentage
Age	138	
18 – 19	9	6.5%
20 – 29	22	15.9%
30 – 39	28	20.3%
40 – 49	28	20.3%
50 – 59	23	16.7%
60 – 69	23	16.7%
70 and above	5	3.6%
Gender	136	
Male	36	26.5%
Female	100	73.5%
Diagnosis	138	
Crohn's Disease	74	53.6%
Ulcerative Colitis	57	41.3%
Both	2	1.4%
Not clearly diagnosed with either	5	3.6%
Diagnosis age	138	
19 and below	39	28.3%
20 – 29	41	29.7%
30 – 39	27	19.6%
40 – 49	17	12.3%
50 – 59	10	7.2%
60 - 69	4	2.9%
Other medical conditions	138	
Yes	79	57.7%
No	57	42.3%
Anxiety or depression named as other medical condition	138	
Yes	20	14.4%
No	118	85.6%
Colostomy or ileostomy	139	
Yes	22	16.2%
No	114	84.8%
Perceived cause of IBD	139	
Stress or worry	84	60.4%
Hereditary or genes	54	38.8%
Diet or food	45	32.4%

Measures

The illness focused perceptions mean score was found to be similar to other IBD population studies (Knowles et al. 2013, Knowles et al. 2013). The Alexithymia mean score was found to be higher than the general population and other studies investigating IBD populations, suggesting higher levels of alexithymia (Franz et al. 2008, Barbera 2017). For defence styles, the immature defence style was the most common response, similar to previous studies (Hyphantis 2005). The HRQoL total score was found to be lower than in other IBD studies (Pallis et al. 2002, Han et al. 1998), but higher than the De Boer et al. study (1995), suggesting a low quality of life (see Table 2).

Table 2. Descriptive Data for Illness Factor, Alexithymia, Defence Styles and HRQoL Measures

Measures	N	Mean scores	SD
Illness factor subgroup			
Total score	138	24.99	6.61
Alexithymia			
TAS-20 Subscale 1 (difficulty identifying feelings)	138	22.15	7.844
TAS-20 Subscale 2 (difficulty describing feelings)	138	15.14	4.785
TAS-20 Subscale 3 (externally oriented thinking)	138	21.19	5.340
TAS-20 Total Score	138	58.97	14.603
Defence styles			
Mature defence style total	137	43.05	11.09
Neurotic defence style total	137	28.65	8.69
Immature defence style total	137	57.98	15.60
HRQoL			
Total score	137	129.39	42.01

Correlation

A series of correlations were performed to examine the relationship between the variables and the HRQoL outcome measure, Inflammatory Bowel Disease Questionnaire (IBDQ). A significant relationship was found between each of the variables and HRQoL. The alexithymia subscale, “difficulty identifying feelings”, had the strongest association, with a strong, negative and significant relationship with HRQoL ($r = -0.54, p < 0.001$) (see Table 3).

Table 3. Relationship between Illness Factor, Alexithymia, Defence Styles as measured by HRQoL

Measures	HRQoL total
Illness factor subscale	$r = -0.26,$ $p = 0.002$
Alexithymia	
TAS-20 Subscale 1 (difficulty identifying feelings)	$r = -0.54,$ $p < 0.001$
TAS-20 Subscale 2 (difficulty describing feelings)	$r = -0.45,$ $p < 0.001$
TAS-20 Subscale 3 (externally oriented thinking)	$r = -0.22,$ $p < 0.01$
Mature defence style total	$r = 0.21,$ $p = 0.02$
Neurotic defence style total	$r = -0.23,$ $p < 0.01$
Immature defence style total	$r = -0.22,$ $p < 0.01$

Multiple Regression Analysis

Multiple regression analysis was conducted to examine the relative strength of the relationship between demographic information, alexithymia, defence styles and illness perceptions (the covariates) with HRQoL (the outcome measure).

Overall, time since diagnosis (beta = .224, $p=0.01$), gender (beta = 0.20, $p<0.01$), difficulty identifying feelings (beta = -.339, $p<0.01$) and neurotic defence style (beta = -.187, $p=0.04$) were all statistically significant measures for explaining variance in HRQoL. Difficulty identifying feelings recorded the highest significant beta value out of all the contributors thereby identifying that it made the strongest unique contribution to explaining the total IBD HRQoL score. A total of 45.1% variance of HRQoL was explained by the model (see Table 4).

Table 4. *Multiple Regression Analysis for Illness Factor, Alexithymia, Defence Styles with HRQoL Total Outcome Score*

Measures	Beta	Sig
Crohns vs colitis	-.162	.060
Unclear vs colitis	-.036	.632
Both vs colitis	-.079	.292
Gender	.201	.009
Age	-.174	.086
Time since diagnosis	.224	.018
Other medical conditions	.111	.139
Difficulty identifying feelings	-.339	.003
Difficulty describing feelings	-.153	.190
Externally orientated thinking	-.021	.802
Mature defence style	.122	.191
Neurotic defence style	-.187	.041
Immature defence style	.066	.458
Illness perceptions- illness focussed subscale	-.062	.466

Discussion

This study examined the extent that defence styles (mature, immature and neurotic), alexithymia subgroups (difficulty identifying feelings, difficulty describing feelings and externally orientated thinking) and illness perceptions, are related to HRQoL in IBD.

It was found that all of the variables were significantly correlated to HRQoL. However, in the multiple regression analysis, only the alexithymia subgroup, “difficulty identifying feelings” and the neurotic defence style had a significant relationship with HRQoL. From the demographic information, gender and time since diagnosis, were also both significantly related with HRQoL, suggesting that females and participants more recently diagnosed with IBD, have a worse HRQoL.

These findings are similar to those found in recent research which identifies that alexithymia, along with the neurotic defence style, are related to severe physical conditions in females with IBD (Barbera et al. 2017). Barbera et al suggested that females with alexithymia are more likely to develop IBD than males because

females somaticize their emotional pain, whereas males with alexithymia develop behavioural issues. It has also been suggested that such difficulties associated with alexithymia might have a significant effect on the symptomology of IBD (Filipovic & Filipovic 2014).

The association between the alexithymia subgroup “difficulty identifying feelings”, as was found in this study, and a low HRQoL in people with IBD has also been found in previous research (Iglesias-Rey et al. 2012). It has been suggested that an individual’s difficulty in effectively identifying their own feelings can limit their ability to differentiate between psychological experiences, such as anxiety, and IBD symptoms. As a result, IBD symptoms may be interpreted as an emotional response or emotions may be interpreted as a symptom of IBD. Therefore, people who have “difficulty identifying feelings” might be more likely to somaticize psychological experiences such as emotional distress, and potentially experience them as physical pain (Barbera et al. 2017, Bar-On & Parker 2000, Sifneos 1996, Taylor et al. 1997).

The significant relationship between neurotic defence style and a poor HRQoL has been identified in previous research (Jordan et al. 2016, Moreno-Jimenez et al. 2007, Barbera et al. 2017, Hyphantis et al. 2009). The neurotic defence style includes thoughts and behaviours such as repression, isolation and denial which attempt to avoid the experience of painful emotions, such as shame and anxiety. Therefore, “difficulty identifying feelings” which may involve the misinterpretation of feelings, combined with more neurotic defence styles, can lead to an emotional detachment from the IBD symptoms and an inaccurate perception of the illness (Hyphantis et al. 2009, Moreno-Jimenez et al. 2007).

Illness perceptions have been identified as being important in the IBD population (Knowles et al. 2013, Rochelle & Fidler 2013). However, for this study, the lack of a significant relationship between illness perceptions and HRQoL is potentially due to only a subgroup of the BIPQ being investigated. Therefore, it is potentially the case that the inclusion of only the illness focussed perceptions, without the consequence focussed perceptions, distorted the relationship with HRQoL.

Future Directions

A recent systematic literature review has identified that a small proportion of people with IBD have access to psychotherapy despite it being found to be effective in treating psychological issues (Tarricone et al. 2017). On the basis of this study, psychological interventions could be tailored to individual needs, and might benefit from focusing on emotion based psychoeducation to provide an in depth awareness and understanding of a person’s abilities to recognise individual emotions, the purpose and function of emotions and the positive and negative connotations associated with each.

The Tarricone review (2017) also found that third wave psychotherapies that assist in developing a mind-body link are effective in improving adjustment outcomes. Such psychological therapy may contribute to encouraging a better awareness of emotional recognition and the importance of self-care in attempting to manage IBD as a chronic condition.

Limitations

When measuring complex personality traits such as alexithymia and defence styles, questionnaires might not give a true representation of the complex nature of such personality constructs. Therefore, perhaps a thorough interview and observation of participants might give a better representation of their personality.

Summary

These findings were similar to those recently found in the Barbera et al. (2017) study, suggesting that females who are recently diagnosed with IBD and have difficulty identifying feelings as well as a reliance on neurotic defence styles have a worse HRQoL. Therefore, it might be beneficial to conduct a screening at the time of diagnosis to identify this population and offer psychotherapy to assist with emotional care and long term HRQoL.

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