Predicting relationships of Quality of Life and Fear of Negative Evaluation in Crohn’s Disease.

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Abstract

Aim: To explore the relationships between predictors of social anxiety, symptom severity, support and control in predicting fear of negative evaluation and health related quality of life in participants who have been diagnosed with Crohn’s Disease.

Method: Questionnaires were administered to participants who were diagnosed with Crohn’s Disease. There were 116 responses in total.

Findings: As age and control increase fear of negative evaluation decreases in Crohn’s patients. Also it was found that as support increases quality of life increases and as symptom severity increases health related quality of life decreases as predicted. Symptom severity was tested as a mediator of support and quality of life but this was not supported.

Conclusion: Age may influence feelings of negative evaluation as social inclusion may be of importance at particular stages of a person’s life cycle. Quality of life and symptom severity has been previously researched and correlated, however this study found that there was a relationship at mild and severe levels of disease but no relationship at moderate level. Control and support were both associated with coping outcomes in chronic disease. Further research would be recommended to assess the type of coping style and early intervention of support. Also fear of negative evaluation studies in an adolescent sample of Crohn’s patients would be beneficial.
**Introduction**

*Crohn’s Disease.*

Crohn’s Disease (CD) is a gastrointestinal illness which attacks the walls of the intestine. It is an episodic illness which has an unpredictable and varied list of symptoms. The intestines become inflamed causing them to swell. This can leave behind scarring and abscess and can cause a thickening in the intestine which makes it difficult for food to pass through. The symptoms of CD are varied. Patients can experience period of remission followed by unpredicted flare ups with an extensive list of internal and external symptoms. Boyer and Pahari, 2008 state that the symptoms which can occur are abdominal pain, diarrhoea, weight loss, fever, lack of nutritional absorption and blockages. Also Zonderman and Vender, 2000 explain that external manifestations can arise such as redness and inflammation under the skin and in the eyes known as uvutis. Joint pains, skin lesions, ulcers and deficiency in growth and sexual maturation are some of the additional symptoms which are associated with the disease. Due to the demanding nature of the disease it can hinder a person’s ability to lead a full and healthy life and could make it difficult to maintain normality in social situations. Research on social anxiety and CD has been extensive with a relationship between the two variables a common finding (Mackner & Crandall, 2005, 2005, 2006, Kunz et al, 2010). Taking into account the various symptoms and the increasing rates of diagnosis, with 150,000 people in Ireland alone diagnosed with the disease, there is a need for exploration of the impact on psychological wellbeing and what contributes to this. The aim of this study is to examine patients with CD and evaluate the roles of social anxiety, control, support, age, gender and symptom severity and what relationship these variables have on fear of negative evaluation and quality of life.

*Quality of Life*
With the increased longevity of life in recent time there has been a focus on the examination of quality of life (QOL). By measuring QOL it allows researchers to look at the ability to live a normal and healthy life to the quality of the external environment. The use of studying the Quality of Life (QOL) in patients with CD is to assess the impact that the disease has on the patient’s life as a whole. Fyers and Machin (2007) state that quality of life is determined by people’s perceptions and may mean different things to each individual. Bowling (2001) supports this and states that the hopes and needs of a certain person at a certain time will be the outcome of their quality of life and that it is influenced by past experiences, current feeling and future goals. This applies to generic quality of life studies and disease specific measurements. Previous research in the relationship of chronic disease and quality of life would suggest that the benefits of examining a CD-specific model of QOL are that they examine a true representation of the disease which includes symptoms, psychosocial, emotional and systematic function. Fayers and Hays (2005) explain that the benefits of this are that more attention to detail is paid to the patient and it is more sensitive in dealing with the issue. The use of these health related QOL measurements have proven to be beneficial for other chronic diseases such as Heart Disease, Anorexia nervosa, Multiple Sclerosis and COPD (Kuspinar & Mayo, 2013, Johnson et al. 2006, Wilke et al, 2012, Mitchison, D et al 2013) in comparison to generic questionnaires. By using these measures we can get a full view of the extent of impaired functioning in patient. There have been studies conducted in the area of Quality of Life in CD patients and the findings have been that the symptom severity is an indicator of QOL. Cohen (2002) found in a meta-analysis of 22 studies that disease activity correlated directly with symptom severity in social, systematic, emotional and psychical functioning in all but one study. He also states that as CD is a disease which has chronic symptoms that will persist throughout a patient’s adult life. The disease shows statistics of a low mortality rate which is the reason that the investigation
of quality of life in aiding improvement in all areas of life is imperative. The areas of functioning which are impaired span beyond social functioning and symptoms. The QOL of a CD patient can also affect professional and personal achievements as Lichtenstein et al (2004) found when they conducted a study using 573 patients. They found that as symptom activity increased so did unemployment rates. The results showed that quality of life was severely impaired in patients who were not in remission and that there was a 16% difference in unemployment in patients who were displaying active symptoms. They also found a lower score of physical and mental functioning. These findings in different areas of functioning associated with CD has provided a broader view of the domains which contribute to quality of life that also go beyond disease activity, making it achievable to identify other causes of impaired QOL like Lienichstein found. This study will look at various contributing factors to create a better understanding of the relationships which predict QOL. The aim of studying HRQOL is so that it can be applied to clinical trials and improving symptom relief. It is also helpful in identifying what the patient would like to gain from this as well as gaining more knowledge on the quantifiable knock on effects of their disease. Fayers and Machin reported that a correlation between HRQOL in Chrons disease and psychosocial and emotional and systematic issues are identified as Factors using the Irritable Bowel Disease Questionnaire (IBDQ). Using this measure this study aims to look at the relationship between quality of life as an outcome of social support, control, age and symptom severity and to measure the impairment of quality of life. This will provide a better understanding of the some areas associated with quality of life and contribute to the growing research of CD.

Fear of Negative Evaluation

CD patients suffer from internal and external symptoms of an embarrassing nature. From a social perspective, there may be an inability to function socially in fear of unpredictable diarrhoea; soiling and chronic fatigue which would alter a patient’s ability to
carry out social functions as well as others. Fear of negative evaluation is described by McClean and Woody (2001) as a cardinal trait of social anxiety. This is the fear of scrutiny from others and usually involves a fear of social situations, particularly public speaking. However this can apply to any social scenario such as holding a conversation with somebody or being seen in public. The perception that people will evaluate you in a negative way may add to your social anxiety before you enter into the situation. Shyness as a trait has seen a significant relationship with fear of negative evaluation with heightened fear of rejection as a common perceived cause of this (Jackson et al 1997, 2000, 2002). Social interaction becomes more difficult for socially anxious individuals who possess this fear. Examining the impact of this in observational setting and the powerful effect that FNE can produce, Gilbert and Meyer (2005) found that restrictive eating patterns in students starting college were reflective of the fear they had of being negatively evaluated by their peers at a time of this heightened social scenario. A result of this was a change in eating behaviour. Similarly the constant feelings of heightened vulnerability of the symptoms of CD patients could impact on daily social functioning creating a stressful reaction. Negative evaluated situations were found by Dickerson et al (2008) to produce levels of cortisol when there is a social evaluation threat. This would elicit a stress response in an event of an unplanned bathroom break or an urgent need to pass wind for example. Stress has shown to be a main trigger for CD symptoms and therefore FNE could create a chain reaction between symptoms and stress which in turn may heighten FNE. This is a recurrent factor and has been found in many chronic diseases such as Parkinson’s disease and psoriasis which would display more visible symptoms than CD (Simers et al, 1993). McCarroll et al (2008) found that people suffering from chronic illness can be seen from adolescence to display lower level of peer contact, more social anxiety and display social inhibition in completing daily activities such as going to school or work or participating in leisure active. For these reasons ties with social peer groups could become
severed causing lower self esteem in social situations. At times of severe symptoms this could affect a CD patient, especially with the unexpected appearance of symptoms. To date research of FNE and disease has been quite limited with the main body of research conducted on patients suffering from visible disorders such as psoriasis and visible disfigurement (Kent & Keohane, 2001, Leary M et al 1998) The research has shown that FNE rises with the impression that the symptoms can be seen and judged. There has been no research conducted on FNE and disease which elicits internal and external symptoms with socially embarrassing consequences such as Crohn’s Disease. Based on the findings on FNE and visible symptoms, the social response to the embarrassing symptoms of CD would expect a similar finding.

This study aims to look at some of the contributing factors of FNE in Crohn’s Disease which are control support, anxiety and symptom severity to predict what influence the variables have on FNE.

Social Anxiety

CD can cause normal social situations to become daunting to the patient. With the nature of the symptoms and associated issues, it can be socially inhibiting, for example to complete activities which would require the absence of a toilet for a long period of time or compete in strenuous or sporting activities when suffering from fatigue. Guthrie et al (2002) found that the presence of a psychological disorder, particularly anxiety and depression has an effect on health related quality of life in Crohn’s patients. However it is not known what directly causes anxiety in CD. With the presence of social anxiety it may become difficult for the individual to participate in normal social activities or to engage in large groups of people. It has been a topic of research in CD and there has been a consistent finding that higher levels of social anxiety are found in patients with chronic diseases. For example Poder et al (2009) who studied the correlation between Multiple Sclerosis and social anxiety disorder found that anxiety led to avoidance of future social situations which could lead to social isolation, loss
of social peers, dissatisfaction with life and destructive coping mechanisms. These would all contribute to feelings of poor quality of life. The nature of the symptoms can be perceived as embarrassing to some people, causing social repercussions and psychosocial issues which in turn increase can disease activity. In support of Poders findings, to date the role of social anxiety in patients suffering from Crohn’s disease has been examined closely and has shown significant relationships between the two variables (Mackner & Crandall, 2000, 2005, 2006, Kunz et al, 2010 Steinhausen Iglesias, 2009). It is difficult to explain the exact reason why CD illicit anxiety responses as there may be a varied list of contributing factors. For example, Reigada et al (2011) found in adolescents with CD that when predictors of anxiety in thirty-six participants were examined and it was found that the biological symptoms which contributed to reports of poorer health did not have as much of an impact on anxiety as the psychosocial factors such as missing school. These findings could be limited as different age groups display a greater need to socialise and form peer relationships than adults would. Also the stage of the disease may contribute the anxiety. For example Kurina et al (2001) found while conducting a meta-analysis of 5231 patients hospital records that anxiety was significantly reported at the time of diagnosis or in the first year after diagnosis of the disease, indicating that the actual diagnosis may cause these feelings of anxiety. In addition to this, a recent meta analysis conducted by Greenley et al (2010) showed that patients who are newly diagnosed with disease showed higher rates of anxiety in internalizing disorders than in any other disease. These findings may suggest that due to the diagnoses of the disease there were feeling of anxiousness which faded with acceptance of the disease. This is conflicting to previous studies which have found that there is a significant relationship between symptom severity and anxiety in CD. In support of this a study conducted by Meder et al (2010) reports that anxiety disorders declined from 78% of a sample of 41 patients with CD to 54% after relapse occurred and they were back in remission. The same study also
found a negative correlation between anxiety disorders in patients with CD and their quality of Life. The debate into the findings that anxiety is created at diagnosis or persists with symptoms is conflicting and this study will examine the role of anxiety as both a predictor using a social anxiety measure and an outcome which examines the relationships which affect FNE. Based on previous finding, it is evident that a correlation exists with anxiety and CD, however to explain how much impact it has on quality of life and FNE, this study will also examine the relationships and also examine the role of symptoms as a mediator.

Symptom Severity

As mentioned, previous research has seen that symptom severity correlates directly with Quality of Life (Wexner and Frattini, 2010, Cohen 2002). The severity of symptoms at any given time will change. These can occur simultaneous to each other. Most people will find themselves in periods of remission followed by flare ups. When flare ups occur, they could last for a short period of time or may be followed with heightened medication and/or hospitalisation (Potter, 2003). The flare ups can affect any part of the digestive system from the oesophagus to the anus; however it is most common in the small intestine. Symptoms can range from moderate to severe and illicit a broad spectrum of internal and external symptoms. Porter (2009) explains that it is not just the flare ups that cause the problems but when remission begins again the patient can be left with deep scarring which may cause obstructions and ulcers on the bowel. Even when a flare up is not present there may be still inflammation of the eyes and joints. Also future symptoms could affect patient’s quality of life as Porter explains a correlation between CD and increased risk of colon cancer would cause worries about the future symptoms in patients. This again could cause anxiety and stress levels which initiate further symptoms and may impair quality of life. The symptoms are unpredictable and would affect not only the person psychically but emotionally and socially. For example if a person experiences a flare up and symptoms include unpredictable
diarrhoea, they would become unable to leave the house in fear of sudden diarrhoea or plan ahead with peers as they would not know how long the symptom would last. As a knock on effect and similar to findings of anxiety and FNE they also may experience emotional effects from this social isolation or feel why me? It has been argued that the role of pre-existing personality traits may cause a higher report of pain or symptoms in studies related to CD (Boye et al, 2014, Bavinda et al) particularly in neurotic patients, however the use of the Harvey Bradshaw index will eliminate this as the majority if the questions are in relation to psychical symptoms with one question in relation to subjective well being. The levels of severity will be categorised and correlated with QOL and fear of negative evaluation. As FNE has not been previously tested it is predicted that this will increase as symptoms increase due to previous social anxiety findings.

*Symptom severity as a mediator*

This study will look at symptom severity in relation to psychosocial issues and how they act as a mediator between the variables. It is predicted that as symptom severity increases, fear of negative evaluation will increase and quality of life will decrease. Regression will be carried out to confirm if symptom severity acts as a mediator between the two outcome variables and the predictors using Baron and Kenny’s model (1986) of variable distinction.

*Social Support*

Social support can be defined in many different ways, such as resources provided, resources exchanged, assistance or perceived help (Schwarzer and Knoll, 2007). The main body of research which looked at social support studied this as a coping mechanism for patients with chronic disease and this model originated from Lazuras and Folkman (1984). The study suggested that perceived support of the patient initiates a cognitive appraisal. Due
to this appraisal occurring, coping is the outcome. Therefore the more social support is available to a patient, the better the coping. Waters, Schootman and Jeffe (2013) conducted a study using 542 controls that were healthy and compared them with 542 women who had been diagnosed with breast cancer. They examined a good level of perceived support at baseline but with the patients with cancer they reported a large decline in this perceived support 6, 12 and 24 months after initial contact was made. To explain this, it could be that the initial announcement of an illness might see a burst of support from family member and friends. In studies such as this, perceived support could be affected by the withdrawal of this initial burst. Also similar to the findings of Regida in relation to diagnosis, the anxiety which was found in the first year would require more social support while the individual accepts their illness. Waters, Schootman and Jeffe also reported that patients who reported low levels of support at baseline experienced a decline psychologically. To control for this, the role of support could be assessed after initial diagnoses of CD to judge the psychosocial and psychological impact of the disease on the patient. This may also influence the style of coping which is adopted as disengaging styles of coping are regularly seen in patients who are socially anxious about their disease. Friends, family, peers and medical staff who provide a good level of support will create an active coping style for the person who is in need. However it has been found in previous studies that when actual support is provided it has minimal effect compared to a patient’s perceived support. (McDowell and Serovich, 2007, Moskovitz wt al, 2000, Jones et al 2006). The presence of neurotism, even in the absense of chronic disease can affect perceived support according to Lutz and Lakley (2001).The correlation between social withdrawals as a form of coping can leave feelings of isolation. This social isolation can become an outcome of disease particularly chronic disease and may cause feelings of social anxiety or as noted in relation to peer activity, an emergence of FNE. Similarly in connection with the design of this study, there have been previous findings in
disease which suggest that an increase in quality of life is influenced by social support. Bosworth et al (2000) found in a large study which collected data from patients with Coronary Heart Disease that social support impacted on quality of life. Support for this finding has been found in other research in chronic disease such as AIDs by Motl et al (2009) and in type II diabetes by Tang et al (2009). Based on these findings, it is predicted that social support will influence quality of life in participants with CD. As this is a disease which is incurable, there may be a need for constant social support to help cope with the disease. There may be, as we seen in feeling of negative evaluation, a reluctance to talk about the diseases or its symptoms at the risk of embarrassment or risk of creating negative feelings which may give others the impression that their support is not needed. The relationship between social support, fear of negative evaluation and quality of life will be examined.

Control

Cohen (1988) explains that with the presence of Chronic illness there is supporting evidence to suggest that a feeling of helplessness and vulnerability prevail with a loss of personal control. Perceived control is the perception that events are within your control, which would be the disease and its related effects. CD patients would experience a loss in physical control with unpredictability of the flare up of symptoms. Like social support, control can be perceived by the patient rather than be actual support but according to Lazuaras and Folkman (1984). It also creates a positive appraisal which helps with coping and encourages active styles of coping Loonen et al (2004) have confirmed that that control was observed less in chronic disease than in healthy controls and that a more avoidance approach of coping style was adopted. In addition to this Folkman also states that the larger the threat to an individual, the greater the need for perception of control is needed. This was supported by Hegelson (1991) who in studying patients with chronic disease, found that the greater the
threat of severity of the disease, the greater need for control. As discussed the nature of the symptoms of CD would compromise the control on bodily functioning, integrity, embarrassment and social functioning. Poor perceived control has been reported in cases of decline in mental and physical health in disease reoccurrence as Tomich and Hegelson (2006) found that in patients with re-emergence of breast cancer suffered from this decline. The reoccurrence of symptoms in CD could possibly produce a similar decline due to its unpredictable nature. Thompson and Kyle (2000) also found consistent findings that perceived control in chronic illness resulted in better psychological results in patients and emergence of positive coping styles. Similar to the findings in support, a more positive coping style will reduce the risk of disengagement and anxiety disorders such as FNE. The type of disease is important in predicting the amount of control which a participant will perceive. For example in a meta analysis of neurodegenerative diseases, Eccles and Simpson (2011) found when looking at a meta analysis of 44 past papers of neurodegenerative diseases that symptom control based on the knowledge of the disease and its symptoms resulted in feelings of lower psychological health. This could be applied to CD as it is known to have incurable symptoms which last throughout a person’s life with few mortality rates related to the disease. Along with the unpredictable flare ups of the disease, feelings of control could be higher in CD than a disease which is easier to control with a change of lifestyle changes through diet and exercise such as Coronary Heart Disease. Surprisingly to date, there has been little research conducted on control and Crohn’s disease with no known research in control and the effect it has on fear of negative evaluation and quality of life in CD patients and this study will explore this in further detail.

Aim
The aim of this study is to explore the predictive relationships which contribute to the outcomes of poor quality of life and fear of negative evaluation in patients who have been diagnosed with Crohn’s Disease. The study will measure the relationships of age, gender, control, social support and symptom severity on both the outcome variables. Unlike previous research, the exploration of fear of negative evaluation is measured as an outcome of an internalizing disease rather than a disease which displays visible symptoms. The impact of severity of symptoms has been evident in the role it plays in predicting quality of life; however this study also aims to look at the role of symptom severity as a mediator in predicting quality of life. There were three main hypotheses which were: There will be significant correlations between demographic details, support, control, social anxiety and symptom severity in predicting quality of life in CD patients. The second was that there will be significant correlations between demographic details of age and gender, control, support, social anxiety and symptom severity in predicting fear of negative evaluation in CD patients. Lastly the third hypotheses predict that symptom severity will act as a mediator in predicting quality of life in CD patients.
Procedure

Participants

There were 116 participants in total (Mean= 2.16, SD=.812, Range=4). Inclusion factor for participants was a diagnosis of Crohn’s Disease. The type of sampling which was used was snowball sampling. Questionnaires were distributed to Crohn’s Disease support groups on social media sites and on Forums associated with Crohn’s Disease. In addition questionnaires were sent to participants who were known to have CD and who had agreed to take part in the study. Overall there was a response rate of 117 participants after the removal of one questionnaire which had insufficient information, there was a remaining 116 used for this study. Criteria for the participants to meet were that they had been diagnosed with CD and were over 18. Due to the various sites which the questionnaire as sent to it, the locations of each participant were not known. These participants were a total of 10 men and 106 women who ranged from the age groups of 18-25(N=22), 26-40(N=60), 41-55(N=28), 55-60(N=5) and 60+ (N=1). The age group of 26-40 was predominating in responses with 51.7% of the responses in this age bracket.

Design

This study is a correlation study. The independent variables are social anxiety, symptom severity, control, social support, age and gender. The dependent variables are quality of life, fear of negative evaluation and symptom. Symptom severity will be tested as a mediating variable in relation to quality of life

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correlations between demographic details of age and gender, control, support, social anxiety and symptom severity in predicting fear of negative evaluation in CD patients. Lastly the third hypotheses predict that symptom severity will act as a mediator in predicting quality of life in CD patients.

**Materials**

The following questionnaires were given to the participants to complete. All questions required an answer.

1) Cover page which included the aim of the study and details of access to the information. The participants were told on the covering sheet that once the questionnaire was submitted that the data could not be withdrawn. This also made participants aware that the questionnaire was anonymous.

2) Demographic details were asked which were age and gender. The participants were required to be over 18.

3) Brief Fear of Negative Evaluation (Leary, 1983). This is a 12 item scale which measures the extent of how people are concerned with others negative feelings and evaluations towards them. It is used in judging fear of negative evaluation as a construct of anxiety and used in assessing how this negative evaluation may contribute to social anxiety. This is high in reliability and internal consistency (Cronbachs α= 90, Leary, 1983, Carleton et al 2006, 2007). It consists of 8 straightforward questions and 4 reverse coded questions which are rated on a five point Likert scale which answers from 1 (Not very characteristic of me) to 5 (Extremely characteristic of me).

4) The Social Avoidance and Distress Scale: The SAD scale was developed by Watson and Friend (1969) and consists of 28 questions which have a True or False answer. This is used to
measure the experiences of Social Anxiety including anxiety and fear and the avoidance of certain situations. This was tested by Watson and Friend and found to be high in reliability and internal consistency which was measured at .94. There was a moderately high consistency between the SAD scale and the BFNE also.

5) Inflammatory Bowel Disease Questionnaire IBDQ. This consists of 36 questions which evaluates the quality of life in a patient with CD. This is divided into four areas which are systemic functioning, emotional functioning, symptoms and social functioning. For this study this has been modified. The 9 questions which are in relation to the symptoms have been removed as we have evaluated symptoms using the Harvey Bradshaw Index. The responses for the IBDQ are on a Likert scale of one to seven with 7 corresponding to the highest level of functioning and 1 corresponding to the lowest. This has shown adequate level of reliability and validity. (Alcala, 2004) This is changeable due to disease activity also. (Cronbachs α = .96.)

6) Harvey Bradshaw Index. This is a 5 question measure which evaluates the category of symptom severity in CD patients. The questionnaire scores one for each answer and has a sole aim of assessing symptoms. There is a score of 2 for each response. The scoring is <5 - Remission, 5-7 Mild disease, 8-16 Moderate disease, >16 – severe disease. Cohen states that this is a simplified version of the CDAI ad has been simplified for our target participants and this was correlated at a coefficient of .55 with the IBDQ.

7) Control – This was measured using a four question likert scale which ranged from 0 to 5. This was used to judge the amount of control a patient felt they had in relation to the disease. The measure by Gibbons (2010) was found high in reliability and consistency and has a Cronbachs alpha which exceeded 7.
8) Support was also measured using a 5 point measure likert scales ranging from 0 to 5. This was used to measure the amount of support that each patient received from a number of different social groups. This included Family, friends, partner and doctor. Gibbons (2006) also fund this to score high in reliability and validity and to have a Cronbachs alpha which exceeded .7.

The questionnaires were distributed by method of snowball sampling to a target population of participant who were diagnosed with Crohn’s Disease. They were sent online via email to some participants. Permission was sought by administrators of social networking sites and forums which were dedicated to participation from CD patients. This appeared as a link could chose to follow. An explanation and description of the study was posted with the link and the participant was informed that once the data was submitted that it could not be withdrawn. All completed data was submitted to the author via email and collated for data analysis. During data collection there were objections from potential participants in relation to online fraud attempts and the exclusion of patients with colitis.

Ethical procedures:

The study was approved by the Ethics Committee in Dublin Business School. The link to the questionnaires which was sent to all participants contained a cover sheet which stated that the information provided was anonymous and that all information would be stored on a person laptop of the author in an encrypted folder. It also informed the participants that once the questionnaires were complete that they could no longer withdraw their data. Details of the researcher and supervisor were given. There was information provided on associated support groups on the cover page and the last page of the questionnaire in the event that any participants were affected by nature of the questions.
Results:

The data was analyzed using SPSS version 21. There was 116 participants in total (Mean= 2.16, SD=.812, Range=4). The age of the participants was grouped with the highest percentage of participants between 26-40 (51.7%) and the lowest number of responses from the age group of 60+ (9%). A t-test was conducted to interpret the gender difference in the outcomes. Results indicate a non-significant result in age and FNE scores between males (M=30.10, SD=8.31) and females (M=26.10, SD=8.69), t (114) =1.40 p=1.66. This indicates that there was little difference between males and females in fear of negative evaluation. There was also a non significant result when a t-test was conducted between health related quality of life in males (M=60.50, SD=22.56) and females (M=68.70, SD=17.48), t (111) =-1.38, p=127. This indicates that there was also little difference between male and females feelings of quality of life.

Table 1: Correlations between Significant Factors, Quality of Life and Fear of Negative Evaluation

<table>
<thead>
<tr>
<th>Factors/predictors</th>
<th>Quality of Life</th>
<th>Fear of Negative Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.90</td>
<td>-.238*</td>
</tr>
<tr>
<td>Social Anxiety</td>
<td>.89</td>
<td>-.159</td>
</tr>
<tr>
<td>Control</td>
<td>.293**</td>
<td>-.129</td>
</tr>
<tr>
<td>Support</td>
<td>.162</td>
<td>-.375**</td>
</tr>
<tr>
<td>Symptom Severity</td>
<td>-.547**</td>
<td>.197</td>
</tr>
</tbody>
</table>

*Significant at .05 level

**Significant at 0.01 level

Regression analysis was conducted to predict the relationships between predictors and outcomes. The regression co-efficient table for table 1 are shown below. The assumptions for conducting regression were checked and confirmed. The criterion variables were
continuous, the Mahalanobis distance values did not account for any substantial outliers, the
cores were normally distributed and the tolerance values did not exceed .02, indicating that
there was no multi-collinearity Table 1 shows correlations were conducted between predictors
which were age, social anxiety, control, support and symptom severity and outcomes which
were quality of life and fear of negative evaluation. There was no correlation found between
the predictor which is social anxiety and the outcome factors. Regression analysis was
conducted on the remaining significant findings.

Table 2: Multiple Regressions with Age, Support and Fear of Negative Evaluation

<table>
<thead>
<tr>
<th>Model</th>
<th>Un-standardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Standard Err</td>
</tr>
<tr>
<td>Constant</td>
<td>23.895</td>
<td>3.052</td>
</tr>
<tr>
<td>Support</td>
<td>-.990</td>
<td>-.230</td>
</tr>
<tr>
<td>Age</td>
<td>-2.996</td>
<td>.999</td>
</tr>
</tbody>
</table>

Dependent variable: Fear of Negative Evaluation

R squared= .215. Adjusted R squared= .199

Three questionnaires were unanswered in the Brief Fear of Negative Evaluation
(BFNE) measure, leaving the mean to be calculated from 113 Responses. The total BFNE
range was 34. The mean total score was 26.44(SAD 8.70), the distribution of values was
skewed (skewness -0.549, SD 0.05), Table 2 explains that 21.5% of the variance were found
in regression analysis of FNE and support. This is displayed in the beta values. Support was
shown to have the largest predictive value of the two predictors. The model shows that as
there is a decrease in support, there is an increase in FNE. The model also shows that when
age decreases, FNE increase. Both predictors are significant at a p>.01 value

Table 3 shows that control and symptom severity explain 33.9% of the variance in
quality of life. The beta value for symptom severity shows a high negative coefficient of -.511. This explains that as symptom severity decreases, quality of life also decreases. Control
did not predict as strong as a relationship but showed that as control increased that quality of life also increased. To further explain these standardized coefficients the model was broken down into the different stages of symptom severity in accordance with the Harvey-Bradshaw measure. These sub scales were remission, mild disease, moderate disease and severe disease. Questions were not answered with a response of 113 from 116 participants. To calculate the mean the scores of quality of life, the scores were calculated from the other items of the questionnaire. The mean total score was 67.98 (SD 18.02). The distribution of values was skewed (Skewness -0.30, SD .227).

Table 4 shows that there is a variance of 26.5% in health related quality of life scores. The largest predictor in this is mild disease. This can read in the Beta values. The scores show that as mild scores, it shows as predicted that a decrease in severe scores decreases quality of life. The table also shows that when the feeling of control with the disease increases that quality of life increases. The model was conducted to illustrate the standardized coefficients at the different levels of symptom severity. While symptom severity as a whole was found to be statistically significant at a >.01 level, moderate Disease symptoms were not statistically significant in a regression model and showed a weak beta value of .89. The remaining scales of mild and severe disease showed stronger predictive relationships. When moderate disease was removed from the regression the beta relationship between mild disease became stronger. Multiple regression was used to test whether outgoing personality and social support were predictors of contentment at work. The results of the regression indicated that mild disease, severe disease and control predictors explained 26.5% of the variance ($R^2 = .265$, $F (3,109) = 13.13, p < .001$). It was found that severe disease ($\beta = -.12.21, p = .001$), mild disease ($B = 26.92 p = .003$) and control ($\beta = -.3.27, p < .003$) significantly predicted quality of life. However with the removal of moderate disease less variance was explained with 26.5% explained compared to 27.1% with moderate disease.
included Remission was omitted from the table as there were a nil responses to this category. This also suggests that control may act as a mediating variable for symptom severity leading to increased quality of life as when disease is at a moderate level there is less need for control. Symptom severity was tested as a mediator between control and quality of life. Using

**Table 3: Multiple Regression with Control, Symptom Severity and Health Related Quality of Life**

<table>
<thead>
<tr>
<th>Model</th>
<th>Un-standardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Stan Err</td>
</tr>
<tr>
<td><strong>Constant</strong></td>
<td>128.809</td>
<td>10.324</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td>2.612</td>
<td>-1.018</td>
</tr>
<tr>
<td><strong>Symptom Severity</strong></td>
<td>-2.774</td>
<td>.428</td>
</tr>
</tbody>
</table>

Dependant variable: Health related quality of life

R=.339, Adjusted R Square= .32

Baron and Kenny’s four step model which involves conducting a series of simple regressions were conducted to study the predictive relationship between symptoms. It was found that as symptom severity were reported to decrease, the quality of life increased. \( b = - .346, F (1,108) =14.85, p < .01 \). Similarly, control in a simple regression was found to have a significant result in predicting a relationship with quality of life \( b = - .293, F (1,111) = 10.42, p < .01 \). However the findings of a predictive primary relationship between symptom severity and control was non significant \( b = .076, F (1,110) = .638, p < .05 \). This means that the role of symptom severity as a mediator is not supported in mediating the relationship between quality of life and control but is a partial mediator for predicting increased quality of life with a decreased in symptoms.
**Table 4: Multiple regression with Quality of life, Control and Disease Levels**

<table>
<thead>
<tr>
<th>Model</th>
<th>B</th>
<th>Stan. Err</th>
<th>t</th>
<th>Sig</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>100.986</td>
<td>10.18</td>
<td>9.919</td>
<td>.000</td>
</tr>
<tr>
<td>Control</td>
<td>3.039</td>
<td>1.093-</td>
<td>2.781</td>
<td>.006</td>
</tr>
<tr>
<td>Mild Disease</td>
<td>27.039</td>
<td>8.036</td>
<td>3.365</td>
<td>.001</td>
</tr>
<tr>
<td>Moderate Disease</td>
<td>6.659</td>
<td>7.012</td>
<td>.950</td>
<td>.344</td>
</tr>
<tr>
<td>Severe Disease</td>
<td>-10.593</td>
<td>3.839</td>
<td>-2.759</td>
<td>.007</td>
</tr>
</tbody>
</table>

Dependant variable: Quality of life

- R squared= .271. Adjusted R Square= .245
Discussion

The aim of the study was to explore the predictive relationships between age, gender, social anxiety, control, support and symptom severity on fear of negative evaluation and health related quality of life in patients with Crohn’s Disease. The findings confirmed some of the original research hypotheses. It was found that there was a relationship between age and social support in predicting fear of negative evaluation and it was also found that there was a relationship between control and symptom severity in predicting quality of life in CD patients. Remaining variables of age, gender and social anxiety were not predicted to have a relationship with quality of life or FNE. The role of symptom severity as a mediating variable between control and quality was life was found to have a partial effect of quality of life but not on control. This study is the first known study to find a relationship on how CD patients are affected by fear of negative evaluation. The findings also support previous research which has found that symptom severity predicts quality of life, although while these findings predicted that quality of life decreased as overall symptom severity increase, but this was not supported when the stages of the disease were examined. Moderate disease was found to have no significant relationship with quality of life compared to mild and severe disease. Also it was found that as control increases, FNE decreases and that when a better social support symptom was perceived that quality of life increased. Both control and support were found to have significant relationships and as both are indicators of coping outcomes; this may indicate an application of coping interventions is needed.

The results on table 1 show that there is a predictive relationship between FNE and age. This shows that as age decreases, FNE increases in CD patients. This is supported by previously mentioned studies by Regida et al who found that there was a greater importance of peer related and social activities in adolescents. Regida found that social aspects of a person’s life were a larger predictor for anxiety than the actual symptoms or biological
problems which are associated with the disease. The stage of life which the participant is at may create an importance towards a fully functioning social life. Lack of maintaining peer relationships and socialising may result in an anxiety response. As FNE is an anxiety response it could be that the participant does not want to miss any event or activities which may be deemed socially important by their peers and to be isolated as a result of this. This could leave the participant feeling vulnerable. As 70.7% of participants who responded to this study were in the lower age categories of 18-25 and 26-40, this may explain why the scores were higher due to age. As age increases the responses may be different as health, factors become of more important to an older individual than what their peer’s perception of them may be. It may also become difficult for a younger person to discuss the symptoms of CD in fear of the response from their peers in comparison to an older sample who may be more open in discussing symptoms.

The analyses also showed that social support was a larger predictor of FNE in table two. As discussed by Waters, Schootman and Jeff, there is a report of decline in social support after the initial few weeks of diagnoses of a disease. The result of this was a decline in perceived support and an emergence of avoidant coping styles which resulted in reports of socially anxious feelings. Research such as this would explain why the relationship exists between support and FNE as this is a social anxiety measure. The importance of perceived social support on cognitive appraisal as Laurazus and Folkman explained is what initiates a coping outcome. Perceived support may be negatively perceived even if the individual is receiving support. This may explain for some of the variance in our score as it is difficult to control for perceived support. A recommendation would be that a patient’s level of support is recorded at time of diagnosis as it has been seen that the initial diagnosis stage and the following twelve months are the most vulnerable. If a patient is recognised as vulnerable because of low social support then there could be a level of support given from the hospital or
GP in the first instances. Low support at baseline also predicted a further decline in reported support after diagnosis of the disease in patients. The personality of the patient may also influence the scores as a person who is high in neuroticism or has a pre existing issue with neurotic behaviour may have reported lower level of support and higher levels of pain. Previous research has supported this finding as Lutz and Lakley who studied the judgement of support networks in healthy participants found that participants with neurotic personalities used neurotism when perceiving social support. In addition the embarrassing nature of the disease and its symptoms such as diarrhoea and wind may also be a reason that there is a relationship between social support and FNE. The nature of the symptoms may be difficult to talk about with other people. This does not give a true representation to others of the amount of support which is needed. The need for support may create anxiousness due to FNE. There has been no previous research on the communication of CD and its symptoms to others. Lastly the type of sampling could have affected the amount of variance in this study as the majority of participants answered from a forum or CD support group on social media. This would suggest that the participants were already part of a social support system and were less in need of social support. There was no significant relationship found between social anxiety, control, and symptom severity in relation to FNE. This again could be explained by the importance of peer related evaluations and the not so important biological factor of support. However the results which suggest that social anxiety does not have a significant relationship and is in contrast to previous research finding such as Kurinas findings in conducting when meta analysis were it was strongly correlated. The confounding variable of anxiety which was discussed was the emergence of anxiety at initial diagnosis and the following 12 months as a time of heightened anxiety before acceptance of the disease. This sample may have been diagnosed longer than 12 months.
The findings that there is predictive relationships in Crohn’s patients in relation to fear of negative evaluation has not been previously researched. Previous research by Simren et al found that there was a high level of FNE with visible symptoms of psoriasis and there have been findings of high levels of FNE in people who have visible disfigurements. It was initially predicted that the embarrassing symptoms of CD would elicit a response of FNE. This hypotheses has been rejected, although while this study did not show a significant result there was a moderate correlation in this and this is a hypotheses which should be researched in future studies of CD symptoms

Quality of Life

Tables 3 and 4 show the significant relationship found using multiple regressions between control and symptom severity in predicting quality of life in patients with CD. It is shown that as feelings of control increases that quality of life also increases. There has been limited research to date on control and CD, although there has been literature by Remington, Brownson and Wegner, 2010 which supports the idea of control in management and prevention of symptoms in chronic disease. These findings can help to expand Lazuras and Folkman theory of control in that a greater perception of control initiates a cognitive appraisal which results in positive coping styles. The finding in this study may suggest that the nature of CD and the unpredictable symptoms may leave a patient with constant feelings of a lack of control over their environment and their bodies. This variance would support the findings of Eccles and Simpson who looked at the neurodegenerative properties of chronic diseases such as Parkinson’s and Multiple Sclerosis. These share properties of CD as they all display symptoms which cannot be fully controlled and for which a cure has not been found. Therefore feelings of perceived control are higher than with a disease which can be controlled with lifestyle changes such as Coronary Heart Disease as previously mentioned. The duration of the disease could also contribute to this as feelings of perceived control are based
on the existing knowledge that the disease will be active throughout the remaining stages of the individual’s life. As 70.7% of the respondents of this study were 18-40 this could explain that the feeling of a lack of control could be present as they know that for the remainder of their lives the possibility that their feelings of control would stabilise with the cure of the disease are unlikely. The quality of life measure was a combination of four areas. These were systematic, emotional, social, symptoms and well being. A certain level of control should exist to successfully function in all areas; therefore the type of measure which was used in this study could explain some of the variance as it was disease specific and not a generic quality of life questionare. This may prove to be of greater value as issues such as unemployment which were found to affect quality of life by Leihenstein are reflected in the scores of this model and give a better representation of how the disease affects an individual. The suggestion that participants with CD related to this measure could have reflected in the scores.

To explain the remainder of the variance which did not predict the relationship between control and quality of life, there may have been confounding variables which contributed to this such as severity of disease, vicarious control, lifestyle changes and adaptation factors. Firstly, there may have been responses from participants who had lower levels of disease and did not feel that they had a lack of control or did not have low perceived control as their quality of life was not affected at that moment in time. This would support Helegsons finding that a severe threat results in less perceived control in chronic disease. This assumption cannot be made about participants who were in remission as this category received a nil response. Another factor which may contribute to this is that a sense of vicarious control where the sense of control is placed in the hands of the medical professional, therefore the participant may feel that control is not an issue. This has been supported in the study by Loonen et al and they found that in a study of coping strategies in
adolescents with CD that avoidant coping methods were used more in patients with the disease rather than in healthy controls. This included adapting a vicarious style of control were they worried less when the treatment was in the hands of their doctor and this led to better reports of quality of life. This may provide a false sense of security as a result of this avoidant coping and is similar to the finding of Lazuras and Folkman. It is recommended that similar research is conducted on an adult population to assess the significance of vicarious control. Lastly there is a degree of lifestyle changes which could benefit control. A smoker who has reports of severe disease and gives up smoking under instruction after diagnosis might feel that they are more in control if their symptoms because of this. The feeling of control in CD should be studied further along with the outcome of coping styles used when quality of life is an outcome of low perceived control .This could be beneficial to the adaptation of positive coping styles which has become evident in other chronic illness which display similar results .There was no significant relationship found between quality of life and age, gender, support or anxiety.

Symptom Severity

The finding of a predictive relationship between symptom severity and quality of life using the IBDQ measure has been found in previous research. (Bercelev et al, 2004, Haapamäk et al, 2009, Canavan et al, 2006). There is a strong amount of variance discovered using multiple regression to explain that when symptom severity decreased that quality of life increases. The most explanatory reason for this is that as an individual experiences fewer symptoms that they are more inclined to feel the difference in emotional functioning, systematic functioning and emotional functioning, Indicating that psychological well being and maintaining a social life become easier to manage. In support of the findings of Porter, the threat of flare up can reduce the individuals capacity to leave the house, find gainful employment or on a more serious scale to get out of bed to complete simple daily tasks.
Along with this, there is a fear of when the next symptoms will prevail or the long-term worry of cancer or surgery. Our regression analysis shows that a large proportion of the explanation of an impaired quality of life is explained by the symptom severity. To study this in further detail, the different levels of disease severity were categorised into remission, mild disease, moderate disease, and severe disease. Remission was omitted from analysis as there were no responses. The regression showed that when mild disease increased, quality of life increased, and when severe disease decreased, quality of life increased. However, the findings indicate that reports of moderate disease did not contribute significantly to the result.

Upon removing the predictor of moderate disease from the regression, it was then found that the relationship between quality of life and mild symptoms stayed the same but severe the direction of severe symptoms became slightly stronger. This is not a common finding using this measure as previous research has shown that as disease severity increases, quality of life decreases. An explanation of this could be that the respondents were again part of various support groups on social media where data was collected. Therefore, it could be predicted that the respondents were diagnosed more than a year and had suffered all three stages of the disease severity. If an individual has experienced severe symptoms and they are now experiencing moderate symptoms at this point in time, their perception of quality of life could be optimistic. In stark contrast to this, patients who had reported mild disease may never have experienced the more severe symptoms and their perception of the mild symptoms affected their perception of quality of life.

This study further investigated the role of symptom severity as a mediator between control and quality of life using Baron and Kenny mediation model. The prediction was that as quality of life increases, this causes symptom severity to decrease, which causes control to increase as this could be related to the control we have over our own health and also our bodily functions as a result of relieved symptoms. It was found that the mediation was
significant between control and quality of life but that symptom severity was not a significant mediator between control and QOL. Further research could look at the role of symptom severity on QOL with different predicting variables.

There was also a significant relationship found between both outcomes which indicated that as Quality of life increased, fear of negative evaluation decreased. As this was not the purpose of the study and these are two measures of outcome it could be worth examining this relationship in further studies using a one measure as an outcome and the other one as predictor. In particular the social dimensions of the IBDQ could tell us more about the effect that social events and peer related activities have on FNE. Suggestions would be that in further research to assess the length of diagnosis and to also measure quality of life in addition to health related quality of life. In addition the inclusion of a personality Inventory could be used as this would allow for it to be taken into account that a pre existing condition such as neurotism could be a reflection of the scores and participants who have mild disease or could explain the remainder of the variance which is not predicting quality of life.

*Strengths and weaknesses*

This study aimed to examine relationships with both FNE, a variable which has not been previously researched in Crohn’s patients and find if this is an outcome of the disease and quality of life which has been found to decrease with reports of CD and other chronic disease. The findings using regression analysis confirmed an amount of variance for both outcomes based on the desired predictors and their relationships results which have not been found in previous research of CD and FNE. However a limitation in this study would be that the duration of the disease was not measured as this would have provided a better understanding of the role of anxiety and the explanation of a non significant result for moderate disease as discussed. Also if this study as replicated it would be suggested that the
study was taken at a hospital rather than from support groups to measure differences in
perception of social support or as a longitudinal study to predict the change in relationships
over time, particularly in the importance of peer evaluation in younger samples of
participants to find out if the importance changes and to evaluate the role of diagnosis in
anxiety outcomes.

The findings of this study were interesting as some predictions were not found to be
significant which novel findings were made that could not allow us to predict the outcomes
of. Firstly it was found that as age increased, FNE decreased in CD patients, it was suggested
that the lower the age, the more important that peer interaction is. Along with the
embarrassing symptoms and reluctance to discuss the symptoms with others, there could be a
lack of understanding created about the disease. The majority of respondents in this study
were in the lower age category of 18 to 25 and 36-40 with a small number in the 60 and over
category. This could be examined in further research with adolescents as a prediction would
be that fear of evaluation would increase in adolescents. Also in contrast older groups of
participants could be tested with an expected decline in FNE. Also there was a finding that as
social support increased that FNE decreased. A recurrent theme has been found in this
research that the time of diagnosis has been seen in previously as a contributor to anxiety
disorders in CD. As FNE is an anxiety outcome, the role of social support was found to have
a predictive relationship as expected. Recommendations based on the finding are that
duration of diagnosis question is added to the study to examine if higher rates of FNE are
reported in the first 12 months on diagnosis. As there were no findings as expected that
symptom severity predicts FNE, this could be an explanation. In a clinical setting a
recommendation would be that levels of social support are reported at diagnosis and a support
system put in place for patients who do not have adequate support.
It was found that an increase in symptom severity predicts a decrease in quality of life. This was predicted as previous research has found this correlation, however there was an absence of statistical significance with moderate disease. In order to determine why this result was achieved, duration of diagnosis may again explain whiter this result was in comparison to severe disease. The findings also showed that an increase in control predicting an increase in quality of life. There is little research conducted on control and it is suggested that a better control over symptoms, emotional function and social functioning will increase quality of life. It is recommended that further studies are conducted on control and CD to determine if loss of bodily function leads to a feeling of loss of control. The findings in this study, particularly in control and social support could relate to the coping strategies which are adopted. As it has been found that FNE exists in Crohn’s Disease similar as it does in diseases with visible symptoms like psoriasis, the type of anxiety response FNE produces could be controlled with positive and adaptive coping strategies to prevent social avoidance and isolation. The introduction of a social support system would not only contribute to coping outcomes but could also encourage acceptance of the disease and create a better understanding.
References


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Appendix

Figure 1: Cover sheet and contact information

My name is Lyndsey Redmond. I am an Undergraduate in Dublin Business School and I am undertaking research into the effects which Fear of Negative Evaluation, Symptom Severity and Coping have on Social Anxiety and Quality of Life in Crohn's Disease patients... All participants who have been diagnosed with Crohn's Disease are being invited to take part in the following online questionnaire.

Your participation is entirely voluntary and you are free to leave at any point during the questionnaire, however once the questionnaire is submitted you are unable to withdraw your data. All information will remain fully confidential and will be stored in an encrypted folder on my computer only. The questionnaire will last approximately fifteen minutes. Only myself and my undergraduate supervisor, Dr Chris Gibbons, will have access to the data.

The following questionnaires have been widely used in previous research, however if you find the sensitive nature of the questions to effect you in any way or require more information please contact the following websites for support

www.crohnscolitis.ie

www.GetGutsy.ie

If you have any queries about the study beyond that provided here please feel free to contact me at or my supervisor
Figure 2: Inflammatory Bowel Disease Questionnaire

IBDQ Subject Number: ___________________________________ Subject name: ___________________________________

This questionnaire is designed to find out how you have been feeling during the last two weeks. Please circle only one number for each question.

1. How frequent have your bowel movements been during the last 2 weeks?
   a) Bowel movements as or more frequent than they have ever been
   b) Extremely frequent
   c) Very frequent
   d) Moderate increase in frequency of bowel movements
   e) Some increase in frequency of bowel movements
   f) Slight increase in frequency of bowel movements
   g) Normal, no increase in frequency of bowel movements

2. How often has the feeling of fatigue or being tired and worn out been a problem for you during the last 2 weeks?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

3. How often during the last 2 weeks have you felt frustrated, impatient, or restless?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

4. How often during the last 2 weeks have you been unable to attend school or work because of your bowel problem?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

IBDQ Subject Number: ___________________________________ Subject name: ___________________________________
5. How much time during the last 2 weeks have your bowel movements been loose?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

6. How much energy have you had during the last 2 weeks?
   a) No energy at all
   b) Very little energy
   c) A little energy
   d) Some energy
   e) A moderate amount of energy
   f) A lot of energy
   g) Full of energy

7. How often during the last 2 weeks did you feel worried about the possibility of needing surgery because of your bowel problem?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

8. How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problems?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

9. How often in the past 2 weeks have you been troubled by cramps in your abdomen?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

IBDQ ____________________________ Subject Number: ____________________________
______________________ Subject name: ____________________________
10. How often in the past 2 weeks have you felt generally unwell?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

11. How often during the last 2 weeks have you been troubled because of fear of not finding a bathroom?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

12. How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would liked to have done during the last 2 weeks?
   a) A great deal of difficulty; activities made impossible
   b) A lot of difficulty
   c) A fair bit of difficulty
   d) Some difficulty
   e) A little difficulty
   f) Hardly any difficulty
   g) No difficulty; no limit sports or leisure activities

13. How often during the last 2 weeks have you been troubled by pain in the abdomen?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

14. How often during the past 2 weeks have you had problems getting a good night's sleep, or been troubled by waking up during the night?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

IBDQ

Subject Number: ____________________________________________
Subject name: ______________________________________________
15. How often during the past 2 weeks have you felt depressed or discouraged?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

16. How often during the past 2 weeks have you had to avoid attending events where there was no bathroom at hand?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

17. Overall, in the past 2 weeks, how much problem have you had with passing large amounts of gas?
   a) A major problem
   b) A big problem
   c) A significant problem
   d) Some trouble
   e) A little trouble
   f) Hardly any trouble
   g) No trouble

18. Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be at?
   a) A major problem
   b) A big problem
   c) A significant problem
   d) Some trouble
   e) A little trouble
   f) Hardly any trouble
   g) No trouble

19. Many patients with bowel problems often have worries and anxieties related to their illness. These include worries about getting cancer, worries about never feeling better, and worries about having a relapse. In general, how often during the last 2 weeks have you felt worried or anxious?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

IBDQ ______________________________________ Subject Number:
_______________________________________________________ Subject name:
20. How much of the time during the last 2 weeks have you been troubled by a feeling of abdominal bloating?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

21. How often during the last 2 weeks have you felt relaxed and free of tension?
   a) None of the time
   b) A little of the time
   c) Some of the time
   d) A good bit of the time
   e) Most of the time
   f) Almost all of the time
   g) All of the time

22. How much time during the last 2 weeks have you had a problem with rectal bleeding with your bowel movements?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

23. How much time during the last 2 weeks have you felt embarrassed as the result of soiling, or because of an unpleasant odor caused by your bowel movement?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

24. How much of the time during the past 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels are empty?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time
25. How much of the time during the last 2 weeks have you felt tearful or upset?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

26. How much of the time during the last 2 weeks have you been troubled by accidental soiling of your underpants?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

27. How much of the time in the 2 weeks have you felt angry as a result of your bowel problems?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

28. To what extent has your bowel problem limited sexual activity during the last 2 weeks?
   a) No sex as a result of Crohn’s disease
   b) Major limitation as a result of Crohn's disease
   c) Moderate limitation as a result of Crohn's disease
   d) Some limitation as a result of Crohn's disease
   e) A little limitation as a result of Crohn's disease
   f) Hardly any limitation as a result of Crohn's disease
   g) No limitation as a result of Crohn's disease

29. How much of the time during the last 2 weeks have you been troubled by feeling sick to your stomach?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

Subject Number: __________________________
Subject name: ___________________________
30. How much of the time during the past 2 weeks have you felt irritable?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

31. How often during the last 2 weeks have you felt a lack of understanding from others?
   a) All of the time
   b) Most of the time
   c) A good bit of the time
   d) Some of the time
   e) A little of the time
   f) Hardly any of the time
   g) None of the time

32. How satisfied, happy, or pleased have you been with your personal life during the past 2 weeks?
   a) Very dissatisfied, unhappy most of the time
   b) Generally dissatisfied, unhappy
   c) Somewhat dissatisfied, unhappy
   d) Generally satisfied, pleased
   e) Satisfied most of the time, happy
   f) Very satisfied most of the time, happy
   g) Extremely satisfied, could not have been more happy or pleased

Signature  Date
Brief Fear of Negative Evaluation Scale

Leary (1983)

Read each of the following statements carefully and indicate how characteristic it is of you according to the following scale:

1 = Not at all characteristic of me
2 = Slightly characteristic of me
3 = Moderately characteristic of me
4 = Very characteristic of me
5 = Extremely characteristic of me

_____ 1. I worry about what other people will think of me even when I know it doesn't make any difference.

_____ 2. I am unconcerned even if I know people are forming an unfavorable impression of me.

_____ 3. I am frequently afraid of other people noticing my shortcomings.

_____ 4. I rarely worry about what kind of impression I am making on someone.

_____ 5. I am afraid others will not approve of me.
6. I am afraid that people will find fault with me.

7. Other people's opinions of me do not bother me.

8. When I am talking to someone, I worry about what they may be thinking about me.

9. I am usually worried about what kind of impression I make.

10. If I know someone is judging me, it has little effect on me.

11. Sometimes I think I am too concerned with what other people think of me.

12. I often worry that I will say or do the wrong things.
Harvey-Bradshaw Index (HBI) —
A simple index of Crohn’s disease activity

Patient name: 
Date of HBI calculation:

1. General well-being 
   *(yesterday)*
   - Very well = 0
   - Slightly below par = 1
   - Poor = 2
   - Very poor = 3
   - Terrible = 4

2. Abdominal pain 
   *(yesterday)*
   - None = 0
   - Mild = 1
   - Moderate = 2
   - Severe = 3

3. Number of liquid or soft stools per day *(yesterday)* = ________________

4. Abdominal mass
   - None = 0
   - Dubious = 1
   - Definite = 2
   - Definite and tender = 3

5. Complications
   *(Check any that apply; score one Per item except for first box)*
   - None
   - Severe Joint Pain
   - Eye Inflammation
   - Red nodules of Inflammation under shin
   - Mouth Ulcers
   - Painful Skin Lacerations
   - Anal Fissure
   - Fistula
Abdominal or pelvic abscess

Harvey-Bradshaw Index score:
Remission <5
Mild disease 5-7
Moderate disease 8-16
Severe disease >16
(please add scores of questions 1 through 5)

For formulary co
64. I often feel I don’t have enough control over the decisions I have to make.

65. In general I feel in control of the things that happen to me.

66. The pace of learning often leaves me with little feeling of control.

[format on a 5 point Likert scale from strongly agree to strongly disagree]
Figure 6: Support Measure

[format on a 5 point Likert scale from strongly agree to strongly disagree]

[Support - coping resource]

1. The level of support offered by my family
2. The level of support offered by my friends
3. The level of support offered by partner
4. The support from doctor
Figure 7: Social Avoidance and Distress Scale

SOCIAL AVOIDANCE AND DISTRESS SCALE

The statements below inquire about your personal reactions to a variety of situations. Consider each statement carefully. Then indicate whether the statement is true or false with regard to your typical behavior.

1. I feel relaxed even in unfamiliar social situations.
2. I try to avoid situations which force me to be sociable.
3. It is easy for me to relax when I am with strangers.
4. I have no particular desire to avoid people.
5. I often find social occasions upsetting.
6. I usually feel calm and comfortable at social occasions.
7. I am usually at ease when talking to someone of the opposite sex.
8. I try to avoid talking to people unless I know them well.
9. If the chance comes to meet new people, I often take it.
10. I often feel nervous or tense in casual get-togethers in which both sexes are present.
11. I am usually nervous with people unless I know them well.
12. I usually feel relaxed when I am with a group of people.
13. I often want to get away from people.
14. I usually feel uncomfortable when I am in a group of people I don’t know.
15. I usually feel relaxed when I meet someone for the first time.
16. Being introduced to people makes me tense and nervous.
17. Even though a room is full of strangers, I may enter it anyway.
18. I would avoid walking up and joining a large group of people.
19. When my superiors want to talk with me, I talk willingly.
20. I often feel on edge when I am with a group of people.
21. I tend to withdraw from people.
22. I don't mind talking to people at parties or social gatherings.
23. I am seldom at ease in a large group of people.
24. I often think up excuses in order to avoid social engagements.
25. I sometimes take the responsibility for introducing people to each other.
26. I try to avoid formal social occasions.
27. I usually go to whatever social engagements I have.
28. I find it easy to relax with other people.