

Exploring beliefs about emotions, emotional expression
and support-seeking in persistent physical symptoms

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Declaration of Authorship

I, Hannah Bowers, hereby declare that this thesis and the work presented in it is entirely my own. Where I have consulted the work of others, this is always clearly stated.

Signed



Date

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Abstract

Persistent physical symptoms for which there is no clear physiological pathology can present problems for clinical practice in that they do not fit the biomedical model. Biopsychosocial models of persistent physical symptoms describe the interrelation of beliefs and behaviours which work to maintain symptoms, with early evidence implicating beliefs about the unacceptability of expressing and experiencing emotions in this model. The current thesis explored this in relation to irritable bowel syndrome (IBS) and fibromyalgia (FMS).

Chapters Three, Four and Five describe online cross-sectional research in IBS and FMS which found support for a mediation model where the relationship between beliefs about the unacceptability of emotions and outcomes was serially mediated first by emotional suppression and then by affective distress. The relationship was not mediated by support-seeking.

In Chapter Six a new measure of beliefs about sharing illness experiences was validated. This chapter demonstrated that the relationship between beliefs about sharing illness experiences and outcomes was mediated by support-seeking and by all-or-nothing behaviour in FMS.

Based on the mediation models of Chapters Three, Four and Five, Chapter Seven measured variables of the model before and after treatment for FMS in the NHS, finding that beliefs about emotions changed during intervention, though these changes did not predict changes in outcomes.

The final study in this thesis is presented in Chapter Eight. This study described a mixed methods single case series evaluating an intervention aimed at targeting beliefs about emotions and emotional suppression in IBS. Both quantitative and qualitative evidence suggests that changes in beliefs about emotions are beneficial to those with IBS.

This thesis concluded that while many beliefs and behaviours may be part of a maintain cycle of persistent physical symptoms, beliefs about the unacceptability of emotions and emotional suppression should be included in complex biopsychosocial models of IBS and FMS.

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Contents

| | |
|---|----|
| 1. Chapter One: Introduction..... | 17 |
| 1.1. Persistent Physical Symptoms | 17 |
| 1.1.1. A Cognitive Behavioural Model of Persistent Physical Symptoms | 18 |
| 1.1.2. Irritable Bowel Syndrome | 22 |
| 1.1.3. Fibromyalgia | 25 |
| 1.1.4. Summary | 28 |
| 1.2. Emotional Suppression | 28 |
| 1.2.1. Ironic Processing Effects | 30 |
| 1.2.2. Emotional Suppression and Physical Symptoms | 33 |
| 1.3. Distress is related to Poor Health-Related Outcomes | 42 |
| 1.4. Emotional Expression Interventions | 44 |
| 1.5. Beliefs about Emotions..... | 48 |
| 1.6. Summary..... | 51 |
| 1.7. Aims | 52 |
| 2. Chapter Two: Methods..... | 53 |
| 2.1. Screening Tools | 53 |
| 2.1.1. Manning Criteria for Irritable Bowel | 53 |
| 2.1.2. The London Fibromyalgia Epidemiological Study Screening Questionnaire | 57 |
| 2.2. Measures..... | 59 |
| 2.2.1. Beliefs about Emotions Scale | 59 |
| 2.2.2. Courtauld Emotional Control Scale | 60 |

| | | |
|--------|---|----|
| 2.2.3. | The Hospital Anxiety and Depression Scale | 63 |
| 2.2.4. | General Help-Seeking Questionnaire..... | 65 |
| 2.3. | Outcome Measures | 68 |
| 2.3.1. | Irritable Bowel Syndrome-Quality of Life..... | 68 |
| 2.3.2. | Fibromyalgia Impact Questionnaire revised | 70 |
| 2.4. | Participant groups and recruitment..... | 72 |
| 2.5. | Study Designs..... | 73 |
| 2.6. | Statistical Analyses..... | 76 |
| 3. | Chapter Three: Beliefs about emotions and emotional suppression in irritable bowel syndrome..... | 78 |
| 3.1. | Introduction | 78 |
| 3.1.1. | Hypotheses..... | 83 |
| 3.2. | Methods | 83 |
| 3.2.1. | Procedure | 83 |
| 3.2.2. | Diagnostic Criteria | 84 |
| 3.2.3. | Participants..... | 84 |
| 3.2.4. | Measures | 85 |
| 3.2.5. | Design and Statistical Analysis..... | 86 |
| 3.3. | Results | 87 |
| 3.3.1. | Sample Characteristics | 87 |
| 3.3.2. | Group Differences..... | 89 |
| 3.3.3. | Mediation Analyses..... | 89 |
| 3.4. | Discussion..... | 91 |

| | |
|---|-----|
| 4. Chapter Four: Placing affective distress and support-seeking within a model of beliefs about emotions in IBS..... | 96 |
| 4.1. Introduction | 96 |
| 4.1.1. Hypotheses..... | 101 |
| 4.2. Methods..... | 102 |
| 4.2.1. Participants..... | 102 |
| 4.2.2. Measures..... | 103 |
| 4.2.3. Design and Statistical Analysis..... | 105 |
| 4.3. Results | 107 |
| 4.3.1. Sample Characteristics..... | 107 |
| 4.3.2. Group Differences (Hypothesis One)..... | 109 |
| 4.3.3. Mediation Model One (Hypotheses Two and Three)..... | 112 |
| 4.3.4. Mediation Model Two (Hypothesis Four) | 114 |
| 4.4. Discussion..... | 115 |
| 5. Chapter Five: Beliefs about Emotions and Global Impact in Fibromyalgia | 121 |
| 5.1. Introduction | 121 |
| 5.1.1. Hypotheses..... | 125 |
| 5.2. Methods..... | 125 |
| 5.2.1. Participants..... | 125 |
| 5.2.2. Measures | 127 |
| 5.2.3. Design and Statistical Analysis..... | 128 |
| 5.3. Results | 130 |
| 5.3.1. Sample characteristics..... | 130 |

| | | |
|--------|--|-----|
| 5.3.2. | Group Differences (Hypothesis One)..... | 133 |
| 5.3.3. | Model One (Hypotheses Two and Three)..... | 135 |
| 5.3.4. | Model Two (Hypothesis Four)..... | 137 |
| 5.4. | Discussion..... | 138 |
| 6. | Chapter Six: Validating a new measure of beliefs about sharing illness experiences... | 146 |
| 6.1. | Introduction | 146 |
| 6.2. | Study One: Validating the BASIE..... | 152 |
| 6.2.1. | Hypothesis..... | 152 |
| 6.2.2. | Methods..... | 153 |
| 6.2.3. | Results..... | 161 |
| 6.3. | Study Two: Exploring mediators of the relationship between beliefs about sharing illness experiences and global impact. | 172 |
| 6.3.1. | Hypothesis..... | 173 |
| 6.3.2. | Methods..... | 173 |
| 6.3.3. | Results..... | 174 |
| 6.4. | Discussion..... | 175 |
| 7. | Chapter Seven: Examining beliefs about emotions and emotional suppression in patients attending therapy for fibromyalgia | 182 |
| 7.1. | Introduction | 182 |
| 7.1.1. | Hypotheses..... | 188 |
| 7.2. | Methods..... | 188 |
| 7.2.1. | Participants..... | 188 |
| 7.2.2. | Treatment | 189 |

| | | |
|--------|---|-----|
| 7.2.3. | Procedure | 190 |
| 7.2.4. | Design and Statistical Analysis..... | 191 |
| 7.3. | Results | 193 |
| 7.3.1. | Sample Characteristics | 193 |
| 7.3.2. | Hypothesis one: Mediation | 196 |
| 7.3.3. | Hypothesis two: Changes over time..... | 197 |
| 7.3.4. | Hypothesis three: Changes in processes are related to changes in outcomes | 198 |
| 7.3.5. | Hypothesis Three: Predicting later global impact..... | 200 |
| 7.4. | Discussion..... | 201 |
| 8. | Chapter Eight: An intervention addressing beliefs about emotions and emotional suppression: A single case series | 211 |
| 8.1. | Introduction | 211 |
| 8.1.1. | Hypotheses..... | 214 |
| 8.2. | Methods..... | 215 |
| 8.2.1. | Participants..... | 215 |
| 8.2.2. | Materials | 216 |
| 8.2.3. | Procedure | 217 |
| 8.2.4. | Design and Analysis..... | 219 |
| 8.3. | Results | 220 |
| 8.3.1. | Attendance | 220 |
| 8.3.2. | Beliefs about emotions..... | 221 |
| 8.3.3. | Emotional suppression | 224 |

| | | |
|--------|--|-----|
| 8.3.4. | Affective distress..... | 226 |
| 8.3.5. | Quality of life..... | 228 |
| 8.3.6. | Qualitative analysis..... | 230 |
| 8.4. | Discussion..... | 235 |
| 9. | Chapter Nine: General Discussion..... | 244 |
| 9.1. | Summary of findings..... | 245 |
| 9.2. | Beliefs about emotions and their role in persistent physical symptoms..... | 250 |
| 9.3. | Distress and its role in persistent physical symptoms..... | 251 |
| 9.4. | Support-seeking and its role in persistent physical symptoms..... | 253 |
| 9.5. | Beliefs about sharing illness experiences and their role in persistent physical symptoms | 254 |
| 9.6. | Differences between those with FMS and IBS..... | 256 |
| 9.7. | Implications for clinical practice..... | 259 |
| 9.8. | Relating these findings to other long term conditions..... | 263 |
| 9.9. | Limitations and directions for future research..... | 265 |
| 9.10. | The cognitive behavioural model of persistent physical symptoms..... | 275 |
| 9.11. | Conclusions..... | 280 |
| 10. | Appendices..... | 310 |
| 10.1. | Appendix A: Beliefs about Emotions Scale..... | 310 |
| 10.2. | Appendix B: Courtauld Emotional Control Scale..... | 311 |
| 10.3. | Appendix C: Hospital Anxiety and Depression Scale..... | 314 |
| 10.4. | Appendix D: Irritable Bowel Syndrome Quality of Life questionnaire..... | 315 |
| 10.5. | Appendix E: Revised Fibromyalgia Impact Questionnaire..... | 317 |

| | | |
|--------|--|-----|
| 10.6. | Appendix F: Example recruitment posts | 319 |
| 10.7. | Appendix G: BASIE questionnaire as it appears online..... | 321 |
| 10.8. | Appendix H: Inter-item correlations including items with coefficients greater than .8 (Chapter Six)..... | 323 |
| 10.9. | Appendix I: Group comparisons between those with FMS and healthy controls for BASIE scores after controlling for affective distress using the entire sample (Chapter Six). | 325 |
| 10.10. | Appendix J: Participant booklet to accompany the intervention designed in Chapter Eight | 326 |
| 10.11. | Appendix K: Ideographic measures for each Case..... | 381 |
| 10.12. | Appendix L: Transcript from participant interview following intervention in Chapter Eight | 385 |
| 10.13. | Appendix M: Published papers arising from work presented in this thesis..... | 397 |

List of Tables

| | |
|--|-----|
| Table 3.1 Sample Characteristics for each group | 88 |
| Table 3.2 Means and standard deviations for beliefs about emotions and emotional suppression for both groups..... | 89 |
| Table 4.1 Sample characteristics broken down by group | 108 |
| Table 4.2 Means and standard deviations for all measured variables..... | 109 |
| Table 4.3 Estimated marginal means and standard errors for beliefs about emotions and emotional suppression after controlling for demographic variables. | 110 |
| Table 4.4 Estimated marginal means and standard errors for beliefs about emotions and emotional suppression after controlling for affective distress..... | 111 |
| Table 4.5 Zero order correlations for all variables in the model..... | 112 |
| Table 5.1 Means and standard deviations for all measured variables..... | 131 |
| Table 5.2 Sample characteristics for each group. | 132 |
| Table 5.3 Estimated marginal means and standard errors for emotional suppression and beliefs about emotions after controlling for demographic variables. | 134 |
| Table 5.4 Estimated marginal means and standard errors for emotional suppression and beliefs about emotions after controlling for demographic variables and affective distress..... | 135 |
| Table 5.5 Zero order correlations for all variables in the model..... | 137 |
| Table 6.1 Demographic information for both groups. | 163 |
| Table 6.2 Means and standard deviations for all measured variables..... | 164 |
| Table 6.3 Factor loadings and communality for each item onto each factor. | 166 |
| Table 6.4 Correlation coefficients between the BASIE and its two scales.... | 167 |

| | |
|---|-----|
| Table 6.5 Estimated marginal means, standard errors, F statistics and effect sizes for overall BASIE scores and its two factors after controlling for distress and demographic variables | 170 |
| Table 6.6 Correlations between overall BASIE scores, its factors, and measures of related behaviours and cognitions after controlling for affective distress. | 171 |
| Table 6.7 Correlations between overall BASIE scores and its two factors, and outcome measures..... | 172 |
| Table 7.1 Sample characteristics..... | 195 |
| Table 7.2 Means and standard deviations for beliefs about emotions, emotional suppression, affective distress and global impact..... | 196 |
| Table 7.3 Descriptive statistics of baseline scores for participants who completed one, two and three of the three time points. | 196 |
| Table 7.4 Estimated marginal means and standard error for the three treatment times for each of the four measures. | 198 |
| Table 7.5 Mean and standard deviation of the change scores for each measured variable. | 199 |
| Table 7.6 Correlations between change scores for each variable comparing pre- and post-treatment..... | 199 |
| Table 7.7 Correlations between predictors and outcomes for participants included in the model..... | 201 |
| Table 7.8 Unstandardized regression coefficients for individual predictors for each block of the model..... | 201 |
| Table 8.1 Tau statistics and confidence intervals for BES scores..... | 222 |
| Table 8.2 Tau statistics and confidence intervals for CECS scores..... | 224 |

| | |
|---|-----|
| Table 8.3 Tau statistics and confidence intervals for HADS scores | 226 |
| Table 8.4 Tau statistics and confidence intervals for IBS-QoL scores. | 228 |
| Table 10.1 Inter-item correlations for BASIE | 323 |
| Table 10.2 Estimated marginal means, standard errors and F statistics for BASIE scores after controlling for affective distress | 325 |

List of Figures

| | |
|--|-----|
| Figure 1.1 Ironic processing effects in relation to emotional suppression | 32 |
| Figure 1.2 Hypothesised relation between variables | 52 |
| Figure 2.1 Manning Criteria for Irritable Bowel | 54 |
| Figure 3.1 Unstandardized regression coefficients for the overall mediation model, where the relationship between beliefs about emotions and quality of life while controlling for emotional suppression is presented in parentheses | 90 |
| Figure 3.2 Unstandardized regression coefficients for the mediation model where the relationship between emotional suppression and quality of life while controlling for beliefs about emotions is presented in parentheses..... | 91 |
| Figure 4.1 Model One, testing Hypotheses Two and Three..... | 106 |
| Figure 4.2 Unstandardized regression coefficients for the overall mediation model for IBS, where the relationship between BES and IBS-QoL while controlling for mediator variables is presented in parentheses..... | 113 |
| Figure 4.3 Standardised regression coefficients where the relationship between emotional suppression and quality of life after controlling for beliefs about emotions is presented in parentheses..... | 114 |
| Figure 5.1 Mediation model tested for Hypotheses Two and Three. | 130 |
| Figure 5.2 Standardised regression coefficients for the relationships between the three paths. Each path tested controlling for the unique variance in alternate paths | 137 |
| Figure 6.1. Standardised regression coefficients for the mediation model where the BASIE is the predictor, global impact is the outcome and the four parallel mediators are symptom support-seeking, personal/emotional support-seeking, limiting | |

behaviour and all-or-nothing behaviour. For each path, the parallel mediators are included as control variables.175

Figure 7.1 Flow chart of participation throughout the study194

Figure 7.2 Standardised coefficients for paths in the serial mediation model197

Figure 8.1 ‘Vicious cycle’ presented to participants in the fourth session.....218

Figure 8.2 Beliefs about emotions over time for each case.223

Figure 8.3 Emotional suppression over time for each case.225

Figure 8.4 Affective distress over time for each case.227

Figure 8.5 Quality of life over time for each case229

Figure 9.1 A self-maintaining cycle based on evidence from the current thesis.....279

1. Chapter One: Introduction

The current thesis looks to explore psychological factors associated with persistent physical symptoms for which the aetiology is uncertain, within the context of a cognitive-behavioural framework. In particular, this thesis focuses on beliefs about expressing and experiencing emotions as well as emotional suppression. This will be examined by considering two conditions in which the symptoms are not fully understood by a medical model, namely irritable bowel syndrome (IBS) and fibromyalgia syndrome (FMS). These conditions are often termed ‘medically unexplained’, a notion that will be described in the first section of this thesis. The chapter will then discuss cognitive-behavioural models regarding these disorders. The current chapter will explore the existing evidence on negative affect and emotional suppression in the context of ironic processing theory (Wegner, 1994) to understand the roles of emotional suppression and beliefs about emotions in the maintenance of symptoms and quality of life in these disorders. Though evidence is limited, research on beliefs about emotions in conditions with persistent physical symptoms (where the medical explanation is unclear) is growing and is also discussed.

1.1. Persistent Physical Symptoms

General practitioners, when presented with a patient who describes their symptoms, see their primary role as uncovering any organic disease in attempts to explain and treat the patient’s symptoms (Sharpe, 2013). Cases which present symptoms that, after testing, appear to result from no known physiological pathology are considered to be ‘medically unexplained’. A meeting of an expert review group (NHS Scotland, 2014) developing a competency framework for working with people with ‘medically unexplained symptoms’ and long term health conditions, discussed

the issues in relation the terminology to describe medically unexplained symptoms. It has been suggested to use the term, 'persistent physical symptoms' which may be more effective in avoiding having these symptoms viewed solely as a psychiatric as opposed to being of medical concern.

There are a number of conditions which present as multiple physical symptoms with uncertain aetiology. Examples of these include chronic fatigue syndrome (CFS), IBS and FMS. Psychological aspects of CFS are comparatively well-researched (Nijs et al., 2013; Hughes et al., 2016; Mallet, King & White, 2016; Kempke et al., 2015; Jameson, 2016), while possible psychological factors that may relate to the development or maintenance of IBS and FMS are less understood. Thus, the current thesis therefore focuses on the latter two conditions.

1.1.1. A Cognitive Behavioural Model of Persistent Physical Symptoms

Models have been proposed to explain the development and maintenance of persistent physical symptoms without a clear aetiology, including a Cognitive Behavioural Model of so-called 'medically unexplained symptoms' (Deary, Chalder and Sharpe, 2007), which uses Beck's terminology of predisposing, precipitating and perpetuating factors (Beck, 1976 as cited in Deary, Chalder and Sharpe, 2007). It is proposed that these 'three Ps' work together in the maintenance and development of a disorder in a self-perpetuating cycle.

With regards to predisposing factors, Deary and colleagues highlight genetics and early experience as possible precursors to persistent physical symptoms. In terms of genetics, they highlight evidence showing familial trends in persistent physical symptoms, though the authors acknowledge that this may just reflect the inheritability

of other psychological predisposing factors such as neuroticism and distress (Deary et al., 2007).

Distress, in some cases may be the result of an early traumatic experience, thus it becomes evident that these social, biological and environmental factors are likely to work collectively in predisposing an individual to persistent physical symptoms. Both neuroticism, defined as a predisposition to negative affect, and distress have been found to be higher in people with persistent physical symptoms which are considered to be medically unexplained compared with other groups, and have relationships with outcomes of the condition. For example, Van Middendorp et al. (2008) used self-report questionnaires in 403 participants with FMS recruited from three hospitals in The Netherlands and compared these with 136 healthy control participants. Using the PANAS-X measure of positive and negative affect, they found that compared to controls, individuals with FMS report more fear, hostility, guilt and sadness and report less joviality and self-assurance (Cohen's d ranging from .32 to .76). However, it is possible that this negative affect is a result of the pain and disability associated with FMS as opposed to being a disposition towards negative affect.

However, Hazlett-Stevens, Craske, Mayer, Chang, & Naliboff (2003) found that participants with IBS ($n=47$) scored higher on Eysenck's personality measure of neuroticism compared to people who do not have IBS ($n=352$). Similarly, a more recent study of participants with FMS ($n=48$) and rheumatic diseases ($n=115$) found that participants with FMS scored higher on measures of neuroticism (as well as agreeableness and openness) (Bucourt et al., 2016). Thus, given that personality traits (specifically neuroticism) are considered to be relatively stable over time (Berg & Johansson, 2014), one might argue that this disposition towards negative affect in the form of neuroticism may be a predisposing factor in this model. However, both

Hazlett-Steven et al.'s study in IBS and Bucourt et al.'s in FMS suffer from very unequal sample sizes which may influence the statistical power of the analysis.

Thus, it is possible that neuroticism or a predisposition towards negative affect may play a role in the development of 'medically unexplained symptoms' as per Deary's model, but in IBS and FMS in particular, the evidence could be stronger.

Deary, Chalder and Sharpe (2007) describe factors which might act to perpetuate persistent physical symptoms, bringing attention to sensitisation of and attention to bodily sensations, attributions and beliefs, and response to illness. It is these proposed perpetuating factors, which are targeted in cognitive-behavioural interventions in the hope that by dismantling some of the perpetuating factors the self-perpetuating cycle will discontinue. Regarding perpetuating factors, previous research has tended to focus on illness beliefs (Lackner, Mesmer, Morley, Dowzer, & Hamilton, 2004; Moss-Morris et al., 2002) in addition to response to illness and illness behaviours (Spence, Moss-Morris, & Chalder, 2005). Another aspect focussed on in this model is distress intolerance. Deary et al. (2007) posit that those with persistent physical symptoms with no clear medical explanation perceive symptoms as aversive which encourages maladaptive avoidant behaviours. Though evidence with a clear timeline which supports this idea is lacking, there is evidence of avoidance behaviours in persistent physical symptoms. For example, there is a wealth of research on the fear avoidance approach to pain (see section 1.1.3, page 25).

This cognitive-behavioural model of persistent physical symptoms asserts that particular events can activate a self-perpetuating cycle, known as precipitating factors. The key precipitating factors highlighted by Deary et al. (2007) are life events, which have been found to precede CFS (Hatcher & House, 2003 as cited in Deary et al.,

2007), FMS (Häuser, Kosseva, Üceyler, Klose, & Sommer, 2011) and IBS (Bradford et al., 2012).

It is proposed that neurobiological changes in response to negative/adverse life events can result in later dysfunction resulting in persistent physical symptoms. With regards to IBS as an example, animal models have been proposed whereby perinatal stress such as maternal separation can result in stress-induced visceral hypersensitivity, increased defecation, dysfunction of intestinal mucous and increased hypothalamic-pituitary-adrenal axis responses in adulthood. These neurobiological changes may therefore result in symptoms found in IBS (Bradford et al., 2012). Other models have argued a more psychological perspective, where psychological factors in response to a physiological trigger result in the disorder: For example illness beliefs and behaviours (in particular all-or-nothing behaviour) at the time of acute illness symptoms predict the onset of post-infectious IBS six months later (Spence et al., 2005) (see section 1.1.2, page 22). Using this evidence, Spence and Moss-Morris therefore argued that, while there was a physiological trigger for the symptoms, behaviours, beliefs and emotions contribute to the maintenance of these symptoms over time.

A similar model has been described by Salkovskis et al. (2016) which combines trans-diagnostic features of persistent physical symptoms generally with features of specific symptoms. Much of this model draws upon models of health anxiety, arguing that physical symptoms that are experienced result in an emotional response which is often severe. The authors argue that symptoms are triggered by a perception of change in one's physical sensations (whether this physical sensation is genuinely deviant from normal or just perceived as such is irrelevant in this case). This physical sensation often results in increased vigilance to bodily sensations and is frequently negatively

appraised. These negative appraisals result in strong negative emotions which reinforce negative thinking so as to maintain a cycle. This cycle is then further maintained by subsequent responses to the negative appraisal of bodily sensations, which may be specific to particular diagnoses (such as all-or-nothing behaviour in IBS). Other responses highlighted in this model include avoidance of activity, mood changes, emotional avoidance/suppression and beliefs about emotions. Evidence on these factors is discussed later in this chapter.

Using these models, research can identify possible perpetuating factors, such as particular beliefs, which might be targeted through well-established cognitive-behavioural methods in order to break the self-perpetuating cycle and bring benefits to individuals living with persistent physical symptoms (Salkovskis et al., 2016).

1.1.2. Irritable Bowel Syndrome

IBS is a long term condition with uncertain aetiology, characterised by gastrointestinal symptoms such as abdominal pain, increased frequency in bowel movements, looser stools, mucus present in stools, feelings of incomplete evacuation and abdominal distension/bloating (Manning, Thompson, Heaton, & Morris, 1978). IBS costs around £200m in primary care settings perhaps due to the patient group being frequent attenders as well as the need for repeated testing to rule out other possible diagnoses (Reid, Wessley, Crayford, & Hotopf, 2002).

There has been evidence for physiological factors related to the disorder, such as motility dysfunction, intestinal permeability and immune function (Malone, 2011) though the exact pathophysiology of the disorder still remains unexplained. One key theory in terms of a more physiological approach to IBS is the idea of visceral hypersensitivity, often based on evidence of lower abdominal pain thresholds in IBS

compared with other patient groups (Kanazawa, Hongo, & Fukudo, 2011). Despite this evidence on physiological explanations, there is also evidence that psychological factors contribute to the maintenance and development of the symptoms of IBS and thus more integrative models incorporating psychosocial factors are useful in understanding the disorder, especially when the medical model is currently unsuccessful in fully explaining and treating the disorder (Deary et al., 2007; Mayer, Chang, & Lembo, 1998; Naliboff, 2007).

In a cognitive model of CFS Surawy, Hackmann, Hawton & Sharpe (1995) propose that physical illness (coupled with psychosocial stress) can too be a precipitating factor by being physically and psychologically demanding of individuals. This fits with Spence and Moss-Morris's cognitive behavioural model of IBS given that many cases of IBS occur following a bout of gastroenteritis (Spence & Moss-Morris, 2007). Spence and Moss-Morris state that a disposition to negative affect found in IBS combined with high levels of perfectionism leads to a cycle of overexertion followed by forced rest upon encounter with gastroenteritis (coined 'all-or-nothing' behaviour). This all-or-nothing behaviour works to perpetuate symptoms.

Spence and Moss-Morris (2007) measured anxiety, depression, illness perceptions, perfectionism, perceived stress, somatization and behavioural response to illness in 620 participants with campylobacter gastroenteritis in a primary care setting. These variables were then evaluated as predictors of post-infectious IBS in this sample six months' post-infection (n=49). Although anxiety, stress, negative illness perceptions, limiting behaviour and all-or-nothing behaviour predicted the onset of IBS, perfectionism did not. This is contradictory to later evidence on post-infectious CFS where perfectionism was a significant predictor (Moss-Morris, Spence, & Hou, 2011), suggesting a need to explore other persistent physical symptoms to

identify possible differences in predisposing factors. This prospective investigation supports the cognitive behavioural approach to understanding IBS by demonstrating a role of predisposing psychological factors in the development of post-infectious IBS. However, the study is limited by the small number of cases of IBS that developed, resulting in very unequal sample sizes between groups.

One further model of IBS has proposed self-silencing as a maintaining factor in the disorder (Ali et al., 2000). Ali et al. recruited a sample of 50 participants with IBS (n=25) and inflammatory bowel disease (IBD) (n=25) from gastroenterology services across three hospitals. Along with measures of emotional, physical and sexual abuse, and self-blame, Ali et al. measured self-silencing, where self-silencing is the silencing of one's thoughts or feelings in order to maintain stable interpersonal relationships (Jack, 1991). They found that participants with IBS scored higher than the 'norm' score for self-silencing in the female general population and that there was a significant difference between those with IBS and IBD on this measure. They proposed this may relate to worsened symptoms through increased levels of distress – though they found that depression was not related to any of their psychosocial variables. Participants with IBD did not score significantly differently from the norm.

This finding suggests silencing one's emotions to be an important construct that is specific to IBS and not another medically explained gastrointestinal disorder. However, after controlling for other psychosocial factors measured (self-blame, physical/sexual abuse and emotional abuse), the found differences were no longer significant. Thus, it is possible that the differences between the two conditions could be explained by differences in other psychosocial variables between the two groups. Additionally, they did not control for depression in this multivariate analysis which may have also explained the differences between groups. Further to this, the sample

(25 participants per group) is very small and perhaps not powerful enough to detect differences after controlling for multiple confounds. Thus, further research using a larger sample (which directly compares the two groups to each other and healthy controls and not to a 'norm' value) is needed to explore the role of self-silencing in IBS.

In a systematic review and meta-analysis, medium to large effect sizes for changes in quality of life and symptom severity were found following psychological therapy, with no differences between treatment types (Altayar, Sharma, Prokop, Sood, & Murad, 2015). However, of the 15 randomised control trials included, most of the trials evaluated CBT, with the remainder evaluating psychoeducational, mind-body, psychodynamic and contingency management therapies. Thus, there is evidence (in particular for CBT) that psychological intervention is beneficial to individuals with IBS.

According to a Cochrane review of 25 studies evaluating treatments for IBS the evidence on psychological treatments for IBS is in need of improved quality in order to truly evaluate the effects of treatment (Zijdenbos, de Wit, van der Heijden, Rubin, & Quartero, 2009). Zijdenbos et al. conclude that psychological interventions show only a slight benefit to those with IBS over usual care and waitlist controls. However, the clinical significance is disputed. Perhaps evidence exploring possible mechanisms involved in the maintenance and development of IBS would aid in improving the efficacy of treatment through more targeted interventions.

1.1.3. Fibromyalgia

FMS is another condition that is not currently fully explained by the medical model and is characterised by widespread pain, fatigue, sleep disturbance and tender

points across the body (Wolfe et al., 1990). Its prevalence varies somewhat depending on the criteria used with prevalence ranging from 1.7 to 5.4% (Jones et al., 2015).

Research into a cognitive-behavioural model of FMS is somewhat limited compared to that in IBS. In reference to Deary et al.'s (2007) model of 'medically unexplained symptoms', there is evidence that adverse life events (such as physical, emotional or sexual abuse or trauma) are a predisposing factor in FMS (Häuser et al., 2011). Häuser et al.'s systematic review and meta-analysis found that having experienced abuse predicted whether a person had FMS. However this was conducted across 18 cross-sectional studies of low quality. Prospective designs testing abuse as a predictor of FMS would support the role of abuse as a predisposing factor further.

Possible routes through which these stressful events predispose and/or maintain the disorder have been suggested though the evidence is inconsistent and not specific to FMS samples (Häuser et al., 2011). These potential mechanisms revolve around hypothalamic-pituitary-adrenal axis dysfunction with evidence for elevated corticotrophin-releasing factor concentrations in cerebrospinal fluid and increased cortisol levels (Zhang & Yu, 1998; McLean et al., 2006; as cited in Häuser et al., 2011). These neurobiological responses to stress may therefore be one way in which stress results in problematic symptoms and disability.

Using the theories, ideas and evidence of the transition from acute to chronic pain, van Koulil and colleagues highlight a more integrative biopsychosocial model of FMS (van Koulil et al., 2007). They draw attention to three systems involved in response to pain; behavioural, cognitive and bodily reactions to pain. A particular behavioural response to pain which has been well-evidenced is avoidance behaviour, as part of a fear-avoidance model of chronic pain (Lethem, Slade, Troup, & Bentley, 1983). Under this model, individuals with pain experience a fear of pain recurrence

and as such avoid activities which, in their view, might trigger pain. This avoidance behaviour may then be reinforced by cognitions regarding beliefs about which activities will cause pain. Through conditioning, this behaviour is reinforced in that the avoidance of pain is attributed to successful avoidance of activity. Furthermore, reduction in activity leads to deconditioning of muscles and increased pain, thus forming a maintaining cycle.

This fear-avoidance relationship is further exacerbated by catastrophizing beliefs. Individuals who have inflated interpretations and expectations of pain exhibit more pain-related fear (Crombez, Vlaeyen, Heuts, & Lysens, 1999), which may then feed into this fear-avoidance relationship. Furthermore, increased fear of pain is related to hyper-vigilance to pain and increased attention to bodily sensations, which may encourage avoidance behaviours by increasing perceptions of bodily discomfort and pain in the face of activity (McCracken & Gross, 1993). Evidence from chronic back pain patients shows that safety-seeking behaviours are greater in those with health anxiety and that safety-seeking behaviours are related to catastrophizing (Tang et al., 2007). This evidence demonstrates a clear role of avoidance in chronic pain conditions.

Along with activity avoidance, there has been growing evidence supporting a role for emotional avoidance and suppression in FMS, finding correlations between suppression and outcomes in FMS (van Middendorp et al., 2008) through emotional expression interventions (Broderick, Junghaenel, & Schwartz, 2005; Gillis, Lumley, Mosley-Williams, Leisen, & Roehrs, 2006) and through experimental pain procedures (Sullivan, Rouse, & Bishop, 1997). Thus, based on the existing biopsychosocial models of FMS and models of pain more generally, it appears that emotional avoidance may also be part of a maintaining cycle of FMS.

1.1.4. Summary

Existing literature on persistent physical symptoms (in particular IBS and FMS) has explored a multitude of psychological and physiological factors that appear to be associated with the onset and maintenance of the symptoms. While these physiological factors are not yet fully understood, the evidence to date suggests that psychological factors play a part in at least the maintenance, if not also the development, of symptoms.

Though it is likely that some of the psychological variables explored in this evidence may play a role in other physical conditions – including those with medical explanations (Salkovskis et al., 2016)– the lack of understanding surrounding the aetiology of IBS and FMS and the need for improved treatments warrants an exploration into possible psychological factors which may be involved in these two conditions. The research to date, as discussed above, suggests a potential role of emotional suppression in the presentation of individuals with persistent physical symptoms.

1.2. Emotional Suppression

Before understanding the effects of the suppression of emotions, one must understand why the presence of emotions is necessary. There are a number of models which attempt to explain why we experience emotions.

From an evolutionary standpoint, emotions can be seen as adaptive in that they can be an indicator of a threat and may then facilitate an adaptive response to that threat (Shariff & Tracy, 2011). For example, the experience of fear may alert the individual to a threat which may result in the behavioural response of avoidance –

which would be adaptive (at least in the short term). Similarly, the experience of disgust can alert one to a noxious substance which may pose a threat. The facial expression related to disgust then restricts the intake of air which is an adaptive automatic response to a potentially noxious environment (Shariff & Tracy, 2011). Emotions may also inform the prioritising and maintenance of multiple goals occurring at the same time (Oatley & Johnson-laird, 1987).

Focussing on distress in particular, the Affect Alarm model of control argues that distress can bring attention to the presence of conflict. This can then motivate behaviour aimed at reducing the distress, including attempts to resolve the conflict itself (Oatley & Johnson-laird, 1987). This is then moderated by acceptance of emotions as the acceptance of emotion enables the individual to orient towards the distressing conflict and find a resolution. By directly address the cause of the distress as opposed to avoiding or suppressing this emotion, the cause of conflict can be resolved which can thereby reduce distress. Those who are not accepting of emotions will find addressing the cause of the distress more difficult, highlighting one way in which the suppression or avoidance of an emotion can be maladaptive.

There are a number of ways in which the suppression of an emotion can be considered maladaptive. The suppression of emotion occurs after the emotion has already been experienced. Thus while other strategies (e.g. cognitive reappraisal – defined as a cognitive change where the perception of a potentially emotion-eliciting situation is seen in a new light that alters its emotional impact (Brockman, Ciarrochi, Parker, & Kashdan, 2017)) can reduce the experience of an emotion by being used in response to an emotional cue before the onset of the emotional experience, emotional suppression cannot reduce the experience of emotion, only the expression (John &

Gross, 2004). This therefore means those who suppress emotions still feel the emotions they do not want to experience.

Furthermore, suppression, as opposed to cognitive reappraisal (largely considered a more adaptive form of emotion regulation (Brockman et al., 2017)) is cognitively demanding meaning that the suppression of emotion can result in cognitive impairment, such as impaired working memory (John & Gross, 2004).

Thinking beyond internal consequences of emotional suppression, an individual who is externally emotionally suppressive is at a disadvantage socially. Firstly cognitive impairment is likely to affect social interaction. Secondly, the suppression of emotion can inhibit the development of emotionally close relationships through avoidant, strained and distracted behaviour, leaving the individual alienated (John & Gross, 2004).

Through this array of mechanisms, emotional suppression can result in an increase in distress. Another theory of the consequences of internal suppression is ironic processing effects.

1.2.1. Ironic Processing Effects

Wegner's theory of ironic processing suggests that suppressing thoughts can lead to an ironic increase in those thoughts when there is a high cognitive load (Wegner, 1994). It was proposed that there are two cognitive processes which work in cooperation to provide successful mental control. The first of these two systems is a conscious and effortful operating process which intentionally searches for mental contents that pertain to the desired mental state. The second is an unconscious monitoring process which searches instead for mental contents which indicate that attempts to achieve the desired state have failed. The operating process brings to mind

thoughts and feelings that will lead to the desired mental state while the monitoring process checks that this process is effective and reactivates the operating process when it detects any signs of failure of mental control. This system can function successfully, however it comes under threat when there is a high cognitive load. By increasing one's cognitive load, the operating process (which is more cognitively demanding and effortful than the monitoring process) can become limited such that when the monitoring process detects mental contents indicative of failure, the operating process is compromised in rectifying the failure. This can be compromised to such an extent where the monitoring system's search for thoughts or feelings that are counterproductive to the desired state can be enough to bring such thoughts into the consciousness, thereby producing an ironic effect where these negative thoughts are experienced, despite efforts to suppress them.

Dalgleish and colleagues applied Wegner's theory to emotional suppression in people with high and low negative affect, under the assumption that high negative affect leads to a high cognitive load (Dalgleish, Yiend, Schweizer, & Dunn, 2009). Twenty-eight participants were grouped by high or low negative affect based on the Hospital Anxiety and Depression Scale (HADS), with participants scoring eight or higher on either the anxiety or depression subscale assigned to the high negative affect group. Participants completed an emotion regulation task in three different conditions. They were asked to think about distressing memories and write down their stream of consciousness. Participants in the no-instruction condition were asked to think about their distressing memory as vividly as possible and were instructed not to try to regulate their emotions in any way. In the suppression condition however, participants were asked this time to think of a different memory but to try to suppress their

emotions regarding this memory. In a third condition, the task was the same however participants were instructed to accentuate any emotions they felt.

They found that participants with high negative affect showed an ironic increase in negative emotions when asked to suppress their emotions compared with the no instruction condition. Low negative affect participants were able to successfully regulate their emotions and did not show such ironic processing effects, instead, low-negative affect participants showed a significant lowering of negative mood in the suppression condition compared with other conditions. Furthermore, it was found that HADS anxiety and depression scores are individually correlated with increases in negative mood in the suppression and experience conditions.

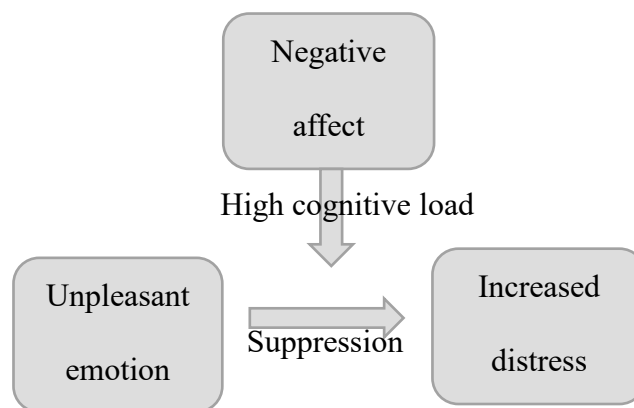


Figure 1.1 Ironic processing effects in relation to emotional suppression

Thus, there are two requisites for ironic processing effects in regards to emotion regulation. First is negative affect, which exerts a high cognitive load leading to a resulting failure of the operating process and second the presence of efforts to suppress one's emotions (see Figure 1.1). Furthermore, the presence and recognition of negative affect is necessary in that the individual must experience an unpleasant emotion in order to desire to suppress it.

Increased negative affect is well-evidenced in those with persistent physical symptoms, with some distress considered an expected or even healthy response to diagnosis (Moss-Morris, 2013). Research has shown higher levels of trait anxiety in students with IBS compared with healthy controls (Gick & Thompson, 1997). Furthermore, using the “negative affect” subscale of the Beck Depression Inventory, Kovács and Kovács (2007) found that patients with IBS and not those with inflammatory bowel disease scored significantly higher than healthy controls, a finding which mirrors the findings of Ali et al. (2000).

van Middendorp and colleagues measured positive and negative affect in patients with FMS and found that compared with healthy controls, patients with FMS reported higher levels of negative affect (fear, hostility, guilt and sadness) and lower levels of positive affect (joviality and self-assurance) (van Middendorp et al., 2008).

Thus, given the increased negative affect found in persistent physical symptoms, and that this negative affect can act as a high cognitive load resulting in ironic processing effects, it would appear that people with persistent physical symptoms may be more prone to ironic processing effects if they exert any efforts to suppress their emotions. Further to this, the presence of increased negative affect in persistent physical symptoms means there are undesirable emotions present that individuals may attempt to suppress.

1.2.2. Emotional Suppression and Physical Symptoms

The terms emotional suppression, emotional avoidance and emotional control (among others) are used differentially in research to refer to similar concepts. As the literature on emotion regulation grows, there is an increasing need to establish distinct definitions for these terminologies.

It should be noted that there is a distinction between ‘internal’ and ‘external’ emotional suppression. For the purpose of this thesis internal emotional suppression is defined as the avoidance of experiencing one’s emotions and external emotional suppression is the avoidance of expressing that emotion to others. Emotional suppression encompasses both of these. Different measures (including those in the current thesis) capture the cognitive strategy of avoiding experiencing one’s emotions to varying degrees.

A separate, though related line of research has found alexithymic traits in individuals with persistent physical symptoms. Alexithymia is a personality trait characterised by difficulty regulating one’s emotions (including identifying, describing and expressing emotions) (Graeme, Taylor, Bagby, & James, 1999). There is a range of evidence, beyond the aims of this thesis, which argues that alexithymia is related to persistent physical symptoms, with specific studies in FMS (van Middendorp et al., 2008) and IBS (Phillips, Wright, & Kent, 2013) finding higher levels of alexithymic traits in these groups compared to healthy controls. Other similar approaches have explained the relationship between emotional suppression and clinical outcomes with regards to those with somatoform disorders (diagnosed primarily by the presence of physical symptoms in the absence of medical explanation) demonstrating impaired emotion regulation and instead attending to and reporting physical as opposed to psychological symptoms (Waller & Scheidt, 2006). While this line of research shows how emotion dysregulation more broadly might be related to persistent physical symptoms, the current thesis focussed on emotional suppression in particular and thus issues with the identification and description of emotions, though perhaps related, are beyond the scope of the current thesis.

In terms of Acceptance and Commitment Therapy (ACT) experiential avoidance is defined as an unwillingness to experience, and attempts to control or avoid negatively evaluated private thoughts, feelings and bodily sensations (Hayes, 1994 as cited in Kashdan, Barrios, Forsyth, & Steger, 2006). According to ACT models, experiential avoidance can in some cases be beneficial in the short-term however when applied rigidly and inflexibly it becomes problematic. Instead acceptance of undesirable experiences is encouraged (McCracken, 2011). Indeed, in a systematic review of ten randomised control trials of ACT interventions for chronic pain conditions, it was found that across seven studies with an inactive control group, ACT showed small to large improvements in a range of primary outcomes (including physical functioning and disease impact) (Hann & McCracken, 2014). In particular, two of the three studies which looked at FMS specifically and found improvements in both physical function (Wicksell et al., 2013 as cited in Hann & McCracken, 2014; Wicksell et al., 2013) and disease impact (Luciano et al., 2014; Wicksell et al., 2013 as cited in Hann & McCracken, 2014; Wicksell et al., 2013). The third reviewed study investigating ACT intervention for FMS only examined changes in values (in relation to intimate relations and work) (Luciano et al., 2014). Though there were significant improvements in these measures, these were not maintained at follow-up and more evidence with comparisons to active control conditions is needed.

Evidence on ACT in IBS is more limited with a recent systematic review finding no randomised control trial evaluating this particular intervention in IBS, despite having clearly defined search terms for ACT (Altayar et al., 2015). However it has been previously noted that the principles of ACT may well apply to those with IBS based on their style of emotional processing (Naliboff, Fresé, & Rapgay, 2008), even if this particular intervention has not been subject to a randomised control trial.

Evidence into emotional processing in IBS would therefore be useful to help build a rationale for further treatment options directed towards acceptance of emotion, such as ACT.

This evidence supports the idea that encouraging acceptance (of emotions and of pain) and discouraging avoidance in participants with FMS can illicit benefits. However, with only a limited number of randomised control trials looking specifically at FMS, further exploration into the role of experiential avoidance in FMS is needed. Furthermore, research looking specifically at the avoidance and acceptance of emotions as opposed to experiences more generally (which would include physical symptoms such as pain) is warranted.

The investigation of emotional suppression in clinical and health psychology has been growing. There has been research into the role of emotional suppression in anorexia nervosa with one study finding that participants with anorexia (n=40) and those with CFS (n=45) scored higher on measures of affect avoidance and self-silencing compared to healthy controls (Hambrook et al., 2011). Similarly, in breast cancer patients (n=40) anger suppression predicted higher reports of symptoms (Schlatter & Cameron, 2010). With regards to psychological disorders, participants with anxiety or depression diagnoses (n=60) were found to be more suppressive than those without psychiatric diagnosis (n=30). While all of this evidence suggests that emotional suppression is of interest when researching persistent physical symptoms, these studies did not control for negative affect when comparing groups on measures of suppression. As such, it could be that those with physical symptoms may experience some negative affect as a result of their condition and this increase in negative affect may drive them to become more suppressive. The sample sizes of these studies are also generally very small.

Research into persistent physical symptoms has suggested that people who suffer from persistent physical symptoms might also be more likely to suppress their emotions. Using a sample of 403 women with FMS from The Netherlands, van Middendorp and colleagues measured emotional approach, emotional avoidance, affect intensity and symptomatology (van Middendorp et al., 2008). Emotional approach was defined to include emotional processing, cognitive reappraisal, emotional expression more generally and the expression of anger specifically. Emotional avoidance was measured to include emotional suppression and alexithymia. Compared to controls (women without FMS with no exclusion criteria for other disorders), participants with FMS showed significantly lower levels of emotional expression, higher levels of emotional suppression and more difficulty identifying and describing feelings.

Findings regarding the role of emotional suppression in FMS have been mirrored in research looking at participants with IBS (Ali et al., 2000, see section 1.1.2, page 13), comparing patients with IBS to those with inflammatory bowel disorder (IBD) on the Silencing of the Self Scale (Jack & Dill, 1992). The research found that patients with IBS showed higher levels of self-silencing. However this self-silencing measure (also used in evidence on CFS (Hambrook et al., 2011)) incorporates not just emotionally suppressive tendencies but also motivations and beliefs pertaining to emotional suppression. It would therefore be useful to explore emotional beliefs and behaviour separately, fitting with a cognitive-behavioural approach to persistent physical symptoms.

Consistent with findings on the role of emotional suppression in maintenance of symptoms, other researchers have focused on thought suppression. Based on evidence showing patients who catastrophize report more pain during pain experiments

(Heyneman, Fremouw, Gano, Kirkland, & Heiden, 1990), Sullivan and colleagues argue that this relationship is mediated by thought intrusions; patients who catastrophize during a pain experience will encounter more thought intrusions and this will result in more pain (Sullivan et al., 1997). They also argued that due to the higher level of thought intrusions, catastrophizers are more likely to engage in thought suppression. Seventy undergraduate participants were informed of an upcoming ice water immersion pain procedure and asked to write their on-going thoughts on paper for nine minutes. Half of the participants were instructed to suppress thoughts about the upcoming procedure. Following the thought recording task, participants then underwent the pain procedure. Through analysis of the thought records, Sullivan et al. found that participants in the suppression condition, compared to those in the control condition experienced more thought intrusions during the thought recording task and experienced more pain during the pain procedure.

Their finding supports ironic processing theory (Wegner, 1994) in that those who attempted to suppress their thoughts experienced an ironic increase in those thoughts. Furthermore, Sullivan et al. demonstrate that suppressing thoughts about upcoming pain can result in the experience of more pain (Sullivan et al., 1997). Thus, it may be that those with more catastrophic beliefs are more inclined to suppress their fearful thoughts about pain. This may then in turn modulate the perception of pain. Once the frequency of thought intrusions was controlled for, there was no longer a significant difference in pain ratings between those who did and did not suppress their thoughts, suggesting thought intrusions might mediate the relationship between suppression and pain. This supports the notion that attempts to suppress a thought can result in an increase of that particular thought and that these intrusive thoughts are then related to the perception of pain.

More recent evidence conducted with participants who have CFS has demonstrated a role for emotional suppression in fatigue (Rimes, Ashcroft, Bryan, & Chalder, 2016). In a behavioural experiment, 80 participants with CFS and 80 healthy controls took part in a negative mood induction task involving watching a distressing film clip. Half of each patient group was instructed to suppress thoughts about how they feel and to hide how they feel. The other half of each patient group was instructed to regulate their emotions as they wish. Measuring sadness, anger and anxiety as outcomes revealed a main effect of patient group whereby participants with CFS were sadder than controls. For anger, there was a main effect of time where all participants were angrier after watching the clip. For sadness and anger, there were no interactions. For anxiety, there was a significant interaction in which both controls' and patients' anxiety increased after watching the video in the suppression condition demonstrating that the suppression of anxiety can result in an increase in that emotion.

However, using a comparison condition of the participants' choice in emotional regulation could be problematic. Previous research has reported increased beliefs about the unacceptability of the experience and expression of emotions in CFS (Rimes & Chalder, 2010) and therefore it might be that those in the CFS condition would choose to suppress more than healthy controls when given the choice. Asking participants in this condition which method of regulation they used revealed this to be true. This might explain the lack of significant findings in sadness and anger conditions. Measuring skin conductance response while watching the distressing clip revealed greater skin conductance in response to the clip in the CFS group, regardless of whether they suppressed their emotions. This increase in skin conductance found after watching the video clip was significantly related to fatigue, the primary symptom of CFS.

In addition, a main effect of condition was found whereby participants in the suppression condition had greater skin conductance responses regardless of patient group. This finding indicates increased physiological arousal in response to negative mood induction when emotional suppression is exercised. While no group by condition by time interaction was found, this could again be due to the high levels of suppression in the free regulation condition in the CFS group in that for healthy controls (who experience less negative affect and therefore reduced cognitive load) the suppression condition had little effect while for the CFS participants (who have greater negative affect and higher cognitive load) this suppression may have resulted in an ironic increase in emotion. However, since the free-regulation condition for the CFS participants may have still involved the suppression of emotion, no interaction would be detected.

Thus, given that those with persistent physical symptoms exhibit both increased levels of negative affect and higher rates of emotional suppression, it seems possible that such individuals might be prone to ironic processing effects whereby they experience an unpleasant emotion, attempt to suppress this emotion and consequently experience an ironic increase in that unpleasant emotion. Furthermore, it could be that individuals with persistent physical symptoms who are emotionally suppressive may also avoid asking for help or avoid certain social situations, which may further maintain the cycle of distress and symptoms (Rimes & Chalder, 2010). These indirect relationships warrant further investigation.

The study of emotional suppression is particularly important in physical symptoms for which there is no clear physiological explanation due to the role of stigma. In particular, it has been noted that those with long term conditions perceive social stigma surrounding their disorder, with a distinct role of secrecy in disorders

where pathophysiology is uncertain such as CFS and FMS (McInnis, McQuaid, Bombay, Matheson & Anisman, 2015). In reference to FMS, Griffith and Ryan (2010) have argued that a person with FMS ‘feels obligated to act as though normal before others, despite high internal distress, since revealing one’s authentic suffering could risk judgement, rejection, or punishment’ (p. 178). Further evidence that secrecy in FMS and in CFS is related to reduced social support (McInnis, McQuaid, Bombay, Matheson & Anisman, 2015) suggests a need to test beliefs about sharing illness experience in relation to support-seeking and indeed the impact on a person’s life.

While the study of the relationship between disclosure and social support is limited in FMS and IBS, a study of 500 clients of a mental health outpatient service in The Netherlands showed that perceived stigmatisation was related negatively with disclosure and perceived social support, while disclosure was related positively with social support. It is worth noting here however that the coefficients were small ($r=.24-.40$) suggesting that stigma and disclosure may only explain a small amount of the variance in social support. Additionally, the study is based on correlations so the causal direction cannot be inferred: It may be that disclosure results in increased social support, or it could be that having a good support network better facilitates disclosure (Bos, Kanner, Muris, Janssen, & Mayer, 2009). However in an online study of 451 healthy individuals, support-seeking was not a significant mediator of the relationship between beliefs that emotional expression is unacceptable and three outcomes (depression, anxiety and fatigue) (Sydenham, Beardwood, & Rimes, 2016), which is unexpected and warrants further investigation in other samples with persistent physical symptoms.

To surmise, the suppression of unpleasant emotions can result in a counter-intuitive increase in psychological distress. The above evidence suggests that those

with IBS and FMS may be more prone to these ironic processing effects through their higher levels of negative affect and their possible higher levels of emotional suppression. Thus, the impact of this increased distress on the individual and their condition warrants further discussion.

1.3. Distress is related to Poor Health-Related Outcomes

Research into long term conditions has demonstrated a clear link between distress and health related outcomes. The extensive research into biopsychosocial models of pain has demonstrated how fear of pain is related to feeling more pain through increased attention, hypervigilance to bodily sensations, deconditioning and increased bodily tension (van Koulil et al., 2007), with experimental (Lee, Watson, & Frey-Law, 2013) and prospective research designs (Montgomery, Schnur, Erblich, Diefenbach, & Bovbjerg, 2010) providing support for this. Thus, there is clearly a role for distress in the maintenance of pain in FMS. This is further evidenced by Van Middendorp and colleagues who found in 403 participants with FMS that negative affect was related to more pain and fatigue (van Middendorp et al., 2008).

The neurobiopsychosocial model of pain (Moseley & Butler, 2015) proposed the mechanism through which increased distress, and perceived ‘dangers’ lead to an output of pain, and thus experience of pain. Experimental evidence that negative affect can increase the perception of pain (Wiech & Tracey, 2009) further demonstrates a relationship between increased distress and pain supporting the notion of increased distress being associated with greater symptoms of FMS.

Research into IBS has demonstrated a possible causal link between distress and symptoms. Blomhoff and colleagues investigated intestinal reactivity to emotive words in people with and without IBS (excluding those with constipation-predominant

IBS) (Blomhoff, Spetalen, Jacobsen, Vatn, & Malt, 2000). Participants' rectal tone was recorded throughout exposure to auditory tones and words relating to anger, sadness and anxiety. They found changes in rectal tone in response to emotive words compared to the auditory tone in all participants. However, these changes varied in terms of increases and decreases among the participants suggesting a more complex relationship between emotive stimuli and gastrointestinal response. Furthermore, the authors acknowledged that rectal tone changes have been found in dichotic listening tasks and thus the changes across participants in rectal tone may simply be a result of attention to auditory stimuli with semantic meaning which requires a deeper level of cognitive processing compared to an auditory tone.

Turning to evidence in clinical samples, Dancey, Taghavi, & Fox (1998) asked 31 participants with IBS to complete measures of daily symptoms, stress and daily hassles every day for 28 days. The authors examined the time series of these variables to test whether symptoms are a consequence of stress or if the inverse is true. Dancey and colleagues found that the best model that suited their data had symptoms as a function of hassles and symptoms on the previous two days and hassles on the same day. Furthermore, the authors found that the reverse relationship was also true; finding that for over a third of participants, worsening symptoms resulted in an increase in their perceived stress.

Consequently, the observed relationships between distress and symptomatology in IBS, FMS and perhaps other disorders, are likely bidirectional whereby the worsening of symptoms can lead to more distress and distress can result in worsening symptoms, fitting with Deary et al.'s (2007) idea of a self-perpetuating cycle.

1.4. Emotional Expression Interventions

Some of the best experimental evidence for the role of emotional suppression in persistent physical symptoms comes from randomised trials whereby an intervention that encourages emotional expression (often through emotive writing) is investigated in terms of its effects on quality of life and/or symptoms.

These studies involve inviting participants to express their emotions in writing (usually about a specific upsetting or traumatic event) with the expectation that this will elicit improvements in well-being. There are a number of proposed mechanisms of this effect, though it is not yet clear what these mechanisms are: It is likely that there are multiple mechanisms working in parallel or interacting and that the mechanisms may vary across individuals (Halpert, Rybin, & Doros, 2010). It has been argued that written emotional disclosure allows for previously avoided emotions to be experienced, which may facilitate emotional processing and cognitive reflection and reframing. There may be habituation or desensitisation which may then result in the emotions becoming less intense or overwhelming and may result in cognitive and/or interpersonal changes, all of which may result in improved well-being and quality of life (Gillis et al., 2006; Halpert et al., 2010).

In a sample of 72 participants with FMS, Gillis et al. (2010) conducted a randomised control trial using a written emotional disclosure intervention. After completing baseline measures, participants were instructed to write for four consecutive days for around 20 minutes. Those in the disclosure condition were asked to write about a particular stressful experience and told to focus on the facts about the experience as well as their deepest feelings. The control participants were asked to write about their plans across different time periods with a focus on actual plans and behaviours as opposed to their own feelings about these plans.

At the one month follow-up, there was no significant group by time interaction on global impact measured using the Fibromyalgia Impact Questionnaire (FIQ). However, they did find a significant interaction for sleep quality whereby disclosure participants improved and control participants worsened. There was also a significant group by time interaction for social support and negative affect. However, this was explained by a reduction in negative affect and increase in social support for the control group.

Three months after the intervention was completed, there was a significant group by time interaction whereby participants in the disclosure condition improved in FIQ scores compared to controls who showed no significant changes in FIQ scores. Significant interactions were also found for sleep quality and health care utilization in which the disclosure participants showed improvements (better sleep quality and less health care utilization) compared to slight non-significant worsening for the control group. While participants in the disclosure condition showed higher levels of negative affect and lower levels of social support compared to controls at the one-month follow-up, these differences had disappeared by the three-month mark. While this does support the notion that emotional expression may result in improvements for people with FMS, the quality of this evidence should be questioned due to its small sample size, brief intervention and the delay in the effect of the intervention.

Gillis and colleagues argue that the delay in improvements could be due to mediating processes which take more time to transform, such as changes in cognitions which may then lead to behaviour changes. Thus, it is proposed that changes in behaviour may need to continue for benefits to be seen. Once this behaviour continues, they propose it may also influence cognitions. In particular, it could be that continued expression of emotion may modulate beliefs about emotions which might then

influence outcomes. Thus this cycle would become self-maintaining, in line with Deary, Sharpe and Chalder's (2007) cognitive behavioural model. However, the mediating effects of cognitions were not investigated by Gillis et al. (2007) and warrant further investigation.

Similar to Gillis and colleagues, Broderick et al. (2005) conducted a randomised control trial using a written emotional disclosure intervention for participants with FMS. Participants were randomly allocated to one of three conditions, emotional disclosure writing, neutral writing and usual care. In both the writing conditions participants were asked to write for 20 minutes on three occasions, each roughly one week apart. Participants in the emotional disclosure condition were asked to write about a past or current traumatic event and were instructed to include their deepest thoughts and feelings about the event. Although Broderick and colleagues found improvements in pain and fatigue, and less worsening of psychological wellbeing at four-month follow-up (compared to neutral writing controls and treatment as usual controls); these differences were not maintained at 10-month follow-up (Broderick et al., 2005). They argue this could be due to the brevity of the intervention. However, it could be argued that it may also be due to the intervention addressing simply the act of suppression as opposed to the beliefs which precede it. In order to encourage longer lasting changes in behaviour, perhaps beliefs relating to the expression of emotion that determine suppressive behaviours should also be addressed.

There has been little research into written emotional disclosure for individuals with IBS, with only one non-randomised pilot study without a control condition having been published. Halpert, Rybin and Doros (2010) recruited participants with IBS online and asked them to write emotively. They found a significant reduction in IBS severity at one-month and three-month follow-up, in addition to significant

improvements in cognitive function and coping strategies at one-month and three-month follow-up. Quality of life measures showed significant improvements at three-month follow-up but not at one-month, suggesting that improvements in the overall impact of the disorder on a person's life may take longer, perhaps due to slower mediating processes (such as those discussed by Gillis et al., 2010).

Further to this is a randomised-control trial of written emotional disclosure in 11-18 year olds with medically unexplained abdominal pain attending a gastrointestinal speciality clinic found significant treatment effects (Wallander, Madan-Swain, Klapow, & Saeed, 2012). With 27 participants in the standard care condition and 36 in the treatment condition, they found significant reductions at six months, but not at three months, in pain frequency for the written emotional disclosure group compared to controls. Furthermore, they found significantly less service use in participants in the written emotional disclosure condition at six-months compared to baseline and this was not found in the treatment as usual group. While there was no significant difference in measures of quality of life at three and six months, there was a non-significant trend at six months in the expected direction; a slight improvement in quality of life for the written emotional disclosure group (Wallander et al., 2012). However, the use of treatment as usual as opposed to a neutral writing control group does not sufficiently rule out the possibility of placebo effects.

Despite methodological issues, Wallander and colleagues' findings, taken in addition to findings in FMS (such as Gillis et al., 2010; and Broderick et al., 2005) and the pilot study in IBS (Halpert et al., 2010) support the role of emotional suppression in persistent physical symptoms and indicate that targeting this may have some therapeutic benefit. It therefore seems plausible that by encouraging the

expression of emotions, it might be possible to improve outcomes in persistent physical symptoms.

1.5. Beliefs about Emotions

Given the current trend towards cognitive-behavioural treatments (with CBT specifically recommended in the treatment of FMS, IBS and CFS (Häuser et al., 2008; NICE, 2007, 2008)), attention should be turned towards the beliefs that might relate to such suppressive tendencies. These beliefs about emotions have been researched in terms of worry and anxiety, with limited research in the realm of health psychology and more limited still, in persistent physical symptoms.

Evidence exploring a cognitive-behavioural model of worry has established a possible role of meta-cognition (Wells, 2009). This research proposes that there are two types of cognition to be considered when looking at emotional disorders; these are appraisals of external events and non-cognitive internal events (such as somatic sensations) and appraisals of cognition itself.

Wells argues that beliefs about cognitions can motivate an individual by encouraging attempts to control cognitions (Wells, 2009). He describes two types of beliefs, which can do this. The first is beliefs about the process of cognition, for example the belief that one should be able to control their thoughts and feelings. The second is beliefs about the content of cognitions, for example believing that a particular thought is 'bad'. In a similar vein, within the context of worry and meta-worry, Wells argues that meta-worry can drive attempts to control and can increase worry through a number of mechanisms. These include priming the cognitive system for detection of worry (which relates to Wegner's (1994) description of an over-representation of the monitoring system) and incomplete processing of the original

worry due to limited cognitive resources. Thus, these appraisals and beliefs regarding mental events seem to be crucial in emotion regulation.

A similar line of research has been conducted with regards to emotional schema (Leahy, 2002), stating that the experience of an emotion is something to which individuals will respond differently through activation of beliefs about the implications of this emotional state. Leahy (2002) asserts that individuals will conceptualise their emotions differently; they have different emotional schemas which are understood through 14 dimensions. Furthermore, Leahy goes on to state the importance of uncontrollability as a dimension for emotional schema, highlighting the problems that occur with beliefs that emotions are uncontrollable or that one might feel a sense of losing control in the face of certain emotions.

In a study of 53 psychiatric patients from a cognitive behavioural clinic, Leahy demonstrated that depression and anxiety were related to the belief that emotions were uncontrollable but that emotional expression (measured by the items “I believe that it is important to let myself cry in order to get my feelings out” and “I feel that I can express my feelings openly”) was not related to anxiety and depression. While emotional schemas provide valuable early evidence on the importance of thinking about emotions, the focus of the current thesis is on beliefs that more directly relate to the expression of emotions. Furthermore, Leahy’s measure of emotional expression is poorly defined in that crying is only one form of expression and does not apply as well to anxiety compared to sadness. In addition, feeling as though one can express their emotions is not strictly measuring their level of emotional expression. For example, one might feel like they should not express their emotions (perhaps due to a belief that this is unacceptable) or it may be that they have difficulty in identifying the correct emotion or expressing this accurately.

Despite the research dedicated to meta-cognition and emotional schemas, there is a comparative lack of research looking into cognitions which might relate to emotional suppression. Rimes and Chalder (2010) constructed a scale which measures beliefs about the unacceptability of expressing and experiencing one's emotions, the Beliefs about Emotions Scale (BES). Using this measure, they found higher levels of beliefs concerning the unacceptability of emotions in people with CFS compared to healthy controls. They also found in those with CFS that these scores were moderately significantly correlated with perfectionistic self-beliefs, dysfunctional attitudes, self-sacrifice schemas, anxiety and depression, and fatigue (effect sizes ranging from .25 to .59). Twenty-two of the participants with CFS underwent CBT and completed the BES before and after the 12-week intervention. There were significant changes in beliefs about emotions following CBT, whereby there was a reduction in scores, indicating that these beliefs can be manipulated through cognitive behavioural techniques.

Further research using the BES has shown beliefs about emotions to be related to emotional suppression, emotional avoidance (i.e. the avoidance of experiences which might elicit undesired emotions), alexithymia and the ability to distinguish emotions from physical symptoms (Rimes, 2015). Rimes puts forward the idea that beliefs about emotions could be related to fatigue in CFS through a number of mechanisms, including emotional suppression, emotional avoidance, difficulty recognising and describing emotions and difficulty identifying physical sensations related to emotions. In an online study with healthy individuals, Sydenham et al. (2016) found that beliefs about the unacceptability of emotions were related to more emotional avoidance, reduced support-seeking and lower levels of self-compassion. They also found that the relationships between beliefs about emotions and anxiety,

depression and fatigue were mediated by emotional avoidance and by self-compassion, but not by social support. While the research on these beliefs about emotions thus far is limited to those with CFS, it becomes clear with the aforementioned research that beliefs about emotions are likely to relate to suppression in clinical samples. Under the cognitive-behavioural paradigm, identifying these beliefs is crucial for shaping CBT in such a way to incur long-lasting benefits for individuals with persistent physical symptoms where behaviours and cognitions can both be addressed.

1.6. Summary

Given the above evidence that suggests that negative affect combined with emotional suppression can result in an ironic increase in the distress which is being suppressed, and given the evidence suggesting that the requisites for ironic processing effects are more common in those with IBS and FMS; it seems likely that these individuals may be particularly prone to these ironic processing effects. Further to this, research demonstrating a relationship between distress and health-related outcomes in these disorders coupled with the growing literature on the benefits of written emotional disclosure interventions, suggests that these higher levels of emotional suppression might work to perpetuate symptoms and that encouraging the expression of emotion may have therapeutic benefits. Evidence on beliefs about emotions suggests that holding such beliefs about the unacceptability of emotions might result in poorer health-related outcomes for people with persistent physical symptoms (see Figure 1.2).

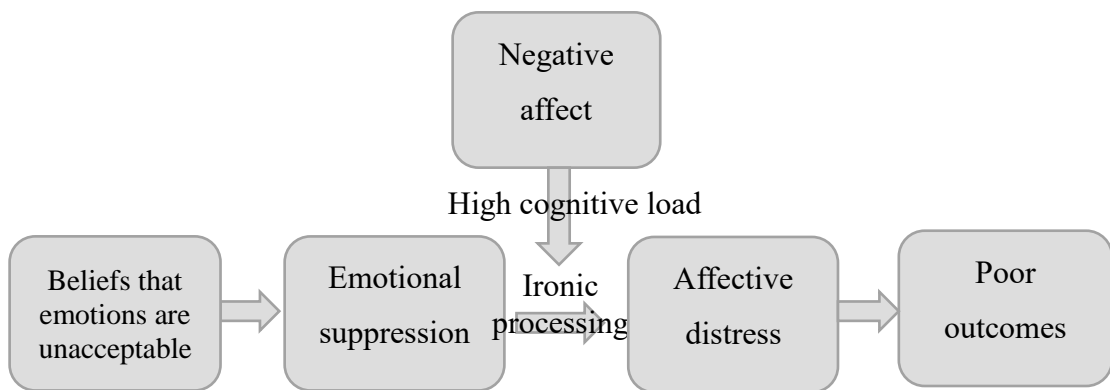


Figure 1.2 Hypothesised relation between variables

1.7. Aims

The current thesis aims to investigate the role of beliefs about emotions and emotional suppression in FMS and IBS. In this way, the thesis will investigate cognitive behavioural factors in relation to persistent physical symptoms; in particular, the thesis describes research into the role of emotional suppression, proposing a model whereby believing emotions to be unacceptable is hypothesised to be related to more emotional suppression, which can result in increased distress. This distress is then hypothesised to result in worse outcomes. Through cross-sectional, longitudinal and experimental methods, the current thesis explores these variables with the aim of using this model to inform cognitive-behavioural intervention.

2. Chapter Two: Methods

The current thesis used correlational and experimental methods to explore the role of emotional suppression and beliefs about the unacceptability of experiencing and expressing emotions in IBS and fibromyalgia. Across the six studies in this thesis, a number of complementary methodologies and analyses were used to address the aims of this thesis (see sections 2.5 and 2.6 of this chapter, pages 73 and 76). Throughout these studies a number of questionnaires were used consistently to screen for particular diagnoses (i.e. IBS and fibromyalgia) and to measure psychological constructs, namely, beliefs about the unacceptability of emotions, emotional suppression, affective distress, quality of life in IBS and global impact in FMS. These questionnaires are discussed in detail below. Details on how these measures were modified to suit particular studies and details of measures which were used only in particular instances in this thesis can be found in the methods sections of the experimental chapters.

2.1. Screening Tools

2.1.1. Manning Criteria for Irritable Bowel

In addition to participants reporting a diagnosis of IBS from a clinician, the Manning Criteria for Irritable Bowel were used as inclusion criteria for participants with IBS. The Manning Criteria for Irritable Bowel is a set of six items used to determine the presence of IBS (Manning et al., 1978). This is used primarily for diagnosis as opposed to being used as a measure of severity. Participants are presented with six statements about the symptoms of IBS and are asked to indicate whether they regularly experience this symptom. A positive diagnosis categorised by meeting three criteria (see Figure 2.1)

Manning Criteria for Irritable Bowel

- Visible abdominal distension
- Pain relief with defecation
- More frequent stools at pain onset
- Looser stools at pain onset
- Mucus per rectum
- Feeling of incomplete evacuation

Figure 2.1 Manning Criteria for Irritable Bowel

In the current thesis, participants who met three or more of the Manning Criteria and stated a diagnosis of IBS were considered to have IBS. Participants who state a diagnosis of IBS but did not meet at least three of the criteria were excluded. In Chapter Three, participants were included if they had self-diagnosed IBS or if a physician had provided a diagnosis. However, in order to improve the validity of the diagnoses, in Chapter Four participants were only included if the participant reported that a physician had diagnosed them with IBS.

Using the six criteria in 33 participants with organic bowel disease and 32 with IBS, Manning et al. (1978) found that people with IBS tend to meet three or more of the six criteria (n=27) whereas for those with an organic bowel disorder (i.e. peptic ulcer disease), fewer patients reported three or more of the six criteria (n=8). However, the statistical significance of this was not examined. Building on from this study whose sample is small, Talley et al. (1990) investigated the ability of the Manning Criteria to discriminate between those with IBS (n=82), non-ulcer dyspepsia (n=33), organic bowel disease (n=101) and healthy controls (n=145) in a larger sample.

Talley et al. found that those with IBS scored significantly higher on the Manning Criteria than healthy controls, patients with non-ulcer dyspepsia and those with organic diseases. Specifically, when looking at the percentage of participants meeting three or more of the criteria, 53% of those with IBS met three or more criteria compared to 27%, 26% and 7% of the non-ulcer dyspepsia, organic disease and healthy control groups (respectively). This demonstrates a large difference between groups in the proportion meeting three criteria, however it is perhaps more informative to explore the sensitivity (correctly identifying those with the disorder) and specificity (correctly identifying those without the disorder) of the measure.

Talley et al. tested the sensitivity and specificity of the Manning Criteria for each of their control groups. The comparison with healthy participants demonstrated 65% sensitivity and 86% specificity, which is good. The tool's ability to identify those with and without IBS was slightly weaker for the other groups however, with 58% sensitivity and 75% specificity when compared with organic bowel disease, and 97% sensitivity and 3% specificity with non-ulcer dyspepsia.

The Manning Criteria for Irritable Bowel, while demonstrating some discriminability between those with organic and functional bowel disorders, does not include criteria relating to constipation symptoms. Constipation type IBS (IBS-C) is less common than alternating or diarrhoea type IBS (Brandt et al., 2009) and is not represented in the Manning Criteria. In the original creation of the criteria, Manning tested multiple items which included the criterion "less frequent stools at the onset of abdominal pain". However this item did not discriminate between those with organic and functional bowel disorders, having only one out of 31 patients with IBS report this, and two out of 30 patients with peptic ulcer disease (Manning et al., 1978). Though Manning et al. found this in a small sample, when comparing patients with

IBS-C and diarrhoea predominant IBS (IBS-D) in a larger sample, Talley et al. (1990) found that there were no significant differences in Manning Criteria scores. In the same experiment, Talley et al. tested the validity of additional symptoms added to these criteria that addressed constipation and found that they did not provide any additional value to the diagnostic tool. These symptoms included having less than three bowel movements a week, often having hard stools, straining more often and laxative use. Thus, while this symptom is an important part of the experience for patients with IBS, and indeed may constitute a subgroup of the disorder, it is arguably not necessary as a criterion for the diagnosis of IBS.

The Rome Criteria are another diagnostic tool that are more frequently used and have been recommended for the diagnosis of IBS by clinicians, though this is not the current NICE recommendation for practice in the NHS (NICE, 2008). The current thesis used the Manning Criteria to validate self-reported diagnosis which varies slightly from the Rome Criteria. However, the American College of Gastroenterology Task Force state that there is a slight improvement in specificity in the Rome criteria compared to the Manning criteria (85% compared to 72%) and comparable sensitivity (78% for the Manning criteria and 71% for Rome). They argue that the Rome criteria require further evaluation and importantly, cases should be identified based on the presence of abdominal pain associated with alternating bowel habit over a period of at least three months (Brandt et al., 2009). Thus, perhaps the only key difference is that the Manning criteria do not specify the duration for which participant must have experienced these regular symptoms.

The six Manning criteria have good discriminative validity in IBS (Manning et al., 1978; Talley et al., 1990) and also capture a broader scope of symptoms across six criteria compared with fewer criteria listed in the Rome criteria, making these more

limited diagnostic tools unnecessarily more restrictive considering their comparative sensitivity and specificity (Boyce, Koloski, & Talley, 2000).

2.1.2. The London Fibromyalgia Epidemiological Study Screening Questionnaire

In order to screen for fibromyalgia, The London Fibromyalgia Epidemiological Study Screening Questionnaire (LFESSQ) was used in studies with participants who had FMS. This screening tool was chosen over the American College of Rheumatology (ACR) classification for FMS due to its better sensitivity (100%) compared to the ACR (88.4%) and the specificity of the LFESSQ is higher (100%) compared to the ACR (81.1%) (White et al., 1999; Wolfe et al., 1990). The Fibromyalgia Rapid Screening Tool (FiRST), is similarly inferior in terms of sensitivity (90.5%) and specificity (85.7%) as a diagnostic tool for FMS (Perrot, Bouhassira, & Fermanian, 2010). Based on this evidence, the LFESSQ was considered advantageous as a screening tool in the current thesis.

The LFESSQ (White et al., 1999) asks participants to select the symptoms they have experienced in the past 3 months. These include symptoms of pain in muscles, bones or joints; shoulders, arms or hands; legs or feet; and neck, chest or back. Participants must respond yes to all of these symptoms in order to meet the criteria for a diagnosis of FMS. Additionally, for the symptoms regarding shoulders/arms/hands and legs/feet, participants must state on which side of their body they experience the pain; left, right or both sides. To meet the criteria for a diagnosis of FMS, participants must either state that the pain occurs on both sides across these two items. For example, participants who state that both arm and leg pain only occurs on the right or only on the left side, would not meet the criteria. Conversely if a participant states that their

arm pain is on the right and their leg pain is on the left or vice versa, they would meet the criteria. Thus, it is a requirement that the pain across the body parts must be present on both sides. In addition to the pain criteria, there are two items relating to fatigue. Specifically, these items ask about the presence of fatigue and whether it significantly limits activity. Diagnosis can be determined by either yes responses to all items across the pain and fatigue criteria, or to the pain criteria alone (Marcus & Deodhar, 2011).

Testing of this screening tool in participants with FMS who were diagnosed using the 1990 American College of Rheumatology criteria (n=31), rheumatoid arthritis (n=30) and healthy controls (n=30) demonstrated that when using pain criteria alone, 100% of people with FMS were correctly identified (White et al., 1999). This was 93.5% when using the fatigue criteria as well. In participants without chronic pain, 100% were correctly not diagnosed with FMS, regardless of whether the fatigue criteria were included. Test-retest reliability in a community sample of 672 adults was high for both pain criteria alone (95%) and for pain and fatigue criteria together (81%). However, this sample size for testing specificity and sensitivity is small and thus further exploration of the tool's validity is needed.

For the purpose of the current thesis, participants were diagnosed using only the pain criteria as the specificity and reliability of this is superior to using alongside the fatigue criteria. In the current thesis, participants who met the LFESSQ Criteria and stated a diagnosis of FMS by a physician were considered to have FMS (those who stated they had self-diagnosed FMS were excluded). Those who reported a diagnosis of FMS but did not fulfil the necessary criteria were excluded.

2.2. Measures

2.2.1. Beliefs about Emotions Scale

To measure beliefs about the unacceptability of experiencing and expressing emotions, the Beliefs about Emotions Scale (BES) was used (Rimes & Chalder, 2010). This scale was selected over other similar measures due to its particular focus on beliefs as opposed to focussing more broadly on emotionally suppressive/expressive behaviours. The full questionnaire can be found in Appendix A.

Participants rate, on a seven-point (0-6) Likert scale (from ‘totally disagree’ to ‘totally agree’), their agreement with twelve statements which each represent a belief about emotional experience and expression. These statements were based on clinical reports and cognitive models of CFS (Surawy et al., 1995) and eating disorders (Corstorphine, 2006). High scores are indicative of high levels of beliefs that the expression and experience of emotion is unacceptable.

In 121 patients with CFS, the construct validity of this scale was evaluated (Rimes & Chalder, 2010). Beliefs about emotions scores for participants with CFS were correlated with scores on the subscales of the Perfectionistic Self-Beliefs Scale (aside from the Perfectionist Striving subscale), all subscales of the Dysfunctional Attitudes Scale-24, and both subscales of the Hospital Anxiety and Depression Scale. The questionnaire has been demonstrated to be internally consistent (Cronbach’s $\alpha = .91$) indicating excellent reliability of the scale (Rimes & Chalder, 2010). The scale was correlated with distress in 94 patients with multiple sclerosis ($r = .33$) (Dennison, Moss-Morris, Silber, Galea, & Chalder, 2010) and showed large improvements (partial $\eta^2 = .19$) following mindfulness-based cognitive therapy in sample of 35 participants with CFS (Rimes & Wingrove, 2013).

In addition to the BES, there exists a Beliefs about Emotions Questionnaire (Manser, Cooper, & Trefusis, 2012). The BES was chosen over this alternative measure as the Beliefs about Emotions Questionnaire focuses on beliefs purely relating to the experience of emotions and not the expression of emotions. Another scale measuring a similar construct is Leahy's Emotional Schema Scale (Leahy, 2002). This 50-item scale measures schema surrounding values, views, comprehensibility, guilt, validation, numbness and control regarding emotions. Of these factors, only the three items relating to emotional control would be of interest for the current thesis, and these are specific to the experience of emotion (e.g. "I worry that if I have certain feelings I might go crazy") as opposed to emotional expression. Thus, due to the focus of the current thesis on emotional suppression, the BES is better suited.

The BES does not make use of reverse scoring and therefore all items are worded in the direction that expressing and experiencing emotions is unacceptable. It is possible that the negatively worded items could prime participants to view the expression of emotion as unacceptable. From Chapter Four onwards, the questionnaires were presented in randomised order so as to avoid order effects such as these.

2.2.2. Courtauld Emotional Control Scale

Emotional suppression was measured in this thesis using the Courtauld Emotional Control Scale (CECS). This scale was chosen partly because it places behavioural responses to emotions within the context of a particular emotion (i.e. anger, depressed mood and anxiety). Doing so provides participants a clear scenario which may enable them to better estimate how they are likely to react. Furthermore, for the purpose of the current thesis, only the suppression of emotions which are

undesirable or unpleasant are considered and thus providing clear examples of emotions in these statements rules out the possibility that participants may consider to what degree they are also likely to suppress or control pleasant emotions. This measure predominantly focusses on external suppression (i.e. sharing emotions with others) though one item of each scale regards ‘smothering’ one’s emotions, which can be viewed as internal suppression (i.e. avoiding the experience of emotions). The full questionnaire can be found in Appendix B.

The CECS was constructed based on interviews with 71 patients with breast cancer (Watson & Greer, 1983). Patients were asked to describe how they react to feelings of anger, anxiety and depression in order to develop a scale that measures the controlling of a particular emotion. This scale measures how much a person expresses or suppresses anger, unhappiness and anxiety with seven items for each subscale.

Participants are presented with statements regarding certain behaviours pertaining to emotional expression/suppression and state on a four-point scale how often they behave in such a way (from almost never to almost always). Each item begins with “When I feel [angry/upset/worried] ...” and ends with a reaction, for example “I refuse to say anything about it.” It has been used widely in breast cancer patients and found to be related to adjustment to cancer and its progression (e.g. Schlatter & Cameron, 2010).

Using item correlations, Watson and Greer found the scale to be internally consistent (Cronbach’s alphas=.86-.88), with significant correlations between the three subscales (anger and anxiety $r=.45$, anger and depressed mood $r=.62$, anxiety and depressed mood $r=.62$) as well as correlations between each subscale and overall scores (anxiety $r=.79$, anger $r=.81$, depressed mood $r=.89$) indicating reliability of an overall score of emotional control.

Test-retest reliability over a three to four-week period indicated strong reliability with correlation coefficients for anger, anxiety and upset being .86, .84 and .89 respectively. Overall emotional control scores over the three to four week period were also significantly correlated ($r=.96$), again suggesting reliability of scores across the three subscales as an overall measure of emotional control (Watson & Greer, 1983). The Lie subscales of the Eysenck Personality Questionnaire were significantly positively correlated with total CECS scores ($r=.34$). This Lie subscale has been previously used as a measure of the tendency of individuals to falsely present themselves in a positive light and thus its correlation with the CECS suggests good construct validity of the scale (Watson & Greer, 1983).

The CECS demonstrated significant correlations with only some of the related questionnaires when convergent validity was tested by the original authors (Watson & Greer, 1983). The lack of consistent significant findings in testing the convergent validity of this measure can in part be explained by the selection of questionnaires used in this testing. The Marlowe-Crowne (which was not related to CECS scores), for example, was used under the assumption that those who control their emotions do so for the purpose of social desirability, which may only be part of the explanation. For example, one might exert less control over their emotions, not because they do not consider social desirability, but because they are seeking support for their problem.

While it may be considered beneficial that the CECS addresses three emotions in particular, these emotions may not truly encompass the range of emotions that are being suppressed. For example, while an individual may not suppress feelings of depressed mood, anxiety and anger, they may try to control feelings of stress or being overwhelmed.

While previous research on emotional suppression in persistent physical symptoms has used other measures of emotional suppression (e.g. the Self-Silencing scale), the current thesis aimed to look at beliefs about emotions and emotional suppression as distinct constructs (thereby distinguishing between beliefs and behaviours). This meant that scales such as Jack's (1991) Self-Silencing scale were inappropriate due to including items on motivations behind the expression or suppression of emotion (for example "I try to bury my feelings when I think they will cause trouble in my close relationship(s)").

2.2.3. The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used in the current studies as a measure of affective distress. This measure was selected as the HADS has been used reliably to detect anxiety and depression in participants with physical symptoms due to its lack of reference to somatic features of depression and anxiety compared with other measures such as the Patient Health Questionnaire-9 and Beck's Depression Inventory (Bjelland, Dahl, Haug, & Neckelmann, 2002; Smarr & Keefer, 2011). The full questionnaire can be found in Appendix C.

This scale asks participants to rate their symptoms on varying four-point scales across 14 items. For example, for the item "I still enjoy the things I used to enjoy" the responses are on a scale from "definitely as much" to "hardly at all." Seven of the 14 items pertain to depression and the remaining seven to anxiety.

For the purpose of the current thesis, scores were summed across the two subscales (anxiety and depression) to provide a marker of affective distress that is not contaminated by physical symptoms. Scores were therefore summed over all 14 items

to provide a score where the maximum possible score is 42. High scores on this scale indicate higher levels of affective distress.

While many studies use the anxiety and depression subscales as separate measures, the use of overall HADS scores as a measure of distress has been validated. Pallant and Tennant (2007) demonstrated strong validity of overall HADS scores in a sample of 296 patients attending an out-patient musculoskeletal rehabilitation program. Using Rasch analysis, they found support for the overall fit of the model where psychological distress is measured with all 14 items of the HADS. This has been further validated more recently in primary care demonstrating internal consistency was good for the overall HADS scores (Cronbach's $\alpha=.89$ for the English version of the scale) (Roberge et al., 2013).

In a review of the literature, the two subscales of the HADS were examined in relation to their concurrent validity (Bjelland et al., 2002). In the four studies identified that assess correlations between the HADS depression scale and Beck's Depression Inventory (BDI), correlations ranged between .62 and .73 with a total sample size of 1552 participants (consisting of medical inpatients, patients with HIV, Swedish adults, and patients with motor neuron disease). Overall HADS scores were also strongly correlated with BDI scores ($r=.73$) (Lisspers, Nygren & Soderman, 1997, as cited in Bjelland et al., 2002). The HADS anxiety subscale has been assessed in regards to its relation to the State-Trait Anxiety Inventory (STAI) in five studies with correlation coefficients ranging from .64 to .81 in four empirical studies (totalling 1562 participants) and a review of 200 studies (Herrman, 1997, as cited in Bjelland, 2002). Total HADS scores were also correlated with STAI trait ($r=.71$) and state ($r=.68$) scores in one study included in the review (Lisspers, Nygren & Soderman, 1997, as

cited in Bjelland et al., 2002). Overall this therefore suggests the HADS validly measures anxiety and depression.

There have been a number of criticisms relating to the factor structure and the ability of the HADS to predict cases of depression and anxiety in both clinical and general populations (Coyne & von Sonderen, 2015; Hansson, Chotai, Nordstöm, & Bodlund, 2009; Julian, 2011; Tanaka & Huba, 1984; Watson et al., 1995). It has therefore been suggested that the HADS may not be valid as a measure of depression and anxiety but instead is a strong measure of psychological distress more broadly as the factor structure seems to be better explained by one factor of general distress (Coyne & von Sonderen, 2015; Johnston, Pollard, & Hennessey, 2000; Norton, Cosco, Doyle, Done, & Sacker, 2013; Tanaka & Huba, 1984). For the purpose of the current thesis which aimed to measure affective distress (as opposed to finding cases of depression and anxiety) in individuals with physical symptoms, this scale was therefore still the most appropriate as it is not contaminated by somatic symptoms and loads well onto a factor of general distress.

2.2.4. General Help-Seeking Questionnaire

Both symptom-related and personal/emotional support-seeking were measured in the current thesis using the General Help-Seeking Questionnaire (GSHQ).

This measure was chosen as there were few measures of support/help-seeking identified by the researchers. In particular, measures that existed were not considered appropriate as they did not adequately address support-seeking in relation to physical symptoms but instead focussed on emotional difficulties (e.g. The support seeking subscale of the Coping Strategies Inventory (Amirkhan, 1990)). While scales do exist which are directed towards physical symptoms (e.g. the practical and emotional

support seeking scales of the Behavioural Response to Illness Questionnaire (Spence et al., 2005)), this particular measure is focussed on the negative consequences of overreliance on social support as opposed to measuring support-seeking more neutrally. Additionally, an author of the measure advised that these measures would not be appropriate for the aims of the current thesis (R. Moss-Morris, personal communication, 1st June 2015). As such, the GHSQ was selected for the current thesis.

The General Help-Seeking Questionnaire (GHSQ) was developed in response to growing research demonstrating a preference of young people to seek informal help (i.e. the help of friends and family) before seeking formal help (Wilson, Deane, Ciarrochi, & Rickwood, 2005). Participants using the GHSQ are presented with items in the format “If you were having [problem-type], how likely is it that you would seek help from the following people?” The participant is then asked to rate from one to seven (extremely unlikely to extremely likely) how likely they are to seek help from the people listed (e.g. a parent, friend, religious leader). Participants are also given the option to rate how likely they are to seek help from another person not listed (and are asked to state who that person is) and how likely they are to seek help from no one. Wilson et al. created this template to allow researchers to modify the list of people and the problem statement to suit the target population. The ability to target particular symptoms for specific populations was an advantage to choosing this measure of support-seeking.

For the purpose of the current thesis, the GHSQ was modified to suit symptoms of FMS and IBS. The item relating to emotional and personal problems was retained, however for the second statement; the ‘problem type’ was replaced with ‘particularly troublesome bowel symptoms/symptoms of pain or fatigue’. The pre-modifying statement of “particularly troublesome” was included due to the nature of these

symptoms varying in intensity. Thus, it may be that if a person is experiencing only mild symptoms, there is no need to seek-help.

In addition to the mentioned changes, the word 'help' was replaced with the word 'support' so as to encourage the participants to include forms of emotional help and support as opposed to physical/pragmatic support which is often what the term 'help' can denote. Scores were summed across items for each question to provide two overall support-seeking scores out of 35 for each participant.

Fitting with the focus on informal (social) support as opposed to formal support, sources of formal support (i.e. mental health professional, phone helpline and doctor/GP) were excluded from the questionnaire thus leaving the options, intimate partner, friend, parent, other relative, religious leader.

The GHSQ has been shown to be a reliable measure of help-seeking intentions and its reliability and validity was assessed in a sample of 218 high school students. The original version (containing two problem statements addressing personal and emotional problems, and suicide ideation) was first assessed as a whole, demonstrating good internal consistency (Cronbach's $\alpha=.85$) and had good test-retest reliability over a three-week period ($r=.92$). Due to the distinct nature of the problem types, the scale was again assessed for reliability looking at the two problems separately and found for suicide ideation the scale was internally consistent (Cronbach's $\alpha=.83$) and test-retest reliability over a three week-period proved reliable ($r=.88$). Similarly the personal-emotional problems items were considered reliable (Cronbach's $\alpha=.70$, test-retest reliability over three weeks $=.86$) (Wilson et al., 2005).

To determine the validity of the GHSQ, Wilson and colleagues measured actual help-seeking behaviours of participants using self-report three weeks after completion

of the GHSQ to observe correlations between the two. Analyses revealed significant correlations between help-seeking intentions and actual help-seeking behaviour, though these correlations were only moderately sized with correlation coefficients below .5. While this was found for both problems (personal/emotional and suicide) correlations were not observed for all potential sources of help; with significant correlations occurring for intimate partner, friend, parent, non-parent family member, mental health professional and youth worker for emotional-personal problems, and significant correlations only for intimate partner, non-parent family member and youth worker for suicidal ideation. However, given the validity of the personal/emotional item and the fact that the current thesis is not measuring seeking help for suicide ideation, the measure is likely valid for current purposes.

Due to the modification of this questionnaire in each study, internal consistency is tested in each sample which used this measure. This can be found in the methods sections of these chapters.

2.3. Outcome Measures

2.3.1. Irritable Bowel Syndrome-Quality of Life

Quality of life in participants with IBS was measured using the Irritable Bowel Syndrome – Quality of Life measure (IBS-QoL), a 34-item questionnaire addressing quality of life in relation to symptoms of IBS. This questionnaire covers eight different factors, each addressing different aspects of their lives which might be affected by the disorder: dysphoria, interference with activity, body image, health worry, food avoidance, social reaction, sex and relationships (Patrick, Drossman, Frederick, DiCesare, & Puder, 1998). The full questionnaire can be found in Appendix D.

Participants are presented with 34 statements relating to the impact of IBS on their quality of life and are asked to rate their agreement on a five-point scale from 'not at all' to 'extremely' or 'a great deal' depending on the statement. Scores are summed and converted to a score out of 100 for overall quality of life, whereby higher scores depict better quality of life.

The overall measure of quality of life was tested in 156 participants with IBS and was found to be internally consistent (Cronbach's $\alpha = .95$). Test-retest correlations over a one week period with a random sample of 89 participants suggested good reliability for the IBS-QoL and its subscales whereby the correlation coefficient was .86 for overall scores in participants who reported that there were no changes in their bowel symptoms (Patrick et al., 1998). Convergent validity was tested in patients with IBS by correlating scores on the IBS-QoL with scores on the Medical Outcome Study Short Form (SF-36) and the Psychological General Well-Being Scale. Patrick et al. (1998) predicted whether overall IBS-QoL scores would relate strongly or weakly to each subscale of the SF-36 and Psychological General Well-Being Scale. They found that six out of eight predictions for the SF-36 subscales were met while two out of seven of the predictions for the Psychological General Well-Being Scale were met. However, the authors define strong correlations as coefficients greater than .4 which is not by usual standards considered a large effect size. Thus while they describe these correlations as strong, the largest correlation coefficient was .44, which would generally be considered medium (Fields, 2011).

Although the Psychological General Well-Being subscales were not as strongly related to IBS-QoL scores as expected, IBS-QoL scores were related as authors predicted to the subscales of the SF-36, thereby suggesting some level of convergent validity. Construct validity for the IBS-QoL score was also tested through methods of

discriminant validity, testing the scale's ability to discriminate between mild, moderate and severe cases of IBS, finding that the IBS-QoL scores increased with the severity of cases (as indicated by the Functional Bowel Disorder Severity Index).

This measure of quality of life was selected as it measures quality of life directly related to symptoms of IBS. Other measures of health-related quality life have been used effectively in research into IBS, but lack specificity about the exact symptoms and challenges experienced day-to-day by those with the syndrome. While using the IBS-QoL in the current thesis resulted in a more specific measure of IBS-related quality of life, it also meant that control participants could not produce data about their quality of life. The current thesis piloted the IBS-QoL with control participants asking them to reflect on a time when they have experienced bowel symptoms. However, this resulted in a floor effect and in many participants leaving the questions blank.

2.3.2. Fibromyalgia Impact Questionnaire revised

In order to measure outcomes for participants with FMS, the revised Fibromyalgia Impact Questionnaire (FIQr) was used (Bennett et al., 2009). This measure was chosen as the outcome measure for participants with FMS in the current thesis as it is the most well-used outcome measure that is specific to FMS as opposed to measuring pain more generally. This specificity means the outcome encompasses all symptoms of FMS (including psychological) as opposed to just measuring pain and/or disability (Salgueiro et al., 2013). The full questionnaire can be found in Appendix E.

This questionnaire measures the impact of the disorder across three domains: function, overall impact and symptoms. Participants are asked to rate their ability in nine tasks over the past seven days on a scale of zero (no difficulty) to ten (very

difficult) as part of the 'function' domain, providing a score out of 90. Overall impact is measured across two items on an 11-point scale from never to always. These two items address goal accomplishment and feeling overwhelmed within the same seven-day time frame. Participants are then asked to rate the severity of ten listed symptoms on varying 11-point scales. For example, the item "please rate your level of balance problems" is rated on a scale from "no imbalance" to "severe imbalance".

Scores for each domain are summed and then for domain one, divided by three and for domain three divided by two. The final score is calculated by summing the three calculated domain scores to give a score out of 100, where high scores indicate greater impact of the disorder.

The FIQR was derived from the longer FIQ (Burckhardt, Clark & Bennet, 1991). This previous version has since been criticised for items relating only to more affluent western cultures (for example items asking about the ease of using a washer/dryer and driving a car). Further criticisms were also made with regards to the scoring system as many items were on different scales (Bennet et al., 2009). As a result, the FIQR was developed addressing these issues and adding/replacing items in relation to the growing evidence on other symptoms of fibromyalgia (for example balance issues). The revised questionnaire was evaluated in a sample of 202 fibromyalgia patients demonstrating good internal consistency (Cronbach's alpha = .95) with item correlations ranging from .56 to .93 (Bennet et al., 2009).

Convergent validity was also assessed by Bennet et al. correlating FIQR scores with scores on the original FIQ and the Short-Form Health Survey (SF-36). Overall FIQR scores strongly correlated with the physical functioning and pain subscales of the SF-36 ($r=-.71$ and $-.69$ respectively). Furthermore, the pain item of the FIQR correlated most strongly with the pain subscale of the SF-36 ($r=.66$) while the anxiety

and depression items correlated most strongly with the mental health subscale of the SF-36 ($r=-.72$ and $-.63$ respectively). While there was a significant difference in FIQ and FIQR scores, there was a strong correlation between the two ($r=.88$).

2.4. Participant groups and recruitment

Participants with IBS and FMS were selected as the focus of these studies as they are highly prevalent conditions which significantly impact the individual's quality of life (Patrick et al., 1998; Salgueiro et al., 2013). Both conditions have evidence that psychological factors play a role in the maintenance of symptoms and that further research on psychological factors is needed (Creed, 2007; Deary et al., 2007; Lami, Martínez, & Sánchez, 2013; Salkovskis et al., 2016).

Participants with IBS were recruited in Chapters Three and Four and Chapter Four was replicated in participants with FMS. Chapter Six involved psychometrically evaluating a questionnaire in participants with FMS. FMS was chosen over IBS because this particular questionnaire was thought to be more relevant to this patient group and participants with FMS were involved in the development of the measure. These chapters recruited participants online by posting in forums and social media pages dedicated to the particular conditions. Healthy controls in these studies were also recruited online from participant recruitment webpages (e.g. Reddit's [r/samplesize](#) and [FindParticipants.com](#)) and through the PhD student's and PhD supervisor's social networks (email, Facebook and Twitter). Appendix F contains example recruitment posts for IBS, healthy controls and FMS.

Chapter Seven recruited participants with FMS in an NHS setting due to the opportunities available with contacts in NHS services. Chapter Eight recruited participants who were local to the university and therefore investigated participants

with IBS as this condition is more prevalent than FMS (Jones et al., 2015; Mearin et al., 2001), which improved the ability to find participants locally.

2.5. Study Designs

This thesis investigated the role of beliefs about emotions and emotional suppression in fibromyalgia and IBS across a range of designs. The studies described in Chapters Three, Four and Five used online questionnaire data to investigate mediation models and to also compare clinical groups with control groups using correlational designs and group comparisons. These studies aimed to establish whether a model of beliefs about emotions and emotional suppression would be supported in these samples, and whether beliefs about emotions and emotional suppression are specific to IBS and FMS.

Based on the findings in Chapter Five, a previously designed, but unvalidated questionnaire was validated in Chapter Six, investigating beliefs about illness experiences, in particular relating to sharing experiences with others. Reliability and validity were examined in data collected from online samples using procedures recommended for scale validation (Comrey, 1988; Hinkin, Tracey, & Enz, 1997; Robinson, Shaver, & Wrightsman, 1991). Factor analyses allowed for the investigation of subscales within the measure by exploring the underlying factor structure of the questionnaire. Reliability was then explored with regards to internal consistency of the measure and its factors. Construct validity was evaluated by assessing the relationships between the questionnaire and measures of similar constructs as well as by known-group comparisons (i.e. comparing a group of participants one would expect to score highly with a group of participants one would expect to score lower). Convergence with similar constructs was assessed in order to

determine the scale's criterion validity. The new measure was then examined in a mediation model that was hypothesised based on the findings of Studies One, Two and Three.

Despite testing causal chains using mediation models, the first four studies' correlational methods mean causality cannot be inferred. To build upon the correlational methods used in this thesis, a quasi-experimental design with a clear timeline was adopted for Chapter Seven.

The studies in Chapters Three, Four, Five and Six used online samples. Online data collection is beneficial in that it avoids issues with manual data entry (e.g. human error and time), is less costly and makes it easier for hard-to-reach groups (e.g. those with physical disabilities that make it difficult to leave the house) to take part (Cantrell & Lupinacci, 2007; Lefever, Dal, & Matthíasdóttir, 2007). However these samples have been argued to be different from student samples with regards to financial motive, personality and self-esteem (Goodman, Cryder, & Cheema, 2012). It has also been argued that there is bias among these samples with higher rates of missing data (Cantrell & Lupinacci, 2007). However many of the studies that find characteristic differences between online participants compared with pencil-and-paper participants do not use sufficiently comparable data collection and recruitment methods to accurately contrast the two types of sample (Weigold, Weigold, & Russell, 2013). In a study addressing these methodological issues, online and pencil-and-paper completers were found to be comparable in terms of personality and social desirability though they were faster to complete the questionnaires (Weigold et al., 2013). Given that the evidence is mixed on this matter, further investigation into patient groups in Chapter Seven allows for the findings of this thesis to be applied to wider samples.

A quasi-experimental design with a clear timeline was thereby adopted for Chapter Seven recruiting patients from NHS pain services. This longitudinal study involved measuring variables before and after usual psychological treatment in the NHS in a sample of participants with FMS. This study investigated potential mechanisms of change in psychological interventions and tested whether these variables are manipulable using these techniques. In addition to this, the study investigated relationships between changes in beliefs about emotions and suppression with changes in outcome measures. However, as this study was quasi-experimental, it was necessary to also investigate changes in these mechanisms and outcomes in response to directly manipulating beliefs about emotions and emotional suppress.

Therefore, the final study in this thesis (Chapter Eight) used a single case experimental design to determine whether aiming to modulate participants' beliefs about emotions and emotional suppression in a targeted way would in turn influence outcomes. For the purpose of this study, a short group-based intervention using cognitive behavioural techniques was designed and delivered.

The use of a single case series however is not sufficient to determine the efficacy of this intervention as there is no control condition. Furthermore, the small sample size means findings are difficult to generalise to wider participant groups. However, this design allows for a low-cost, time-efficient method to test the feasibility of this intervention and the theoretical model behind it. While future research using randomised control trials would be necessary, a single case series provides a solid primary investigation of this intervention.

2.6. Statistical Analyses

Studies one, two and three made use of mediation analyses in order to test multiple models. Mediation models aim to test the extent to which a particular variable accounts for the relation between a predictor and outcome variable (Baron & Kenny, 1986). For example, a particular outcome might be predicted by a specific belief. This relationship between the two might be explained by a particular behaviour, which would then be considered a mediator of this relationship.

Though other methods exist (e.g. Baron & Kenny, 1986; Sobel, 1982) a non-parametric bootstrapping method was used in order to provide estimated effect sizes and confidence intervals for the direct and indirect effects (Preacher & Hayes, 2004). Therefore, this analysis was carried out using the Process plug-in for SPSS (Hayes, 2004), using models four and six (depending on the number of mediators being tested in a particular indirect effect).

Process mediation was chosen over structural equation modelling firstly because the models being tested were fairly simple, with only one or two mediators per path and only up to 4 paths being tested within a model. Due to the relative simplicity of the models, Process mediation analysis was appropriate over structural equation modelling. Furthermore, it has been argued that structural equation modelling is preferable in larger samples (over 200) (Kleine, 2011). More recent evidence explored the number of participants required for different models in structural equation modelling and found that when the expected amount of explained variance is small, a sample size of 440 is required (Wolf, Harrington, Clark, & Miller, 2013). Given the constraints of the current thesis in regards to sample size, an analysis which can achieve sufficient statistical power with smaller samples was preferred.

Chapter Six made use of tests of internal consistency, factor analysis and correlational methods to validate a questionnaire in addition to further mediation analyses and group comparisons using this newly developed measure. Chapter Seven compared participants' scores before, immediately after and three months after treatment to investigate whether beliefs about emotions, emotional suppression, affective distress and/or the impact of fibromyalgia on the patient changed following existing psychological treatments within the NHS. Therefore a repeated measures linear mixed model was used to investigate changes in scores before treatment, after treatment and at follow-up. Further to this, to examine beliefs about emotions, emotional suppression and affective distress as mechanisms of change, change scores for beliefs about emotions, emotional suppression and affective distress were investigated in regression models as predictors of change in global impact scores.

The final study, Chapter Eight, used a single case experimental design where only a small sample is required to assess changes in response to an intervention. Idiographic measures were taken regularly before, during and after the intervention. Data were analysed using statistical as opposed to visual analysis, making use of Tau-U non-overlap analyses to assess changes in the level and slope of the trends in each phase of the experiment (Willson, Veale, & Freeston, 2016).

The combination of these methods allows for a comprehensive examination of the role of beliefs about emotions and emotional suppression in IBS and FMS.

3. Chapter Three: Beliefs about emotions and emotional suppression in irritable bowel syndrome

3.1. Introduction

As stated in Chapter One, the current thesis focuses on emotional suppression in persistent physical symptoms. As such, one of the conditions on which the current thesis focussed is IBS. The current chapter explores beliefs about emotions, emotional suppression and quality of life in IBS.

Previous research has shown IBS to be related to psychological factors such as distress, trauma and previous stressful life events (Creed, 2007; Hazlett-Stevens et al., 2003). In addition to this relationship between affective distress and IBS, in comparison to those with IBD, individuals with IBS tend to report higher levels of self-silencing of their emotions (Ali et al., 2000).

In a cross-sectional study, Ali et al. compared patients with IBS (n=25) and patients with inflammatory bowel disease (n=25) on a measure of self-silencing where self-silencing is the silencing of one's thoughts or feelings (Jack, 1991). They found that participants with IBS showed significantly more self-silencing than participants with IBD. This difference was no longer significant after controlling for self-blame and a history of abuse. It could be that this difference in self-silencing can be explained by other psychosocial factors however the sample size may have been too small to achieve statistical power once controlling for confounds.

Ali et al. compared participants with IBS to those with IBD, while other studies on persistent physical symptoms have compared clinical groups to healthy controls (Rimes & Chalder, 2010; van Middendorp et al., 2008). There is value in comparing two clinical groups, especially when one condition has a clear physiological pathology

while the other has a less certain aetiology. However, comparing these two groups alone makes it difficult to uncover whether those with IBS are more emotionally suppressive than average, whether those with IBD are less suppressive than average, or indeed both. Ali et al. did attempt to address this by using a reference score of healthy individuals' self-silencing, though a more statistically sound approach would be to recruit a sample of individuals without IBS and directly compare their scores to those with IBS. Thus comparing participants with IBS to a healthy population would be useful in understanding whether people with this condition tend to be more emotionally suppressive.

Ali et al. had a small sample with just 25 participants in each group meaning this finding may not be representative of other participants with IBS. The current study therefore tests a larger sample of participants with IBS. Furthermore, the Self-Silencing scale used by Ali et al. includes items which reflect more cognitive aspects of emotional suppression that may in fact be reflective of beliefs about emotions as opposed to the behaviour of emotional suppression. For example 'Considering my needs to be as important as those of the people I love is selfish' which is a belief as opposed to a self-reported behaviour (Jack & Dill, 1992). Therefore it may be that patients with IBS may differ from those with IBD on beliefs about emotions and not actual emotional suppression. Similarly they may differ only on actual emotional suppression and not beliefs. Thus it is vital to explore the cognitive and the behavioural concepts surrounding emotional suppression individually in order to truly uncover where these differences lie.

The current study therefore compared a sample of individuals with IBS to a group of healthy controls in line with research on other conditions with persistent physical symptoms (e.g. Rimes & Chalder, 2010; van Middendorp et al., 2008) and

distinguishes between beliefs about emotions and actual emotional suppression by using two separate scales.

Given the predisposition to negative affect found in individuals with IBS (Creed, 2007; Gick & Thompson, 1997) and these individuals' tendency to self-silence (Ali et al., 2000), it would make sense that people with IBS would be more susceptible to ironic processing effects. As explained in Chapter One, such ironic processing effects suggest that under high levels of negative affect (inducing high cognitive load), attempts to suppress emotions would result in an increase of that unpleasant emotion (Wenzlaff & Wegner, 2000). Thus affective distress, when suppressed may be exacerbated.

Research into affective distress and negative affect has demonstrated its role in IBS symptomatology. As discussed in Chapter One, there is evidence that negative affect can influence symptoms in IBS. Biopsychosocial models of IBS discuss the brain-gut axis (in particular its serotonergic pathways) in relation to the link between negative affect and bowel symptoms. Research in this field has found that negative affect affects pain thresholds and the neural processing of visceral stimuli (Muscatello, Bruno, Scimeca, Pandolfo, & Zoccali, 2014). In a longitudinal study with 31 participants with IBS, Dancey Taghavi and Fox (1998) asked participants to report their daily symptoms, stress and hassles for 28 days. They found that the best fitting model had symptoms of IBS as a function of symptoms of IBS and hassles of the previous two days as well as hassles of the same day. Thus, there is evidence that distress and negative affect can lead to symptoms in IBS.

In this way, consistent with the cognitive behavioural view of IBS (Spence & Moss-Morris, 2007), an individual's thoughts, feelings, behaviours and bodily symptoms are likely to be influential in a maintaining cycle. In particular, the evidence

in IBS supports the notion that beliefs about emotions and emotional suppression play a role in this cycle where these factors relate to increased distress and consequently worsened symptoms. Similar evidence has come from other research into other chronic conditions with aetiological uncertainty such as CFS (Rimes & Chalder, 2010).

Cross-sectional research in CFS has shown that people with CFS (n=121) more strongly believe the expression and experience of emotions to be unacceptable compared to healthy controls (n=73), and scores on this measure were positively correlated with fatigue in people with CFS (Rimes & Chalder, 2010). Further research has demonstrated that this relationship is mediated by emotional suppression (as well as self-compassion) in healthy individuals (Sydenham et al., 2016). This mediation model was therefore tested in the current study in participants with IBS, based on the above evidence of emotional suppression.

The relationship between emotional suppression/expression and symptom severity has also been tested experimentally. For example, in another condition with aetiological uncertainty, FMS, it was demonstrated that written emotional disclosure interventions showed benefits in terms of physical symptoms and global impact of the disorder (Broderick et al., 2005; Gillis et al., 2006). Research by Broderick et al. (2005) involved participants (recruited from hospitals and the community) with FMS either writing expressively about trauma (n=31), writing about day-to-day activities (n=32), or receiving treatment as usual (n=29). They found improvements for the emotional disclosure group in psychological well-being, pain and fatigue at four months post-intervention, and not immediately after nor at ten months after intervention. There were no treatment effects on global impact. However the intervention itself was brief (20 minutes of writing on three occasions) and thus it is

possible that this limited treatment duration is insufficient to induce changes in global impact or long-lasting changes in any treatment outcome.

This evidence suggests that benefits from emotional disclosure interventions are not immediate - there is a delayed onset to these beneficial effects, through mediating factors. This delayed benefit has been found in another trial of written emotional disclosure in FMS (Gillis et al., 2006). Gillis et al. argue that the delay in health benefits may be due to mediating mechanisms such as continued emotional processing and decisions to communicate or approach relationships differently. In addition, Gillis et al. (2006) propose “changes in cognitions pertaining to self and others” (pp 11) as a factor which may mediate the delayed change in global impact following written emotional disclosure. It is therefore possible that the relationship between emotional suppression and outcomes (i.e. global impact in the case Gillis et al.) is mediated by beliefs about the unacceptability of expressing emotions in that confronting emotions on paper may shift beliefs towards being more accepting of both expressing emotions externally and experiencing emotions internally.

One online pilot study with 103 participants with IBS has shown promising results for written emotional disclosure interventions (Halpert et al., 2010). Their findings indicated a significant improvement in IBS symptom severity scores one month after intervention (i.e. writing online at home for 30 minutes on four consecutive days). At three months’ post-intervention, this mean change in symptom severity had increased and significant improvements in quality of life were also apparent. While there was no control group, meaning placebo effects cannot be ruled out, these findings demonstrate the delayed onset of benefits in written emotional disclosure interventions, which is consistent with the proposal of possible cognitive mediatory factors in IBS as those Gillis et al. proposed in FMS.

Based on the current theories, and findings in written emotional disclosure interventions, the current study also tested whether the relationship between emotional suppression and quality of life is mediated by beliefs about the unacceptability of emotions.

3.1.1. Hypotheses

1. There will be a significant difference in beliefs about the unacceptability of emotions scores and emotional suppression scores between those with IBS and healthy controls.
2. The relationship between beliefs about the unacceptability of emotions and quality of life in IBS will be mediated by emotional suppression.
3. The relationship between emotional suppression and quality of life will be mediated by beliefs about the unacceptability of emotions.

3.2. Methods

3.2.1. Procedure

Participants (n=166) were recruited online through the IBS Network as well as social networking pages dedicated to IBS (i.e. Facebook and Reddit) and healthy controls were recruited through participant recruitment pages (e.g. Reddit's r/samplesize). They completed a series of questionnaires, following an information page about the study. This online questionnaire included questions about demographic information (including age, sex, employment status, home country and education level) and a checklist for the criteria to reach diagnosis for IBS. Participants then completed questionnaires measuring beliefs about emotions, emotional suppression

and quality of life. Ethical approval was provided by the university's departmental ethics committee

3.2.2. Diagnostic Criteria

Participants were labelled 'IBS group' if they: (i) met three or more of the Manning Criteria for Irritable Bowel (Manning et al., 1978), (ii) stated that they have received a medical diagnosis of IBS or had self-diagnosed IBS; and (iii) stated that the symptoms could not be accounted for by another medical diagnosis. In order to meet criteria for the 'control group' participants were required to: (i) meet less than three of the Manning Criteria; (ii) neither state that they had received a medical diagnosis of IBS nor had self-diagnosed IBS; and (iii) state that any symptoms could not be accounted for by another medical diagnosis. Those who did not fulfil the inclusion criteria for either group were excluded from analysis.

3.2.3. Participants

Participants were recruited online through IBS forums and websites. Participants in the healthy control group were also recruited online, however through non-IBS channels (for example participant recruitment websites and through social media). Both groups were informed that the study was about emotion expression in IBS with the purpose of investigating how this might affect people living with IBS. A priori sample size analyses indicated that 42 participants in each group was an appropriate sample size to achieve sufficient statistical power, while a larger sample was required to detect correlations within the IBS sample. Therefore, the current sample consisted of a larger number of IBS participants in comparison to controls. This sample size analysis was based on the effect size of the difference between

participants with CFS and healthy controls found by Rimes and Chalder (2010), where Cohen's $D=.55$, the hypothesis is one-tailed, the alpha is set to .05 and the desired power is .8.

Of the 166 participants, 87 met the criteria to be in the IBS group and 37 met the criteria to be in the control group, while 42 participants were excluded from the analyses, as they did not meet criteria for the IBS group or the control group. Only the IBS group and control group are considered from this point on.

3.2.4. Measures

Participants completed questionnaires measuring beliefs about emotions, emotional suppression and quality of life in IBS (see Chapter Two: Methods, page 53, for further details on these measures). These were completed in that particular order, following demographic questions and diagnostic criteria.

3.2.4.1. Beliefs about emotions

Beliefs about the unacceptability of experiencing and expressing emotions were measured using the Beliefs about Emotions scale (BES) across 12 statements. Scores can range from zero to 72, where high scores indicate more/stronger beliefs that expressing and/or experiencing emotions is unacceptable (Rimes & Chalder, 2010). In the current study, there was good internal consistency (Cronbach's $\alpha=.896$).

3.2.4.2. Emotional Suppression

Emotional suppression was measured using the Courtauld Emotional Control Scale (CECS) (Watson & Greer, 1983). This questionnaire measures the suppression of anger, anxiety and sadness across 21 items (seven items per emotion). Scores can

range from 21 to 84 where high scores indicate higher levels of emotional suppression. In the current study, there was excellent internal consistency (Cronbach's alpha=.922).

3.2.4.3. Quality of Life

Quality of Life in IBS was measured across 34 items using the IBS-QoL. These items encompass eight sub-domains. Scores across these eight domains are totalled and converted into a score out of 100, where high scores indicate a better quality of life (Patrick et al., 1998). In the current study, there was excellent internal consistency (Cronbach's alpha=.958).

3.2.5. Design and Statistical Analysis

The hypotheses were tested using a cross-sectional, quasi-experimental and correlational design. To test hypothesis one, tests of differences were required and were conducted using two independent measures t tests where the independent variable was group (IBS or healthy control) and the dependent variables were beliefs about emotions and emotional suppression.

In regards to hypothesis two, the Process plug-in for SPSS was used, using model four to test for one mediator variable in a particular relationship (Hayes, 2012). In this model, the predictor variable was beliefs about the unacceptability of emotions and the outcome variable was quality of life. The mediator variable for this hypothesis was emotional suppression.

Similar to hypothesis two, the same plug-in and model were used to test for a single mediator variable. In this test, the predictor variable was emotional suppression and the outcome was quality of life. The mediator for this hypothesis was beliefs about emotions. For the indirect effects of hypotheses two and three to be significant, the

95% confidence intervals of the unstandardised indirect effect size must not contain zero.

Missing values were addressed using the expectation maximisation algorithm in SPSS. Participants with more than 20% of values missing for a variable were excluded in analyses for that variable based on evidence that missing data imputation methods are reliable where between 10% and 30% of values are missing (Shrive, Stuart, Quan, & Ghali, 2006).

3.3. Results

3.3.1. Sample Characteristics

Group differences in demographic information were measured using chi-square tests of association, except age (which was analysed using an independent t test) (see Table 3.1). Analyses revealed frequency distributions significantly different from what was expected by chance for home country ($\chi^2=34.664$, $p=.004$), however 85.3% of the expected values were less than five which means this finding is not robust. All other demographic information did not differ significantly between the two groups.

Table 3.1 Sample Characteristics for each group

| Characteristics | IBS | | Controls | |
|--|------|--------|----------|--------|
| Age (years) (mean (S.D)) | 25.1 | (7.4) | 23 | (4.9) |
| Sex | | | | |
| Female | 62 | (71.3) | 27 | (75.0) |
| Employment status | | | | |
| Full-time employment | 29 | (33.3) | 7 | (19.4) |
| Part-time employment | 15 | (17.2) | 7 | (19.4) |
| Full-time student | 37 | (42.5) | 21 | (58.3) |
| Part-time student | 7 | (8.0) | 3 | (8.3) |
| Self-employed | 3 | (3.4) | 2 | (5.6) |
| Unemployed | 10 | (11.5) | 2 | (5.6) |
| Ethnicity | | | | |
| Caucasian | 78 | (90.7) | 32 | (91.5) |
| White and Black Caribbean | 0 | (0.0) | 1 | (2.9) |
| White and Asian | 0 | (0.0) | 1 | (2.9) |
| Other mixed/multiple ethnic background | 2 | (2.3) | 0 | (0.0) |
| Pakistani | 1 | (1.2) | 0 | (0.0) |
| Other Asian background | 0 | (0.0) | 1 | (2.9) |
| Other ethnic group | 5 | (5.8) | 1 | (2.9) |
| Home country | | | | |
| United Kingdom | 26 | (30.2) | 22 | (61.1) |
| North America | 51 | (59.3) | 6 | (16.7) |
| Other Europe | 6 | (7.0) | 4 | (11.1) |
| Australasia | 2 | (2.3) | 1 | (2.8) |
| Asia | 0 | (0.0) | 2 | (5.6) |
| South America | 1 | (1.2) | 1 | (2.8) |

3.3.2. Group Differences

3.3.2.1. Hypothesis One

Levene's test of homogeneity of variance indicates this assumption has been met for both beliefs about emotions ($F=.125, p=.724$) and emotional suppression ($F=.326, p=.569$) scores. There was a significant difference in beliefs about emotions scores between those with IBS and healthy controls ($t(122)=2.92, p=.002$) whereby those with IBS score higher than healthy controls, suggesting greater beliefs about the unacceptability of emotions in the IBS group (see Table 3.2). There was however no significant difference between those with IBS and healthy controls in emotional suppression ($t(122)=.421, p=.674$).

Table 3.2 Means and standard deviations for beliefs about emotions and emotional suppression for both groups.

| | IBS (n=87) | Healthy Controls (n=37) |
|------------------------|---------------|----------------------------|
| | Mean (S.D) | Mean (S.D) |
| Beliefs about Emotions | 40.73 (12.87) | 33.40 (12.41) |
| Emotional Suppression | 55.09 (12.23) | 54.10 (11.11) |

3.3.3. Mediation Analyses

3.3.3.1. Hypothesis Two

The relationship between beliefs about emotions and quality of life was not significantly mediated by emotional suppression (see Figure 3.1). The significance of the indirect effect (standardised indirect effect=-.120) was tested using bootstrapping procedures. The bootstrapped unstandardized indirect effect was -.202 and the 95%

confidence interval ranged from $-.470$ to $.049$ meaning the indirect effect with emotional suppression as a mediator was not statistically significant.

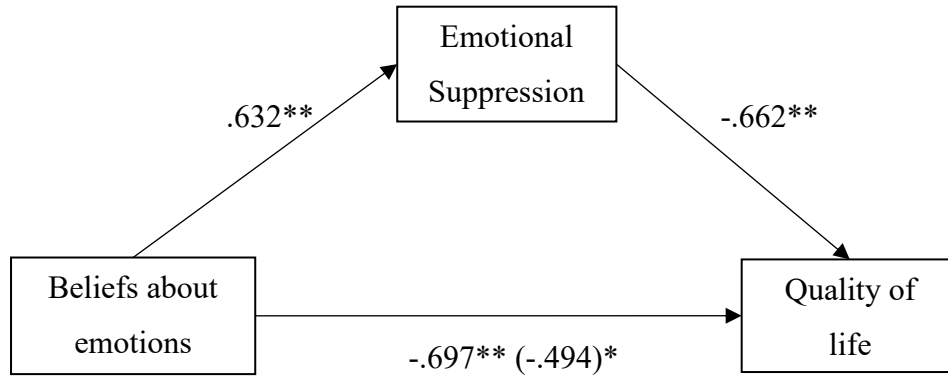


Figure 3.1 Unstandardized regression coefficients for the overall mediation model, where the relationship between beliefs about emotions and quality of life while controlling for emotional suppression is presented in parentheses

Note. ** $p < .001$ * $p < .050$.

3.3.3.2. Hypothesis Three

The relationship between emotional suppression and quality of life was significantly mediated by beliefs about emotions (see Figure 3.2). The significance of the indirect effect (standardised indirect effect= $-.194$) was tested using bootstrapping procedures. The bootstrapped unstandardized indirect effect was $-.343$ and the 95% confidence interval ranged from $-.638$ to $-.055$ meaning the indirect effect with beliefs about emotions as a mediator was statistically significant.

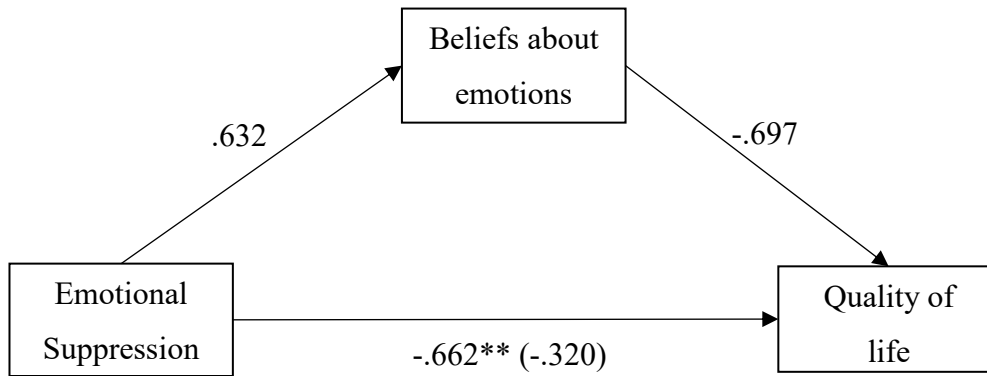


Figure 3.2 Unstandardized regression coefficients for the mediation model where the relationship between emotional suppression and quality of life while controlling for beliefs about emotions is presented in parentheses.

Note. ** $p < .001$

3.4. Discussion

The current study found that participants with IBS held significantly greater beliefs about the unacceptability of emotions than healthy controls, but the groups did not differ with regards to emotional suppression. Emotional suppression did not mediate the relationship between beliefs about emotions and quality of life. However, the relationship between emotional suppression and quality of life was mediated by beliefs about emotions.

This study explored differences between those with and without IBS on measures of beliefs about emotions and emotional suppression, finding a significant difference in beliefs about emotions scores but no difference in emotional suppression. Higher scores on the BES for the IBS group support evidence by Rimes and Chalder (2010) in CFS suggesting these beliefs to be something particularly relevant to those with chronic conditions with uncertainty about the aetiology of the disorder. In order to determine the specificity of this finding to conditions where persistent physical symptoms are not currently explained by the medical model, as opposed to conditions

where the symptoms are explained, further research comparing healthy controls to participants with persistent physical symptoms that are and are not medically explained is needed.

Furthermore, Ali et al. found that after controlling for self-blame and whether the individual had experienced abuse, the difference in self-silencing between those with IBS and those with IBD was no longer significant. Therefore, there may be other psychosocial variables that explain the difference between groups. In particular, it could be that those who experience more negative affect (which is common in IBS (Muscatello et al., 2014)) are likely to score highly on measures of emotional suppression and beliefs about the unacceptability of emotions simply because they experience more unpleasant emotions and therefore have a stronger drive to suppress these. It is therefore possible that by not accounting for affective distress in the current group comparisons, the difference found in beliefs about emotions may be overestimated. Future research should therefore consider controlling for affective distress when testing for group differences.

The fact that there were no differences in emotional suppression is not in line with previous research showing significantly higher self-silencing in IBS participants (Ali et al., 2000). However, Ali et al. tested participants with IBD as a control group as opposed to healthy controls. Thus, those with IBD may differ from those with IBS on measures of emotional suppression, but healthy controls may not. Future research should explore differences between participants with IBS in comparison to both healthy and clinical (IBD) controls.

The non-significant difference in emotional suppression between the two groups could be due to the order in which the questionnaires were completed. In the current study, all questionnaires were completed in the same order with the BES preceding

the CECS. Since the BES has no reverse scored items, it is possible that the wording of this questionnaire primed all participants to score higher on the CECS which may have masked any existing differences between the groups.

Alternatively, those with IBS who are willing to complete questionnaires online asking about emotional experiences may be those who are already slightly more expressive than other subgroups of IBS. That is, the particular sub-group of IBS participants who might have scored higher on the CECS might be less willing to take part in the kind of research that asks these questions or may be more inclined to give more neutral responses. The BES by comparison is less about emotional experience and instead focuses on beliefs, which might be easier to disclose than more experiential information about emotions.

Across the research into emotional suppression in persistent physical symptoms, no single consistent measure has been used and thus the lack of a significant difference in emotional suppression found in this research may in part be due to differences in the measurement of emotional suppression. Ali et al. (2000) used the Self-Silencing scale which incorporates cognitive aspects of emotional suppression. It might be that those with IBS hold more maladaptive beliefs about emotions and may not necessarily suppress their emotions more which might explain the differences found in Ali et al.'s study in comparison to the current study's findings. Further exploration of these beliefs as a distinct construct is therefore needed in IBS.

Due to the need for a larger sample size to conduct mediation analyses, the IBS group was larger than the control group in the current study. This has been found to be problematic with regards to statistical power when using t tests, with larger differences in sample sizes resulting in reduced power. It is therefore possible that the lack of significant difference in emotional suppression could be explained by a

reduction in power. However, a difference in beliefs about emotions was still evident in this unequal sample size and post-hoc power analyses using the expected effect size for emotional suppression (based on Ali et al.'s effect size) with the current unequal sample size indicates that there was sufficient power to detect the expected effect¹.

The two groups were compared on demographic features, finding only a significant difference in the distribution of frequencies for nationality across the two groups. Though the residuals could not be interpreted due to the small expected frequencies, it is possible that there was an overrepresentation of participants from the United States in the IBS group compared with the healthy control group. Given that there are cultural differences in emotion regulation, coping and expression (Matsumoto, 2006), it is possible that this group difference in nationality might have confounded the group comparisons in emotional suppression and beliefs about emotions. Further research should enter demographic variables that differ between groups as confounds in tests of group differences.

Emotional suppression did not mediate the relationship between beliefs about emotions and quality of life in IBS. This is unexpected given the evidence on emotional disclosure interventions and ironic processing effects. However, the current study did not measure affective distress which (according to ironic processing effects) is a key mechanism through which emotional suppression might result in poorer outcomes. Given that an increase in distress is proposed as result of the suppression of undesirable emotions, a statistical model testing this should include affective distress as a second mediator.

¹ For this post-hoc power analysis, the estimated effect size was .72, the alpha level .05 and the n's of the current study (87 and 37). This resulted in a power of .98, which is high suggesting the difference in sample size between the two groups should not have impacted the ability to detect the group differences.

The current study also tested a model whereby beliefs about emotions significantly mediated the relationship between emotional suppression and quality of life. This significant finding is in line with the evidence on emotional disclosure interventions, which commonly finds benefits are not immediate. Gillis et al. (2006) posit that this improvement in outcomes as a result of emotional disclosure is mediated by changes in cognitions. Thus, it would be expected that emotional suppression may result in altered beliefs about emotions which then might influence quality of life, which is supported by the second mediation analysis tested in the current study. However, in the current study, emotional expression was not manipulated, instead cross-sectional data was analysed using mediation analyses. Experimental evidence with a clear timeline would be beneficial in exploring both mediation models further.

The relationships found warrant further research to fully understand the role of beliefs about emotions and emotional suppression in the development and maintenance of IBS and related quality of life. Given that the current study is correlational, this model should be further explored experimentally by manipulating emotional suppression and beliefs about emotions to determine a direction of causality. The current research is a step towards improving our understanding of the relationship between beliefs about emotions, emotional suppression and quality of life in IBS, which alongside further experimental evidence, could be used to develop effective psychological interventions for individuals living with IBS. This evidence also sheds light to potential mechanisms of change in existing interventions; the exploration of which could improve outcomes for those receiving psychological treatment in IBS.

4. Chapter Four: Placing affective distress and support-seeking within a model of beliefs about emotions in IBS

4.1. Introduction

As highlighted in Chapters One and Three, higher levels of emotional suppression have been found in individuals with IBS compared to those with inflammatory bowel disease (IBD) in a cross-sectional study (Ali et al., 2000). An uncontrolled trial of expressive writing as an intervention demonstrated improvements in symptoms and quality of life in IBS (Halpert et al., 2010) suggesting a relation between emotional expression and improved outcomes. Further still, there is evidence from Chapter Three of this thesis that emotional suppression is related to poorer quality of life in IBS.

Other evidence on emotional suppression more broadly has demonstrated that attempts to suppress emotions, particularly unpleasant emotions, can result in an increase in that particular emotion, as detailed in Chapter One (section 1.2.1, page 30). This ‘ironic processing effect’ is thought to occur especially with high negative affect (Dalgleish et al., 2009). Those with IBS commonly experience more negative affect than those without IBS (Gick & Thompson, 1997) and tend to suppress their emotions (Ali et al., 2000). Thus, those with IBS may be more prone to ironic processing effects. As discussed in Chapter One, this increase in distress through emotional suppression may then impact quality of life through psychosocial as well as biological mechanisms (Hall et al., 2011).

Compared to healthy controls, scores on a measure of beliefs about the unacceptability of experiencing and expressing emotions have been found to be higher in participants with chronic fatigue syndrome (CFS) (Rimes & Chalder, 2010) and in participants with IBS (see Chapter Three of this thesis, page 78). These two studies

also found that these beliefs were related to more fatigue and reduced quality of life for CFS and IBS respectively. Together the above evidence highlights the need to investigate emotional suppression and beliefs about emotions in individuals with IBS, in order to understand further any potential maintaining factors of these persistent symptoms.

Chapter Three investigated differences in emotional suppression and beliefs about emotions between participants with IBS and healthy controls in line with previous evidence finding differences in emotional suppression in IBS compared to participants with IBD (Ali et al., 2000). However, Chapter Three found no significant differences between participants with IBS and healthy controls in emotional suppression, only in beliefs about emotions. In line with Ali et al.'s finding that those with IBS are more emotionally suppressive than those with IBD, the current study employed a second control group who have IBD in addition to a healthy control group in order to test whether Ali et al.'s findings can be replicated with a similar comparison group. Having a clinical control group and a healthy control group will also test the specificity of the differences found in beliefs about emotions in Chapter Three, in that it could be that those with bowel-related persistent physical symptoms, and not specifically those with medically unexplained bowel-related persistent physical symptoms, hold more beliefs about the unacceptability of emotions compared with healthy controls. While Ali et al. did find that those with IBS scored significantly higher than a 'norm' value of women in the general population, the sampling methods for this norm value are not clearly reported and therefore the results may not be reliable.

Interestingly, in Ali et al.'s study, after controlling for self-blame and abuse, the difference between participants with IBS and IBD on the measure of self-silencing

was no longer significant. It could be that this is due to the small sample size of the study, where too few participants with too many variables being tested resulted in insufficient statistical power. Alternatively, it could be that self-silencing is explained by other psychosocial variables such as self-blame and previous abuse, or is explained by a variable common to all of these factors (for example increased levels of distress).

Furthermore, Ali et al. used the Self-Silencing scale, which contains items referring to both cognitive and behavioural aspects of emotional suppression. It could thus be that those with IBS and those with IBD only differ in regards to beliefs about the unacceptability of emotions or only in terms of emotional suppression. Therefore, given that those with IBS showed differences from healthy controls in terms of beliefs about emotions and not emotional suppression in Chapter Three, the current study compared participants on separate measures of emotional suppression and beliefs about emotions.

It was argued in Chapter Three that there may have been order effects which might have led to priming participants on the emotional suppression measure which may have masked group differences. Therefore, the current study has randomised the order of questionnaires. Furthermore, it might be argued that any differences found between groups on measures of beliefs about emotions and emotional suppression might be explained by the increased levels of affective distress found in these groups in that those who are more distressed may have greater need to suppress their emotions. Therefore, the current study will also investigate whether the expected differences are maintained after controlling for affective distress.

Due to the unexpected non-significant mediation findings of Chapter Three, where the relationship between beliefs about emotions and quality of life was not mediated by emotional suppression, the current study looked to investigate the

hypothesised model further. Whereas Sydenham, Beardwood, & Rimes (2016) and Chapter Three of this thesis looked at emotional suppression as a single mediator (with mixed results), ironic processing effects suggest an important role of increased affective distress as a consequence of emotional suppression, which may then result in changes in quality of life. Therefore, to test the full model in line with ironic processing effects, the current study investigated a model whereby the relationship between beliefs about emotions and quality of life was serially mediated by emotional suppression, and then affective distress.

Rimes and Chalder (2010) proposed that the relationship between beliefs about emotions and health-related outcomes could be related to social support. They argue that believing the expression of emotions to be unacceptable might then result in a reduction in support-seeking where individuals who do not want to share their emotions will therefore inhibit others from knowing they need help. This reduction in social support-seeking may therefore be another mediating factor in maintenance of persistent physical symptoms.

It has been argued that in disorders with aetiological and prognostic uncertainty (such as IBS, CFS and FMS) there is an element of secrecy and that this secrecy is related to reduced social support in CFS and FMS (McInnis et al., 2015). Interviews with 14 participants with IBD demonstrated a perception of stigma around the embarrassing and unpredictable nature of the symptoms (Frohlich, 2014). Together this research suggests that stigma experienced by those with ‘embarrassing’ symptoms and ‘unexplained’ symptoms might too be present in IBS. Indeed it has been found that perceived stigma and two subscales of internalised stigma (social withdrawal and alienation) were related to poorer quality of life in 243 participants with IBS (Taft, Riehl, Dowjotas, & Keefer, 2014). Given that IBS is related to stigma and secrecy, it

may be that individuals do not express their emotions. Further to this, the evidence that support seeking and secrecy are related suggests that support seeking might be related to beliefs about expressing emotions and to quality of life in IBS.

However, Sydenham et al. (2016) tested the role of social support in a mediation model and found that the relationship between beliefs about emotions and fatigue in healthy individuals was not significantly mediated by social support. Similarly Lackner et al. (2010) found that perceived social support did not predict quality of life or psychological distress in IBS. These findings are somewhat surprising.

It may be argued that measuring support-seeking intentions of the participant as opposed to their perceived social support (as was done in Lackner et al.'s (2010) study) would be a better measure to test this model as perceived social support might be influenced by other confounding variables (for example, the individual's perception of offered support might be influenced by cognitive biases meaning actual offered support and the participant's perception of support are different). This might then consequently weaken the tested relationships. Support-seeking intentions however are behaviours of the participant (as opposed to their perceptions of a third party's behaviour) and may therefore be more accurately measured meaning they may be more closely related to believing that expressing emotions is unacceptable.

Similarly, Sydenham et al. (2016) used the Support Seeking subscale of the Berlin Social Support Scale, which measures very broadly asking others for help as opposed to specifically measuring asking for help in relation to difficult emotional problems or help in relation to physical symptoms. It may be that beliefs about emotions are more specifically related to asking for support when dealing with a difficult emotional situation or when dealing with difficult physical symptoms, and therefore support-seeking in relation to these factors should be measured specifically.

Therefore, the current study tested whether support-seeking significantly mediates the relationship between beliefs about emotions and quality of life in IBS.

In this thesis, Chapter Three found that the relationship between emotional suppression and quality of life in IBS was mediated by beliefs about emotions. Though the evidence is cross-sectional and causality cannot be inferred, it was argued that this model supports Gillis et al. (2006) who argued that the benefits of written emotional disclosure are delayed in onset (occurring after three months as opposed to immediately after intervention) due to the role of mediating cognitions. In order to test the robustness of this finding, this mediation model was tested in a larger sample in the current study where questionnaire order was randomised.

4.1.1. Hypotheses

1. Participants with IBS will score significantly higher than healthy controls and participants with IBD on measures of beliefs about emotions and emotional suppression before and after controlling for affective distress.
2. The relationship between beliefs about emotions and quality of life in IBS will be significantly serially mediated by emotional suppression and then affective distress.
3. The relationship between beliefs about emotions and quality of life in IBS will be significantly individually mediated by both support-seeking measures.
4. The relationship between emotional suppression and quality of life in IBS will be mediated by beliefs about emotions.

4.2. Methods

4.2.1. Participants

Participants were recruited online through websites and forums dedicated to the particular disorders of interest using the same sample size calculations as in Chapter Three. Healthy participants were recruited through online participant recruitment websites and forums as well as through social media and university advertisements. Of the 226 participants who took part, 91 met the criteria for IBS, 43 stated a diagnosis of IBD, and 54 were considered healthy controls as they stated no diagnosis of any of the above disorders and did not meet the Manning criteria. Only participants in the three groups stated above will be considered from this point on. Due to missing data (i.e. participants with more than 20% missing data in a single variable (Shrive et al., 2006)), only 84 participants with IBS were included along with 41 healthy controls and 42 with IBD. Participants with IBD were asked to describe their diagnosis. Sixteen participants reported having Crohn's disease, 22 ulcerative colitis, one microscopic colitis, one intermittent IBD and one indeterminate colitis.

Participants were considered to have IBS if they both met three or more of the Manning Criteria for Irritable Bowel (Manning et al., 1978), and stated a physician had diagnosed them with IBS. Participants who met three or more of the Manning criteria but did not claim to have physician-given diagnosis of IBS (i.e. they had self-diagnosed IBS) (n=18) were not included in the analysis. Participants who stated they have a different diagnosis that might explain the symptoms were also excluded (n=3). Seventeen participants who stated that they did not have IBS but met the Manning criteria were excluded.

4.2.2. Measures.

After completing demographic questions and the Manning Criteria for Irritable Bowel, participants completed questionnaires measuring beliefs about emotions, emotional suppression, affective distress, support-seeking intentions in relation to IBS symptoms, support-seeking intentions in relation to personal and emotional problems and IBS-related quality of life. These measures were presented in a randomized order. Beliefs about emotions were measured using the BES which is scored from zero to 72 (Rimes & Chalder, 2010), emotional suppression using the CECS which is scored from 21 to 84 (Watson & Greer, 1983) and quality of life with the IBS-QoL which is scored from zero to 100 (Patrick et al., 1998), all in the same manner as in Chapter Three. The BES, CECS and IBS-QoL all had excellent internal consistency in this study (Cronbach's alphas=.939, .943 and .945 respectively). Further details on all of these measures can be found in Chapter Two of this thesis (see Chapter Two, sections 2.2.1, 2.2.2 and 2.3.1 on pages 59, 60 and 68). Two questionnaires were included in the current study that were not in Chapter Three, which are described below.

4.2.2.1. General Help Seeking Questionnaire.

The GHSQ is divided into two questions. Both questions ask participants to rate for each person/role listed how likely (on a seven-point scale) they are to go to that person for help (Wilson et al., 2005). Question one of the original questionnaire asks about help-seeking in relation to personal and emotional problems, while the second question asks about suicide ideation. The authors recommend the adaptation of the GHSQ to suit the symptoms of the disorders being researched. Therefore, for the current study, though question one was the same, for question two participants were

asked “If you were having particularly troublesome bowel symptoms, how likely is it that you would seek support from the following people?” For the purpose of the current study, the research was interested in social support-seeking only and therefore removed health care professionals from the list of people/roles one might seek support from. The remaining people/roles included intimate partner, friend, parent, other relative/family member and minister/religious leader. Total scores range from five to 35 with higher scores implying a greater intention to seek support.

In addition to the mentioned changes, the word ‘help’ was replaced with the word ‘support’ so as to encourage the participants to include forms of emotional help and support as opposed to physical support which is often what the term ‘help’ denotes.

The modified personal/emotional support-seeking measure showed poor internal consistency in the current sample (Cronbach’s $\alpha=.580$) while the symptom-related support seeking measure was questionable (Cronbach’s $\alpha=.620$).

4.2.2.2. The Hospital Anxiety and Depression Scale (HADS)

The HADS was included in this study as a measure of affective distress. Fitting with the model suggested by previous research, affective distress appears to be an important component in the relationship between emotional suppression and outcomes. The HADS asks participants to rate symptoms of anxiety and depression on 14 items (seven for depression and seven for anxiety) on a 4-point scale. Total scores across both domains are used as a composite score for affective distress. The minimum possible score is zero and the maximum 42 where high scores indicate greater affective distress (Zigmond & Snaith, 1983). In the current study, the HADS had good internal consistency (Cronbach’s $\alpha=.894$).

4.2.3. Design and Statistical Analysis

To test group differences for hypothesis one, a MANCOVA was first conducted to test for differences between the three groups (independent factor) in beliefs about emotions and emotional suppression (the two dependent variables) while accounting for sample characteristics that significantly differed between groups. In line with the hypothesis, a simple planned contrast (comparing the IBS group to both the healthy controls and the IBD group) was used to break down any significant main effects. A second MANCOVA was then conducted with the same independent and dependent variables, using affective distress as a covariate in addition to the demographic covariates. Main effects were broken down in the same manner as previously reported.

Hypothesis Two was tested in a serial mediation model (Model One). Serial multiple mediation tests a model that “assumes a causal chain linking the mediators, with a specific direction of causal flow” (Hayes, 2012, pp14). Thus, for this hypothesis the particular causal chain was beliefs about emotions → emotional suppression → affective distress → quality of life. As the current study tested a causal flow of mediators using cross-sectional data, an alternate model was also tested to evaluate the direction of the indirect effect. In this alternate model, the causal chain was beliefs about emotions → affective distress → emotional suppression → quality of life, where the two mediators from Hypothesis Two have been inverted to further examine the direction of Hypothesis Two. In this alternate model, and for Hypothesis Two, the variance explained by both support-seeking variables was statistically accounted for as these support-seeking variables were tested as parallel mediators (see Figure 4.1).

The two further paths were tested in the same model (Model One), with parallel individual mediators to test the third hypothesis. These are single mediators that are hypothesised to mediate in parallel to the above proposed serial mediation. The

predictor and the outcome were beliefs about emotions and quality of life (respectively) and the two individual mediators tested in parallel are personal/emotional support-seeking intentions and IBS-related support-seeking intentions. Hypotheses Two and Three were tested simultaneously in the same model so as to account for any overlapping variance explained between mediators (see Figure 4.1).

Hypothesis Four involved testing one mediator in a separate model (Model Two). For this hypothesis, the predictor variable was emotional suppression and the outcome variable was quality of life. The mediator in this model was beliefs about emotions.

Using bootstrapping procedures, the indirect effects were tested. For each indirect effect to be significant, the upper and lower 95% confidence intervals of the indirect effect must not contain zero. Where there was more than 20% missing data in a single variable, cases were excluded. For those with less than 20% missing data in a single variable, values were imputed using estimation maximisation techniques (Little & Rubin, 1987).

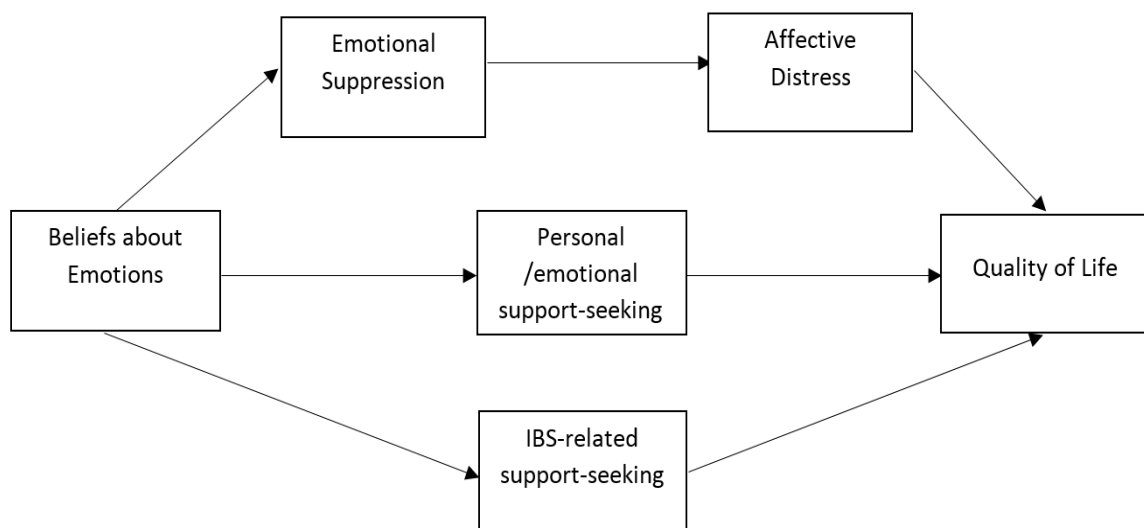


Figure 4.1 Model One, testing Hypotheses Two and Three.

4.3. Results

4.3.1. Sample Characteristics

Chi-Square tests were conducted on demographic information to compare frequencies across the three groups (see Table 4.1 for sample characteristics). Significant results were broken down by examining standardised residuals, whereby residuals above 2 or below -2 are considered significant. There were significant differences in frequency distributions for employment status, with more full-time students than expected in the healthy control group and fewer than expected in the IBS group ($\chi^2=12.530$, $df=2$, $p=.002$). This may be explained by recruitment methods (i.e. people who take part in online research that is not specifically targeted towards them may often be students) as well as disability in the IBS group. There were also significantly different distributions of unemployment across the three groups ($\chi^2=6.260$, $df=2$, $p=.044$), however none of the residuals were above 2 or below -2.

There were significantly fewer males than expected in the IBS group ($\chi^2= 11.9.5$, $df=2$, $p=.003$). There were also significantly different distributions for ethnic group ($\chi^2=38.095$, $df=18$, $p=.004$) and nationality ($\chi^2=81.935$, $df=32$, $p<.001$) however due to 80.0% and 88.9% (respectively) of expected values being less than 5, the Chi-Square test is not considered robust in this instance (Fields, 2011). There was a significant difference in ages between the three groups ($F(2, 161)=23.789$, $p<.001$), though equal variances were not assumed ($F(2,161)= 26.752$, $p<.001$). Participants with IBS were significantly older than the participants in the two control groups (both $ps<.001$). This age difference may also be reflective of differences in student status between the IBS group and the healthy controls. This does not however explain the differences between participants with IBS and IBD. Means and standard deviations were calculated for all variables within the mediation model (see Table 4.2).

Table 4.1 Sample characteristics broken down by group

| Characteristics [n(%)] | IBS (n=84) | | Healthy (n=41) | | IBD(n=42) | |
|--------------------------|------------|---------|----------------|---------|-----------|--------|
| Age [M(SD)] | 43.79 | (17.96) | 28.35 | (12.48) | 27.60 | (7.97) |
| Sex | | | | | | |
| Female | 74 | (88.1) | 28 | (68.3) | 26 | (63.4) |
| Employment status | | | | | | |
| Full-time employed | 26 | (28.7) | 13 | (31.7) | 18 | (43.9) |
| Part-time employed | 18 | (21.4) | 4 | (9.8) | 4 | (9.8) |
| Full-time study | 12 | (14.3) | 17 | (41.5) | 14 | (34.1) |
| Part-time study | 2 | (2.4) | 1 | (2.4) | 1 | (2.4) |
| Self-employed | 3 | (3.6) | 1 | (2.4) | 2 | (4.9) |
| Unemployed | 26 | (31.0) | 6 | (14.6) | 6 | (14.6) |
| Ethnicity | | | | | | |
| White British | 71 | (84.5) | 20 | (50.0) | 21 | (51.2) |
| Other White | 8 | (9.5) | 11 | (27.5) | 13 | (31.7) |
| African Caribbean | 2 | (2.4) | 0 | (0.0) | 1 | (2.4) |
| Indian | 1 | (1.2) | 2 | (5.0) | 0 | (0.0) |
| Other Asian | 0 | (0.0) | 2 | (5.0) | 0 | (0.0) |
| White and Asian | 1 | (1.2) | 0 | (0.0) | 0 | (0.0) |
| Other mixed ethnic group | 0 | (0.0) | 1 | (2.5) | 2 | (4.9) |
| Other ethnic group | 1 | (1.2) | 4 | (10.0) | 4 | (9.8) |
| Home country | | | | | | |
| United Kingdom | 73 | (86.9) | 19 | (47.5) | 13 | (31.7) |
| North America | 5 | (5.6) | 12 | (30.0) | 24 | (58.5) |
| Other Europe | 5 | (5.6) | 5 | (12.5) | 2 | (4.9) |
| Australasia | 0 | (0.0) | 2 | (5.4) | 2 | (4.9) |
| Asia | 0 | (0.0) | 1 | (2.5) | 0 | (0.0) |
| Africa | 1 | (1.2) | 1 | (2.5) | 0 | (0.0) |
| Education level | | | | | | |
| Secondary school | 13 | (15.5) | 1 | (2.5) | 2 | (4.9) |
| Sixth form | 21 | (25.0) | 8 | (20.0) | 9 | (22.0) |
| Undergraduate | 34 | (39.3) | 19 | (47.5) | 21 | (51.2) |
| Post-graduate | 17 | (19.1) | 12 | (30.0) | 9 | (22.0) |

Table 4.2 Means and standard deviations for all measured variables

| | IBS | | Healthy controls | | IBD | |
|------------------------------------|-------|-------|------------------|-------|-------|-------|
| | M | SD | M | SD | M | SD |
| Beliefs about emotions | 42.55 | 15.81 | 36.15 | 12.89 | 40.61 | 14.29 |
| Emotional suppression | 56.80 | 11.56 | 51.73 | 12.53 | 58.85 | 11.11 |
| Affective distress | 19.24 | 8.25 | 11.24 | 5.89 | 17.09 | 7.20 |
| Personal/emotional support-seeking | 23.46 | 5.98 | 25.11 | 6.46 | 22.44 | 5.79 |
| Symptom support-seeking | 22.46 | 5.97 | - | - | - | - |
| Quality of life | 45.80 | 22.41 | - | - | - | - |

4.3.2. Group Differences (Hypothesis One)

Two MANCOVAs were conducted. In both tests the independent factor was participant group and the dependent variables were BES and CECS scores. In the first MANCOVA ethnicity (Caucasian and non-Caucasian), nationality (British and non-British), age, sex, full-time student status and unemployment status were entered as covariates. Levene's test of homogeneity of variances showed the assumption was met for both beliefs about emotions ($F(2,159)=1.189$, $p=.307$) and emotional suppression ($F(2,159)=0.013$, $p=.987$).

Of the covariates entered into the model full-time student status was the only significant confound in beliefs about emotions scores ($F(2,253)=4.315$, $p=.039$). Nationality ($F(2,253)=3.768$, $p=.054$), unemployment ($F(2,253)=3.843$, $p=.052$), sex ($F(2,253)=1.220$, $p=.271$), ethnicity ($F(2,253)=0.582$, $p=.447$) and age ($F(2,253)=1.296$, $p=.257$) were not significant confounds. For emotional suppression however, nationality ($F(2,253)=15.026$, $p<.001$), and sex ($F(2,253)=20.725$, $p<.001$) were significant confounds while unemployment ($F(2,253)=3.843$, $p=.052$), ethnicity

($F(2,253)=.582, p=.447$), full-time student status ($F(2,253)=3.789, p=.053$) and age ($F(2,253)=.996, p=.320$) were not.

There was a marginally significant main effect of group on beliefs about emotions scores ($F(2, 153)=2.481, p=.087, \eta=.031$). There was also a significant main effect of group on emotional suppression scores ($F(2, 154)=4.875, p=.009, \eta=.060$).

Simple planned contrasts (where the IBS group were the comparison group) revealed that the IBS group scored significantly higher on measures of beliefs about emotions ($p=.038$) but not on emotional suppression ($p=.100$) compared to healthy controls and were not significantly different from the IBD group in beliefs about emotions ($p=.683$) or emotional suppression ($p=.155$) (see Table 4.3 for estimates).

Table 4.3 Estimated marginal means and standard errors for beliefs about emotions and emotional suppression after controlling for demographic variables.

| | IBS | | Healthy controls | | IBD | |
|------------------------|-------|------|------------------|------|-------|------|
| | EMM | SE | EMM | SE | EMM | SE |
| Beliefs about emotions | 42.28 | 1.83 | 35.42 | 2.46 | 40.88 | 2.51 |
| Emotional suppression | 56.16 | 1.33 | 52.21 | 1.78 | 59.68 | 1.82 |

In a MANCOVA with the above demographic variables (ethnicity, nationality, age, sex, full-time student status and unemployment status) and affective distress as covariates, equal variances were assumed for beliefs about emotions ($F(2, 159)=1.900, p=.153$) and emotional suppression ($F(2,159)=0.090, p=.914$).

Unemployment ($F(2,152)=7.760, p=.006$) and affective distress ($F(2,152)=31.551, p<.001$) were the only significant covariates in beliefs about emotions scores. Nationality ($F(2,152)=3.036, p=.083$), sex ($F(2,152)=1.752, p=.188$), ethnicity ($F(2,152)=0.885, p=.348$), full-time student status ($F(2,152)=2.164, p=.143$)

and age ($F(2,152)=0.112, p=.738$) were not significant confounds in beliefs about emotions scores. For emotional suppression, nationality ($F(2,152)=14.481, p<.001$), unemployment ($F(2,152)=4.655, p=.033$), sex ($F(2,152)=24.402, p<.001$), age ($F(2,152)=0.059, p=.048$) and affective distress ($F(2,152)=21.428, p<.001$) were significant confounds. Ethnicity ($F(2,152)=0.022, p=.883$) and full-time student status ($F(2,152)=1.982, p=.161$) were not significant covariates in emotional suppression.

There was no significant main effect of participant group for beliefs about emotions ($F(2,153)=0.107, p=.898$). However there was a main effect for emotional suppression ($F(2,164)=3.097, p=.048$) after controlling for affective distress and demographic variables. Planned contrasts revealed no significant difference between those with IBS and healthy controls in emotional suppression ($p=.788$). However those with IBD scored significantly higher than those with IBS ($p=.026$). Estimated marginal means and standard errors are presented in Table 4.4

Table 4.4 Estimated marginal means and standard errors for beliefs about emotions and emotional suppression after controlling for affective distress.

| | IBS | | Healthy controls | | IBD | |
|------------------------|-------|------|------------------|------|-------|------|
| | EMM | SE | EMM | SE | EMM | SE |
| Beliefs about emotions | 40.49 | 1.69 | 40.14 | 2.42 | 39.99 | 2.20 |
| Emotional suppression | 55.79 | 1.31 | 54.87 | 1.87 | 57.90 | 1.70 |

4.3.3. Mediation Model One (Hypotheses Two and Three)

Zero order correlations for all variables in the model are presented in Table 4.5. The relationship between beliefs about emotions and quality of life was significantly serially mediated by emotional suppression and affective distress (see Figure 4.2). The significance of the indirect effect (standardised indirect effect=-.0921) was tested using bootstrapping procedures. The bootstrapped unstandardized indirect effect was -.1302 and the 95% confidence interval ranged from -.2782 to -.0430 meaning the indirect effect containing both emotional suppression and affective distress was statistically significant: There was a significant negative indirect effect where stronger beliefs about the unacceptability of emotions relate to poorer quality of life via emotional suppression and distress.

Table 4.5 Zero order correlations for all variables in the model

| | 1. | 2. | 3. | 4. | 5. |
|---------------------------------------|--------|---------|---------|--------|------|
| 1. Beliefs about Emotions | | | | | |
| 2. Emotional Suppression | .381** | | | | |
| 3. Affective Distress | .384** | .436** | | | |
| 4. Personal/emotional support seeking | -.342* | -.406** | -.358* | | |
| 5. Symptom-related support seeking | -.301* | -.288* | -.204 | .709** | |
| 6. Quality of life | -.346* | -.278* | -.721** | .242* | .101 |

Note. ** p<.001, * p<.050

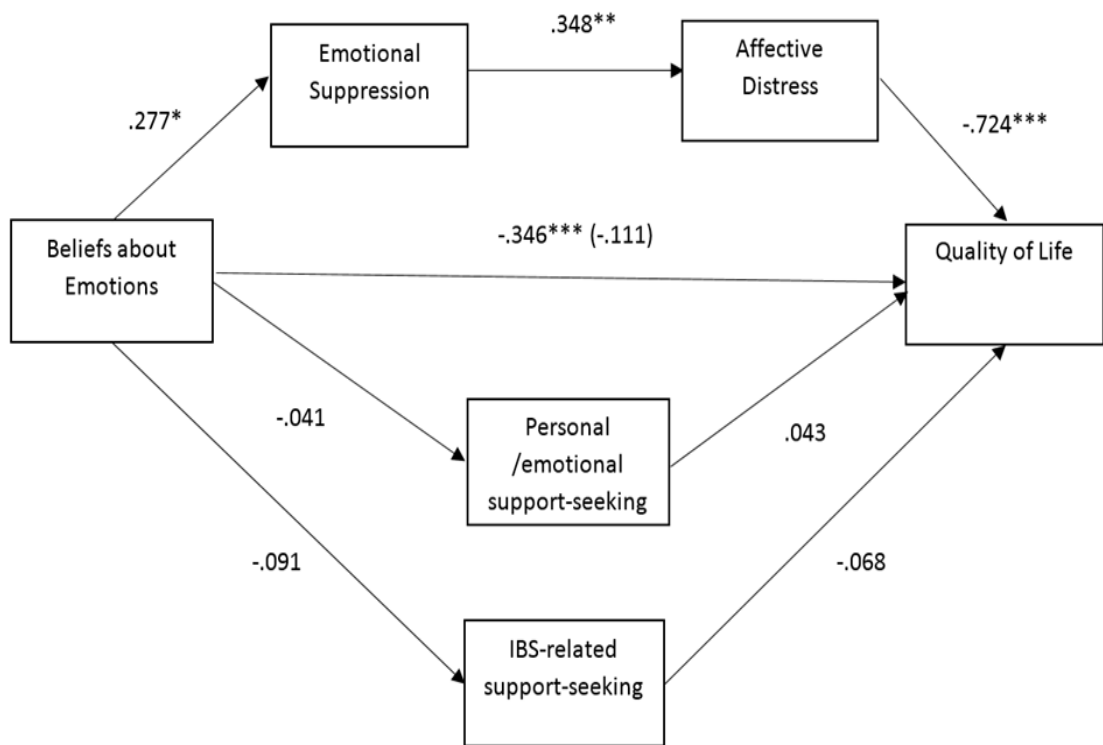


Figure 4.2 Unstandardized regression coefficients for the overall mediation model for IBS, where the relationship between BES and IBS-QoL while controlling for mediator variables is presented in parentheses.

Note. * $p < .010$, ** $p < .001$

An alternate model where the two mediators' order was inverted was also tested in order to support the direction of the effect of Hypothesis Two. In this alternate model the predictor was beliefs about emotions and the outcome was quality of life. The first mediator was affective distress and the second mediator was emotional suppression. This indirect effect was tested using bootstrapping procedures (standardised indirect effect=.0121). Affective distress and emotional suppression, in that particular order, did not serially mediate the relationship between beliefs about emotions and quality of life (unstandardized indirect effect=.0153, 95% CI [-.0132, .0690]).

The relationship between beliefs about emotions and quality of life was not significantly mediated by personal/emotional support-seeking intentions when tested with bootstrapping procedures (standardised indirect effect=-.0061). The bootstrapped unstandardized indirect effect was -.0092 (95% CI [-.1804, .0530]) and was not significant.

The relationship between beliefs about emotions and quality of life was not mediated by IBS-related support-seeking intentions (standardised indirect effect=.0012). The indirect effect was tested with bootstrapping procedures and found to be not significant (unstandardized indirect effect=.0111, 95% CI [-.0130, .1232]).

4.3.4. Mediation Model Two (Hypothesis Four)

The relationship between emotional suppression and quality of life was significantly mediated by beliefs about emotions with a standardised effect size of -.1070. The bootstrapped unstandardized indirect effect was -.2073 (95%CI [-.4590, -.0532]), indicating a significant negative indirect effect (see Figure 4.3 for coefficients).

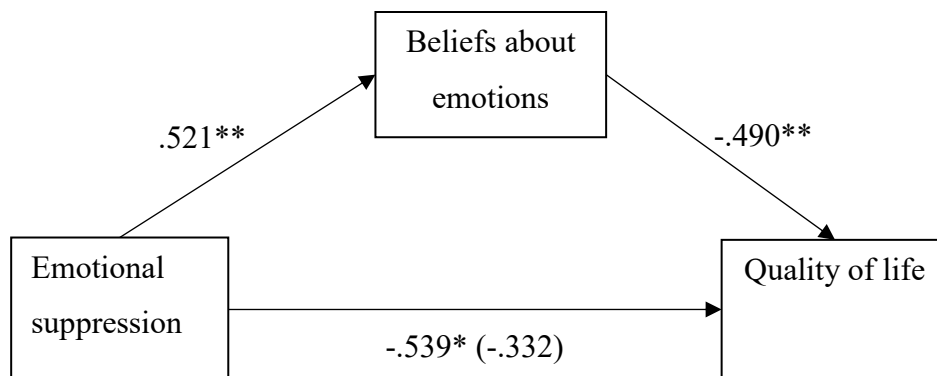


Figure 4.3 Standardised regression coefficients where the relationship between emotional suppression and quality of life after controlling for beliefs about emotions is presented in parentheses

Note: * $p < .050$, ** $p \leq .001$

4.4. Discussion

The current study compared those with IBS to both clinical and healthy control groups. Those with IBS scored higher on measures of beliefs about emotions compared to healthy controls (though the main effect was only approaching significance), but were not different from the IBD group. Though there was a significant main effect for emotional suppression, the planned contrasts (comparing those with IBS to those with IBD and to healthy controls) revealed no significant differences. These findings support the findings reported in Chapter Three in that a significant difference was found for beliefs about emotions and not emotional suppression. Consequently it appears that while those with IBS hold different beliefs about the unacceptability of emotions compared to healthy participants, their actual levels of emotional suppression are not statistically different.

The current study's finding that there is no significant difference between those with IBS and IBD is however discordant with Ali et al. (2000) who found that participants with IBS scored higher on a measure of self-silencing when compared with participants with IBD. This may be explained by Ali et al.'s use of the Silencing of the Self Scale which includes items on both cognitions and behaviours with regards to self-silencing. While some of the cognitions measured by Ali et al. are similar to beliefs about the unacceptability of emotions (e.g. "I try to bury my feelings when I think they will cause trouble in my close relationship(s)"), there are other cognitions and motivations surrounding self-silencing that are different (e.g. "When I am in a close relationship I lose my sense of who I am"). It may be that those with IBD differ from those with IBS on other related cognitions that were not measured in the current

study and that when measuring beliefs about the unacceptability of emotions and emotional suppression specifically, those with IBD score similarly to those with IBS.

There were group differences in employment, sex, ethnicity, nationality and age. Such differences may have influenced the results of the group comparisons and these demographic variables were therefore entered as covariates in the group comparisons. As such the results of the ANCOVAs comparing those with IBS, IBD and healthy controls on beliefs about emotions and emotional suppression accounted for any variance in emotional suppression and beliefs about emotions that might be explained by these demographic variables. Though these demographic differences do not explain the current differences as they have been controlled for, future research may wish to further explore the role of employment, sex, ethnicity, nationality and age in emotional suppression and in beliefs about emotions.

After controlling for affective distress, the group difference in beliefs about the unacceptability of emotions between those with IBS and healthy controls was no longer significant. For participants with IBS, the higher levels of beliefs about emotions compared to healthy controls might be explained by greater affective distress, which is consistent with the idea that the more unpleasant emotions one experiences, the more unpleasant emotions they have that they may want to suppress. Since the difference in beliefs about emotions between those with IBS and healthy controls appears to be explained by affective distress, it is possible there may be a reciprocal relation between distress and beliefs about emotions. Though not tested in the current study, this reciprocal relation may form part of a self-maintaining cycle where higher levels of affective distress in the IBS sample might result in a greater belief that emotional expression is unacceptable and these beliefs in turn relate to more distress (via emotional suppression as indicated in the current mediational findings). Further

research would need to explore group differences in affective distress as well as investigate these variables with a clear timeline in order to explore this potential cycle.

Surprisingly, after controlling for affective distress, those with IBD were significantly more emotionally suppressive than those with IBS. Again, this is contradictory to Ali et al. (2000) who found that participants with IBS showed more self-silencing. This suggests that emotional suppression possibly plays some role in IBD. Given that this difference only became significant after controlling for affective distress, it could mean that individuals with IBS and IBD are equally emotionally suppressive but in IBS emotional suppression is explained by higher levels of affective distress, while in IBD it is not. While the relationship between emotional suppression and distress in IBD is unexplored in the current study, it appears to be different from the pattern found in IBS with regards to distress explaining the variance in emotional suppression.

However, the finding that those with IBS held similarly strong beliefs about emotions to those with IBD supports this idea that beliefs about emotions may be relevant to both disorders. Further evidence exploring the relationships between beliefs about emotions, emotional suppression affective distress and quality of life in IBD would help explore the possibility that beliefs about the unacceptability of emotions and emotional suppression may play a maintaining role in other long term conditions regardless of whether they have explained aetiology. The current study found support for a model in which emotional suppression and affective distress serially mediate the relationship between beliefs about emotions and outcomes, in that particular order. This supports the idea that believing emotions to be unacceptable and suppressing them relates to an increase in that emotion which can then have implications for quality of life. This model is in line with the idea of ironic processing

effects and with evidence on emotional expression interventions (Broderick et al., 2005; Gillis et al., 2006; Halpert et al., 2010; Wenzlaff & Wegner, 2000). The direction of this ‘causal’ chain is supported by the non-significant alternate model in which inverting the two serial mediators resulted in a non-significant indirect effect. However the current study used correlational methods to test a causal model, meaning causality cannot be inferred until experimental methods with a clear timeline have been employed. This cross-sectional evidence does however provide a theoretical basis for exploring emotional suppression and beliefs about emotions in a practical clinical context under experimental conditions.

In line with Chapter Three, the current study also found that beliefs about emotions mediate the relationship between emotional suppression and quality of life in IBS. This is in line with the argument previously highlighted in Chapter One regarding a cyclical relationship between beliefs, behaviours and outcomes (see section 1.1.2 on page 22). This may also be reflective of processes outlined by Gillis et al. (2006) who argued that expressive behaviour can influence outcomes through changes in cognitions. Though this would need to be explored experimentally.

The current study, as in Chapter Three, used the Manning Criteria for Irritable Bowel to screen for participants who had IBS. This criteria is slightly different from more recent diagnostic tools (such as Rome III) and therefore there may be a small number of participants who, for example, met the Manning criteria but may not have met Rome III criteria. However evidence comparing diagnostic tools for IBS have suggested comparable specificity and sensitivity across the measures (Saito et al., 2000). Further to this, participants reported having been diagnosed with IBS by their clinician in Chapter Four and will therefore have met the criteria set out by the NICE guidelines to diagnose IBS (NICE, 2016) which strengthens the reliability of the

current sample selection methods. However, relying on participants to accurately report their symptoms and diagnosis may be unreliable.

The relationship between beliefs about emotions and quality of life in IBS was not significantly mediated by either support-seeking variable. This suggests that the seeking of support may not be a key mechanism through which beliefs about the unacceptability of emotions and quality of life relate. Alternatively, it could be due to problems with the measure itself. As this measure was adapted for the purpose of the current study, the amended version had not been validated and was shown to have poor and questionable internal consistency in the current study. Thus, if reliability and possibly validity were lacking in the measure of support seeking, it is possible the construct was unable to account for a significant portion of the relationship between beliefs about emotions and quality of life.

The current study has furthered previous research by examining the role of emotional suppression separately from the role of beliefs about emotions. In doing so, the current model fits within a cognitive behavioural framework which may have implications for interventions in IBS. Furthermore, the current study has extended upon Chapter Three, not just through improved methodologies (regarding the sample and randomisation of the questionnaires) but also through the addition of measuring affective distress. Firstly, this measure allowed for the exploration of group differences in beliefs about emotions and emotional suppression while accounting for affective distress. Secondly, with affective distress in the mediation model, support for ironic processing effects in has been established.

The current study has therefore found theoretical support, using correlational methods, for emotional suppression and affective distress as mediators of the relationship between beliefs about emotions and quality of life in IBS. However,

support-seeking did not mediate this relationship. Future research should extend the evidence on beliefs about emotions, emotional suppression and distress in IBS using experimental methods with a clear timeline to establish a causal model.

5. Chapter Five: Beliefs about Emotions and Global Impact in Fibromyalgia

5.1. Introduction

Chapter Four found support for a mediation model whereby the relationship between beliefs about the unacceptability of emotions and quality of life was serially mediated by emotional suppression and affective distress in participants with IBS. This particular model can be explained by ironic processing effects whereby the suppression of unpleasant emotions results in an ironic increase of that emotion (Wenzlaff & Wegner, 2000). In particular, this model suggested (using correlational methods) that believing the expression of emotions to be unacceptable is related to an increase in emotional suppression. This emotional suppression was then related to an increase in affective distress and subsequently poorer quality of life in IBS.

However, in Chapter Four, the relationship between beliefs about the unacceptability of emotions and quality of life was not mediated by support-seeking intentions as was proposed by Rimes and Chalder (2010). This non-significant mediation is supported by evidence from Sydenham, Beardwood and Rimes (2016), who found that social support did not mediate the relationship between beliefs about emotions and fatigue in healthy individuals. This relationship was again tested in FMS in the current study in order to explore whether support-seeking is a significant mediator in this sample.

Evidence from participants with FMS has shown that emotional suppression is correlated with fatigue (though not with pain) (van Middendorp et al., 2008). Further to this, as discussed in Chapter One, interventions encouraging written emotional expression have shown to elicit improvements in global impact, health care utilisation,

disability, pain, fatigue and psychological well-being (Broderick et al., 2005; Gillis et al., 2006) (see section 1.4, page 44).

Research into the relationships between cognitions, behaviours emotions and outcomes is essential to develop further treatments for FMS. A meta-analysis of treatments for FMS concluded that CBT is superior to other psychological treatment methods (Glombiewski et al., 2010) and a Cochrane review of chronic pain treatments (including treatments for FMS) suggests the need for further investigation into possible cognitive and behavioural mechanisms of treatment, stating there is a need for better theory driven hypotheses of the mechanisms of change in treatments for pain (Eccleston, Williams, Morley, & Eccleston, 2009). Given the evidence on the role of beliefs about emotions and emotional suppression in the third and fourth chapters of this thesis, current investigations into the role of beliefs about the unacceptability of emotions and emotional suppression are needed in order to provide a more theoretical basis for evidence on treatments in FMS.

Furthermore, evidence for treatments for chronic pain syndromes with comorbid depression have shown that stepped care (involving anti-depressant treatment followed by a self-management pain program) elicits clinically significant improvements in both depression and pain for only 26% of patients (Kroenke et al., 2007). A secondary analysis revealed that the beliefs and cognitions of participants (in particular higher levels of fear avoidance) predicted reduced response to this two-step treatment (Ang et al., 2010). This suggests a need to focus on specific maladaptive cognitions in clinical samples, and in particular those with chronic pain, which is why beliefs about emotions are included in the current study in addition to emotional suppression.

Chapters Three and Four revealed that participants with IBS demonstrated significantly higher scores on measures of beliefs about the unacceptability of emotions compared with healthy controls, though there was no group difference in a measure of actual emotional suppression. In Chapter Four those with IBS did not differ from participants with IBD on either measure. Furthermore, after controlling for affective distress there was no longer a difference between those with IBS and healthy controls in beliefs about the unacceptability of emotions, suggesting this group difference might be explained by distress. Interestingly after controlling for distress, participants with IBD scored higher than participants with IBS in regards to emotional suppression. This contradicted previous research which did not account for affective distress (Ali et al., 2000), indicating the value of testing for group differences with both healthy and clinical controls while controlling for affective distress in these samples. The research highlights the likely role of beliefs about emotions in both IBS and IBD as they did not significantly differ. Furthermore, the role of distress appears to be key in explaining the variance in beliefs about emotions scores and emotional suppression. Given the differences and similarities between IBS and IBD highlighted in the previous chapter's findings, it is essential to examine these variables in other long term conditions with persistent physical symptoms – both those with and without a clear aetiology.

Previous research has found that participants with FMS are more emotionally suppressive than healthy controls (van Middendorp et al., 2008). However, this research compared participants with FMS only to healthy controls meaning this finding may not be specific to individuals FMS and could apply to chronic pain or persistent physical symptoms more broadly. The current study therefore uses a healthy control group and a control group with arthritis (specifically psoriatic arthritis), a

condition that also results in persistent pain and fatigue, but is considered to have a medical explanation for its symptoms. Furthermore, van Middendorp et al. did not control for affective distress. It might be that individuals with FMS suppress their emotions more because they experience a greater level of unpleasant emotions. The current study explored these group differences before and after controlling for affective distress.

Chapters Three and Four also found that the relationship between emotional suppression and quality of life was mediated by beliefs about emotions, suggesting a more cyclic relation between these variables. This was argued to be in line with Gillis et al.'s (2006) supposition that the reason written emotional disclosure interventions show a delay in the onset of improvement is because there are cognitive mediatory mechanisms at play. Thus, it may be that changes in beliefs about the unacceptability of emotions are one of the mechanisms to which Gillis et al. refer. This model was also tested in the current study as emotional disclosure interventions have been shown to improve outcomes in participants with FMS (Broderick et al., 2005; Gillis et al., 2006).

Thus, the current study explores a mediation model in line with ironic processing effects and includes two support-seeking measure as potential mediators in parallel to this mediation effect. The relationship between emotional suppression and global impact is also explored with beliefs about emotions as the mediator. Group differences are tested to examine whether there is greater emotional suppression and/or beliefs about the unacceptability of emotions in participants with FMS and whether this difference is maintained after controlling for affective distress.

5.1.1. Hypotheses

1. Participants with FMS will score significantly higher than healthy controls and participants with arthritis on measures of beliefs about emotions and emotional suppression before and after controlling for affective distress.
2. The relationship between beliefs about emotions and global impact in FMS will be significantly serially mediated by emotional suppression and then affective distress.
3. The relationship between beliefs about emotions and global impact in FMS will be significantly individually mediated by personal/emotional support-seeking and symptom-related support-seeking.
4. The relationship between emotional suppression and global impact in FMS will be mediated by beliefs about emotions.

5.2. Methods

5.2.1. Participants

Participants with FMS and psoriatic arthritis were recruited online through websites and forums dedicated to the particular disorders of interest. Healthy participants were recruited through online participant recruitment websites and forums as well as through social media and university advertisements. A priori sample size calculations based on Sydenham, Beardwood and Rimes' (2016) coefficients for the paths of the mediation effect of emotional suppression were used. Using these coefficients, a sample size of 124 was desired (Fritz & Mackinnon, 2007).

Due to the nature of online questionnaire testing, this number was exceeded and recruitment was terminated once it was apparent the target had been reached.

To detect group differences, a minimum of 41 participants were needed in each group (based on G Power sample size calculations using the effect size of Rimes and Chalder's (2010) comparison between those with CFS and controls on BES scores). Therefore 41 healthy controls and 41 IBD participants were required. This large difference in group sizes is thus explained by differences in required sample size for sufficient power.

As a clinical control group, psoriatic arthritis was chosen as it is a condition involving persistent symptoms of pain that is medically explained and has a lower average age of onset compared to other forms of arthritis, which made the sample more comparable in age to participants with FMS (Scott, et al., 2013; Ramos-Remus et al., 2007; Wilson et al., 2009).

Participants completed the London Fibromyalgia Epidemiology Study Screening Questionnaire (White et al., 1999). Further to these criteria, participants must state that a physician has diagnosed them with FMS. If participants did not meet the criteria (by either stating no to any item, not answering an item or experiencing symptoms only on one side) but state a diagnosis of FMS they were not included in the analysis. Those with other comorbid conditions were not excluded from the analysis so as to represent the complex nature of FMS, which includes frequent comorbidities such as CFS (Ciccone & Natelson, 2003) and rheumatoid arthritis (Wolfe & Michaud, 2004).

Of the 357 participants who took part, after excluding 152 responses that did not complete a sufficient amount of questionnaires within the study, 182 met the criteria for FMS according to the LFESSQ and said they had been given a diagnosis of FMS by a clinician, 42 stated a diagnosis of psoriatic arthritis and 60 stated no diagnosis of any of the above disorders and did not meet the criteria for FMS. Eighteen participants

stated a diagnosis of FMS but did not meet the criteria and seven participants stated they did not have FMS or psoriatic arthritis but met the criteria for FMS and were excluded. Thirty-one participants said they had another diagnosis which would better explain the symptoms listed as opposed to a diagnosis of FMS, and one participant had both FMS and psoriatic arthritis. These participants were excluded, therefore only participants in the three groups stated above (FMS, psoriatic arthritis and healthy controls) will be considered from this point on.

5.2.2. Measures

Participants completed the same measures as in Chapter Four (the BES, CECS, HADS and GHSQ) however they did not complete the IBS-QoL or the Manning Criteria for Irritable Bowel. Instead they completed the LFESSQ and the FIQR. Only questionnaires that differ from those in Chapter Four are outlined below.

The BES, CECS, HADS and FIQR all had excellent internal consistency in this study (Cronbach's alphas=.921, .948, .901, .933 respectively).

5.2.2.1. The General Help Seeking Questionnaire

The GHSQ was modified in the same respect as in Chapter Four regarding the list of possible responses and replacing the term 'help' with 'support'. In line with Chapter Four, the second item of this questionnaire was amended to address "particularly troublesome symptoms of FMS". The amended personal/emotional support-seeking and symptom-related support seeking measures showed good internally consistency (Cronbach's alphas = .797 and .773 respectively).

5.2.2.2. The Revised Fibromyalgia Impact Questionnaire

The FIQR (Bennett et al., 2009) measured global impact of the disorder and contains items measuring the impact of the disorder on a participant's life across three domains: function, overall impact and symptoms. Participants rated their functional ability in eight tasks on a scale from zero to ten, then rated the overall impact across two items on the same eleven-point scale. Scores are summed and converted into scores out of 100, where high scores indicate greater impact of the disorder on the participant's life.

5.2.3. Design and Statistical Analysis

To test Hypothesis One, a one-way MANCOVA was conducted to test for between-group differences in BES and CECS scores after controlling for demographic variables which significantly differed between groups. Significant main effects were broken down using repeated planned contrasts comparing the FMS group to healthy controls and to those with arthritis. To test whether these differences remained significant after controlling for affective distress, the same one-way MANCOVA with affective distress as an additional covariate was conducted, again using planned contrasts to break down significant main effects.

Hypotheses Two and Three were tested in a single mediation model with multiple paths assessing potential indirect effects that might explain the relationship between beliefs about emotions and global impact in FMS. The indirect effects were tested using Preacher and Hayes's (2004) Process plug-in for SPSS with bootstrapping. For an indirect effect to be significant the 95% confidence intervals for that indirect effect must not contain zero.

The first path tested (Hypothesis Two) consists of two mediators working serially: emotional suppression and affective distress. For this path, the particular chain being tested was beliefs about emotions → emotional suppression → affective distress → global impact. As all paths were tested in one model (see Figure 5.1), this path was tested while also accounting for variance explained by the two support-seeking mediators of Hypothesis Three. The direction of this path was further tested by inverting the two mediators in an additional alternate model to produce the following chain: beliefs about emotions → affective distress → emotional suppression → global impact. In this new model (again controlling for support-seeking) the predictor and outcome were the same. However, the serial order of the mediators was affective distress and then emotional suppression.

Hypothesis Three was tested in two paths which consisted of the same predictor (beliefs about emotions) and outcome (global impact). The two mediators were tested in parallel in the same model as Hypothesis Two. For one of the paths, the mediator was personal/emotional support-seeking and for a separate parallel path the mediator was symptom-related support-seeking (see Figure 5.1). As before, since all paths were tested in one model, the variance explained by other mediators is accounted for when testing each individual path.

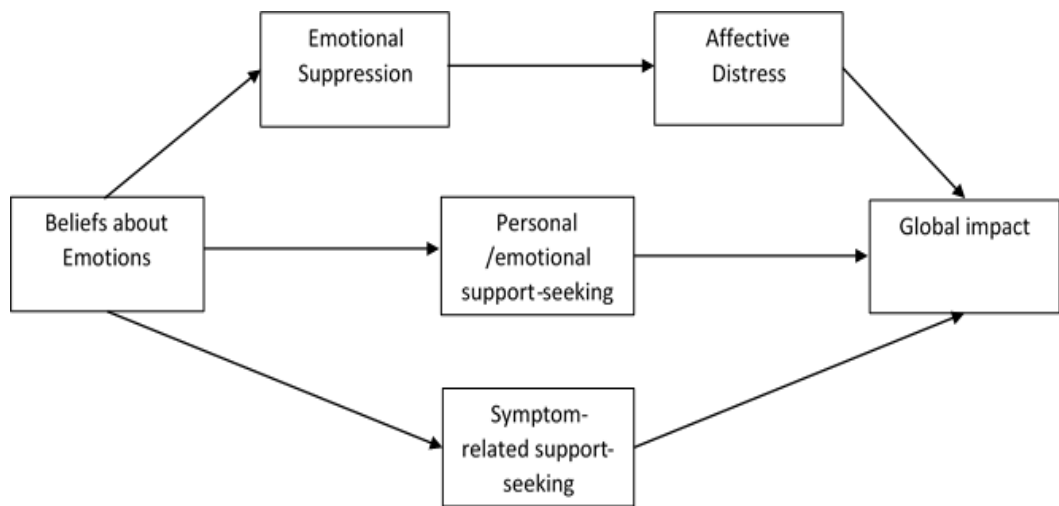


Figure 5.1 Mediation model tested for Hypotheses Two and Three.

Hypothesis Four was tested in a separate mediation model to test a single mediator (beliefs about emotions) of the relationship between emotional suppression and global impact.

Where more than 20% of data were missing for items of a single scale, cases were excluded. Where less than 20% of data were missing values were imputed using estimated maximisation techniques (Little & Rubin, 1987; Shrive et al., 2006).

5.3. Results

5.3.1. Sample characteristics

Means and standard deviations were calculated for all measured variables (see Table 5.1) Chi-Square tests were conducted on demographic information to compare frequencies across the three groups and significant results were broken down by examining standardised residuals, where standardised residuals above 2 and below -2 were considered significant (see Table 5.2 for sample characteristics). There were significant differences in frequency distributions for employment status, with more full-time students in the healthy control group and the FMS group than expected

($\chi^2=66.205$, $df=2$, $p<.001$), more full-time work in the arthritis group and the FMS group than expected ($\chi^2=39.351$, $df=2$, $p<.001$) and more unemployment in the FMS group than expected, while there was also less unemployment than expected in the two control groups ($\chi^2=34.103$, $df=2$, $p<.001$). Though there were fewer males than expected in the FMS group and more males than expected in both control groups ($\chi^2=31.470$, $df=2$, $p<.001$). There were also significantly different distributions for ethnic group ($\chi^2=67.582$, $df=24$, $p<.001$) and country of birth ($\chi^2=102.264$, $df=44$, $p<.001$) however 82.1% and 88.4% of expected values for ethnic group and country of birth (respectively) were less than 5, meaning the Chi-Square test is not considered robust in this instance (Fields, 2011). In the FMS group, there were more people than expected whose highest qualification was secondary education and less than expected for both control groups ($\chi^2=34.484$, $df=6$, $p<.001$). The FMS participants were significantly older than both the control group and arthritis group ($p<.001$ for both comparisons), while the healthy controls were the youngest group ($F(2,293)=52.859$, $p<.001$).

Table 5.1 Means and standard deviations for all measured variables.

| | FMS (n=182) | | Healthy controls (n=60) | | Arthritis (n=42) | |
|------------------------------------|-------------|-------|-------------------------|-------|------------------|-------|
| | M | SD | M | SD | M | SD |
| Beliefs about emotions | 41.56 | 15.40 | 41.07 | 13.99 | 46.21 | 14.79 |
| Emotional suppression | 59.76 | 13.56 | 52.12 | 13.92 | 62.64 | 12.31 |
| Affective distress | 22.75 | 7.75 | 11.65 | 6.11 | 18.53 | 6.90 |
| Personal emotional support-seeking | 22.47 | 7.75 | 22.07 | 6.11 | 17.76 | 7.15 |
| Symptom support-seeking | 21.51 | 8.18 | - | - | - | - |
| Global impact | 68.36 | 16.38 | - | - | - | - |

Table 5.2 Sample characteristics for each group.

| Characteristics [n(%)] | FMS (n=182) | | Healthy (n=60) | | Arthritis (n=42) | |
|--------------------------|-------------|---------|----------------|---------|------------------|---------|
| Age [M(SD)] | 46.75 | (11.95) | 29.10 | (12.33) | 37.39 | (12.52) |
| Sex | | | | | | |
| Female | 174 | (95.6) | 44 | (72.1) | 31 | (70.5) |
| Employment status | | | | | | |
| Full-time employed | 31 | (17.0) | 17 | (15.4) | 27 | (64.3) |
| Part-time employed | 36 | (19.8) | 11 | (18.3) | 7 | (16.7) |
| Full-time study | 6 | (3.3) | 24 | (40.0) | 1 | (2.4) |
| Part-time study | 6 | (3.3) | 4 | (6.7) | 2 | (4.8) |
| Self-employed | 14 | (7.7) | 3 | (5.0) | 4 | (9.5) |
| Unemployed | 90 | (31.4) | 10 | (16.7) | 5 | (11.9) |
| Ethnicity | | | | | | |
| Caucasian | 176 | (96.7) | 48 | (79.9) | 40 | (95.3) |
| Pakistani | 0 | (0.0) | 1 | (1.7) | 0 | (0.0) |
| Bangladeshi | 0 | (0.0) | 1 | (1.7) | 0 | (0.0) |
| Chinese | 0 | (0.0) | 2 | (3.3) | 0 | (0.0) |
| Other Asian | 0 | (0.0) | 2 | (3.3) | 0 | (0.0) |
| Black/African/Caribbean | 2 | (1.1) | 0 | (0.0) | 0 | (0.0) |
| White and Black | 1 | (0.5) | 0 | (0.0) | 0 | (0.0) |
| White and Asian | 1 | (0.5) | 3 | (5.0) | 1 | (2.4) |
| Other mixed ethnic group | 2 | (1.1) | 1 | (1.7) | 0 | (0.0) |
| Other ethnic group | 0 | (0.0) | 2 | (3.3) | 1 | (2.4) |
| Home country | | | | | | |
| United Kingdom | 146 | (80.2) | 19 | (31.1) | 29 | (69.0) |
| North America | 17 | (9.3) | 25 | (41.7) | 10 | (23.8) |
| Other Europe | 13 | (7.1) | 9 | (15.0) | 1 | (2.4) |
| Australasia | 1 | (0.5) | 3 | (5.0) | 2 | (4.8) |
| Asia | 2 | (1.1) | 2 | (3.3) | 0 | (0.0) |
| Africa | 3 | (1.6) | 1 | (1.7) | 0 | (0.0) |
| Education | | | | | | |
| Secondary school | 44 | (24.7) | 1 | (1.7) | 0 | (0.0) |
| Sixth form | 58 | (32.6) | 15 | (20.2) | 19 | (45.2) |
| Undergraduate | 48 | (53.9) | 26 | (43.3) | 14 | (33.3) |
| Post-graduate | 28 | (15.7) | 18 | (30.0) | 9 | (21.4) |

5.3.2. Group Differences (Hypothesis One)

Two MANCOVAs were conducted with beliefs about emotions and emotional suppression as the dependent variables and group (FMS, arthritis and healthy controls) as the independent factor. For the first MANCOVA, ethnicity (coded as Caucasian and non-Caucasian), nationality (coded as UK and not UK), full-time employment, full-time student, unemployment, sex, highest education level and age were entered as covariates.

Before controlling for affective distress, the assumption of homogeneity of variances was met for both beliefs about emotions ($F(2,275)=0.386, p=.678$) and emotional suppression ($F(2,275)=0.283, p=.745$).

Ethnicity ($F(2,267)=0.007, p=.931$), being a full-time student ($F(2,267)=1.385, p=.240$), being unemployed ($F(2,267)=0.077, p=.782$), sex ($F(2,267)=0.418, p=.519$), education ($F(2,267)=0.068, p=.795$) and age ($F(2,267)=0.001, p=.980$) were not significant confounds in beliefs about the unacceptability of emotions. However nationality ($F(2,267)=4.571, p=.033$) and full-time employment ($F(2,267)=4.960, p=.027$) were significant covariates.

For emotional suppression scores, ethnicity ($F(2,267)=0.049, p=.824$), nationality ($F(2,267)=1.861, p=.174$), unemployment ($F(2,267)=1.109, p=.293$) and sex ($F(2,267)=0.058, p=.809$) were not significant covariates. However full-time employment ($F(2,267)=8.886, p=.003$), being a full-time student ($F(2,267)=5.354, p=.021$), education level ($F(2,267)=6.749, p=.010$) and age ($F(2,267)=9.659, p=.002$) were.

There was no significant main effect of group on beliefs about emotions scores ($F(2,267)=2.170, p=.116, \eta=.016$), though there was a significant main effect for

emotional suppression ($F(2,278)=5.309, p=.005, \eta=.038$) whereby those with FMS had higher emotional suppression scores than healthy controls ($p=.017$) but did not significantly differ from those with psoriatic arthritis ($p=.178$) (see Table 5.3 for estimates).

Table 5.3 Estimated marginal means and standard errors for emotional suppression and beliefs about emotions after controlling for demographic variables.

| | FMS | | Healthy Controls | | Arthritis | |
|------------------------|-------|------|------------------|------|-----------|------|
| | EMM | SE | EMM | SE | EMM | SE |
| Beliefs about emotions | 43.23 | 1.22 | 38.33 | 2.32 | 44.85 | 2.46 |
| Emotional suppression | 59.43 | 1.09 | 53.36 | 2.06 | 62.85 | 2.20 |

A second MANCOVA was conducted as above however affective distress was added as an additional covariate. After controlling for affective distress and demographic variables, the assumption of homogeneity of variance was met for both beliefs about emotions ($F(2,275)=1.334, p=.265$) and for emotional suppression ($F(2,275)=0.236, p=.790$).

Ethnicity ($F(2,266)=0.002, p=.964$), nationality ($F(2,266)=3.549, p=.061$), being a full-time student ($F(2,266)=0.893, p=.346$), unemployment ($F(2,266)=0.205, p=.651$), sex ($F(2,266)=0.005, p=.346$), education level ($F(2,266)=1.949, p=.164$) and age ($F(2,266)=0.001, p=.977$) were not significant confounds in beliefs about emotions scores. However being employed full-time ($F(2,266)=4.661, p=.032$) and affective distress ($F(2,266)=28.304, p<.001$) were significant covariates. With regards to emotional suppression, ethnicity ($F(2,266)=0.038, p=.846$), nationality ($F(2,266)=1.265, p=.262$), unemployment ($F(2,266)=0.247, p=.619$), sex ($F(2,266)=0.051, p=.822$) and education level ($F(2,266)=3.013, p=.084$) were not significant covariates. However being employed full-time ($F(2,266)=8.582, p=.004$),

being a full-time student ($F(2,266)=4.642, p=.032$), age ($F(2,266)=10.518, p=.001$) and affective distress ($F(2,266)=17.136, p<.001$) were significant confounds in emotional suppression.

After accounting for affective distress and demographic variables, there was no significant main effect of group on beliefs about emotions scores ($F(2,266)=0.693, p=.501, \eta=.005$).

There was a marginally significant main effect for emotional suppression scores after controlling for affective distress ($F(2,266)=2.468, p=.087, \eta=.018$). There was a trend approaching significance where those with FMS scored lower than those with psoriatic arthritis ($p=.068$) but did not score significantly differently from healthy controls ($p=.555$) (See Table 5.4 for estimated marginal means).

Table 5.4 Estimated marginal means and standard errors for emotional suppression and beliefs about emotions after controlling for demographic variables and affective distress.

| | FMS | | Healthy Controls | | Arthritis | |
|------------------------|-------|------|------------------|------|-----------|------|
| | EMM | SE | EMM | SE | EMM | SE |
| Beliefs about emotions | 41.65 | 1.20 | 43.07 | 2.38 | 44.84 | 2.35 |
| Emotional suppression | 58.31 | 1.09 | 58.31 | 2.16 | 62.85 | 2.13 |

5.3.3. Model One (Hypotheses Two and Three)

Zero order correlations for all variables in this model are presented in Table 5.5. Mediation analyses were conducted with beliefs about emotions, emotional suppression, affective distress, personal/emotional support-seeking, symptom-related support-seeking and global impact in the model.

An indirect effect was tested where the relationship between beliefs about emotions and global impact was mediated by emotional suppression and affective

distress in a serial manner. Emotional suppression and affective distress serially mediated the relationship between beliefs about emotions and global impact (standardised indirect effect=.0809). The significance of this positive indirect effect was tested using bootstrapping procedures (indirect effect=.0862, 95% CI [.1549, .1652]) and was found to be significant.

An alternate model testing the direction of path one was analysed with both support-seeking variables also entered in the model. In this model the two serial mediators were inverted. Affective distress and emotional suppression did not serially mediate the relationship between beliefs about emotions and global impact in that order (standardised indirect effect=-.0045). Bootstrapping procedures were used to test the significance of this indirect effect (indirect effect=-.0047, 95% CI [-.0199, .0002]).

Personal/emotional support-seeking was tested as a mediator of the relationship between beliefs about emotions and global impact, in parallel with paths one and three. Personal/emotional support-seeking did not mediate this relationship (standardised indirect effect = -.0009). Using bootstrapping procedures, this indirect effect was found to be non-significant (indirect effect=-.0010, 95% CI [-.0751, .0479]).

Symptom-related support-seeking was tested as a mediator of the relationship between beliefs about emotions and global impact, in parallel with paths one and three. Symptom-related support-seeking did not mediate this relationship (standardised indirect effect = -.0044). Using bootstrapping procedures, this indirect effect was found to be non-significant (indirect effect=-.0047, 95% CI [-.0402, .0277]). See Figure 5.2 for coefficients.

Table 5.5 Zero order correlations for all variables in the model

| | 1. | 2. | 3. | 4. | 5. |
|---------------------------------------|---------|---------|--------|--------|------|
| 1. Beliefs about Emotions | | | | | |
| 2. Emotional Suppression | .463** | | | | |
| 3. Affective Distress | .229* | .318** | | | |
| 4. Personal/emotional support seeking | -.459** | -.512** | -.253* | | |
| 5. Symptom-related support seeking | -.495** | -.514** | -.172* | .848** | |
| 6. Global Impact | -.009 | .028 | .579** | -.045 | .022 |

Note. **p<.001 *p<.050

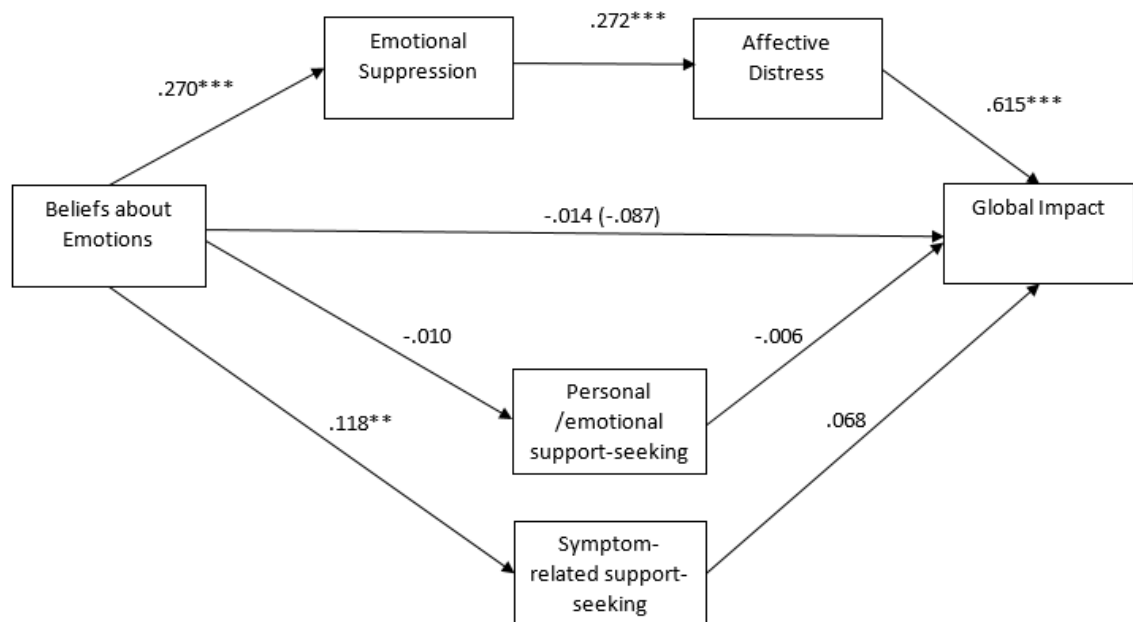


Figure 5.2 Standardised regression coefficients for the relationships between the three paths. Each path tested controlling for the unique variance in alternate paths

Note. ***p<.001 ** p<.010 * p<.050

5.3.4. Model Two (Hypothesis Four)

In a separate model, the relationship between CECS and FIQR was not significantly mediated by BES (standardised indirect effect=-.0130). The

unstandardized indirect effect was -.0161 with 95% confidence intervals ranging from -.1011 to .0910.

5.4. Discussion

In the current study, participants with FMS were more emotionally suppressive than healthy controls but did not differ from participants with psoriatic arthritis. However, there was no significant difference between groups in beliefs about emotions. This could be explained by uncharacteristically high beliefs about emotions scores in the healthy control group in Chapter Five compared with the scores in Chapter Four². This high scoring control group is arguably due to sampling biases from online recruitment, though this perhaps does not explain why this group scores higher on the BES compared to other healthy control groups also recruited online in Chapters Three and Four.

There were also differences in the frequencies of ethnicity, employment status, education level, sex and country of birth across the three groups as well as a difference in age. It is possible that these variables might have influenced the group comparisons and these variables were therefore entered as covariates in all group comparisons in the current study. Only education level, employment status and nationality were significant confounds. The variance in the group differences in beliefs about emotions and emotional suppression that was explained by these confounds was therefore covaried out and all differences found were over and above any potential confounding influence of these variables. However, future research investigating the role of education, employment and nationality in emotional suppression and beliefs about emotions may be useful.

² A one-sample t-test on the healthy controls in the current study using the mean score for healthy controls in Chapter Four as a reference value indicated the controls in the current study scored significantly higher on the BES than the healthy controls in Chapter Four ($t(59)=2.726, p=.008$).

After controlling for affective distress there was still no significant main effect for beliefs about emotions and the main effect for emotional suppression became non-significant (though it was trending towards significant). The planned contrasts for emotional suppression indicated a marginally significant difference between those with FMS and those with arthritis, where participants with arthritis were more emotionally suppressive. While this finding is not statistically significant, the trend is similar to the previous chapter. Therefore, it is possible that the role of emotional suppression is not specific to persistent physical symptoms with an uncertain aetiology, but actually there is something more broadly about persistent physical symptoms and long-term conditions which is related to more emotional suppression.

With regards to the psoriatic arthritis group scoring marginally higher on the measure of emotional suppression compared to those with FMS, there is evidence that those with psoriasis (which is related to comorbid psoriatic arthritis, with estimates of 84% of psoriatic arthritis patients reporting cutaneous symptoms (Gottlieb et al., 2008)) control negative emotions more than healthy controls and demonstrate higher levels of alexithymia than a clinical control group (participants with vitiligo) (Kossakowska, Cieścińska, Jaszewska, & Placek, 2010; Picardi et al., 2005). Thus, it is also possible that psoriatic arthritis comes with its own complex emotion regulation difficulties that are not specifically related to other long-term conditions, which might explain the trend found in the current study.

As the observed differences in emotional suppression scores ceased to be significant after controlling for affective distress, it appears the difference between healthy controls and participants with FMS in emotional suppression might be explained by affective distress. This mirrors the results in Chapter Four where the difference in beliefs about the unacceptability of emotions was no longer significant

after accounting for affective distress. This again supports the postulation that there may be a bidirectional relationship between distress and beliefs about emotions (with distress potentially explaining stronger beliefs that its unacceptable to express emotions in the IBS group, and stronger beliefs about the unacceptability of emotions resulting in more distress) that warrants further investigation.

The current findings also suggest that the role of emotional suppression is not specific to FMS or IBS, given the higher scores in other clinical samples who experience persistent physical symptoms (namely IBD and arthritis) after controlling for affective distress. This suggests that emotional suppression may play a similar role in persistent physical symptoms with and without a clear aetiology (though it is likely that the extent to which distress explains the variance in emotional suppression varies between disorders with and without aetiological uncertainty). This is evidenced by some existing research supporting group differences in emotional suppression between those with and without other conditions and evidence that emotional suppression is related to outcomes in different conditions such as anxiety and mood disorders (Campbell-Sills, Barlow, Brown, & Hofmann, 2006), anorexia nervosa and CFS (Hambrook et al., 2011), depression (Liverant, Brown, Barlow, & Roemer, 2008), breast cancer (Schlatter & Cameron, 2010), social anxiety (Spokas, Luterek, & Heimberg, 2009) and psoriasis (Kossakowska et al., 2010).

The current findings support the proposed model in line with ironic processing effects as the relationship between beliefs about emotions and global impact was significantly mediated by emotional suppression and then affective distress. As such, it appears that having these beliefs that expressing emotions is unacceptable is related to more emotional suppression. The findings are consistent with the proposal that this emotional suppression is then related to an increase in affective distress which in turn

is related to a greater impact of the disorder on the person's life. It appears that these ironic processing effects in relation to beliefs about emotions and emotional suppression may be present in both IBS and FMS.

An alternate model where the two serial mediators were inverted was not significant. This suggests that the particular path being tested is supported in that particular direction. However, the current study has used correlational methods to test a causal chain of variables. While this finding theoretically supports the notion of a causal relationship in this particular direction, experimental methods with a timeline are needed to truly establish causality in this proposed model.

Though there was a significant indirect effect found in both studies, the relationship between beliefs about emotions and global impact in the current study was not significant before or after controlling for the mediators. This suggests that there is no direct relationship between beliefs about emotions and global impact in FMS. This is somewhat unexpected given that there was a significant positive indirect effect via emotional suppression and affective distress. While there may be some detriment to holding these beliefs about the unacceptability of emotions, there may also be a protective factor, thereby cancelling out any significant direct relationship. This is known as inconsistent mediation whereby multiple mediators may elicit separate indirect effects that are in opposing directions, resulting in a non-significant overall effect (Mackinnon, Fairchild, & Fritz, 2010). This therefore might indicate that there is both a positive indirect effect (as found in the current study, where beliefs about the unacceptability of emotions were related to greater impact of the disorder) and a significant negative indirect effect.

Though no mediator measured in the current study indicated a significant negative indirect effect, other possible mediators may exist. For example, it may be

that those who believe it is unacceptable to express their emotions may feel a need to appear unaffected by their condition to others. This may result in less avoidance of activity and limiting behaviours. This may then relate to better outcomes (i.e. less impact on the person's life). It may be that for some individuals, beliefs about emotions relate to more emotional suppression, thereby resulting in poorer outcomes; while for others, these beliefs relate to better outcomes because they are less avoidant of activity. Further research into potential mediators of this relationship may help explain the inconsistent mediation found in the current study.

The existence of subgroups may also explain this inconsistent mediation. There may be individual differences not only in the levels of beliefs about emotions, emotional suppression, affective distress and global impact; but also in the strength and direction of the relationships between these variables. Indeed, there is early evidence that there are clusters within FMS that differ based on their relationships between emotional expression and distress (López-Cicheri, van Middendorp, & Geenen, 2013). Future research with larger samples could explore subgroups with regards to the current mediation model.

The evidence for a significant indirect effect is nonetheless supportive of previous evidence showing emotional expression interventions to be beneficial in patients with FMS (Broderick et al., 2005; Gillis et al., 2006) in that believing emotions to be unacceptable and emotional suppression were related to greater impact of the disorder in this indirect path. The current study has extended this evidence on emotional expression in relation to outcomes in FMS to include beliefs, which enables a more cognitive behavioural approach to be taken when addressing emotionally suppressive behaviours during intervention - though further evidence is required

before addressing beliefs about emotions in a therapeutic context to test other possible factors that might explain the inconsistent mediation found in the current study.

This study also tested models using support-seeking as mediators of the relationship between beliefs about emotions and outcomes. Conversely to the hypotheses, neither support-seeking variable significantly mediated the relationship between beliefs about emotions and global impact. This was also found to be non-significant in participants with IBS in Chapter Four.

In the current study, support-seeking was found to be related to beliefs about emotions but not to global impact. It could be that measuring support-seeking intentions as opposed to actual received social support could explain this finding. There may be confounding variables influencing the amount of social support received which might ultimately be more closely related to impact of the disorder on a person's life. For example, there may be possible interactions between whom they ask for help and how they ask for help that have not been adequately measured in the current study. It is also possible that beliefs associated with support-seeking are different from beliefs specifically about emotional expression, for example the individual may hold beliefs about the acceptability of sharing struggles in relation to the symptoms, which are different from beliefs about sharing emotions. Furthermore, the current measure of support-seeking was adapted for use in the current sample and therefore was not validated. While the amended scales did show good internal consistency, their construct validity may be questioned as the amended item had not been rigorously tested against other measures. Furthermore, the perception of this questionnaire to the target population has not been investigated which means incomprehension of the question cannot be sufficiently ruled out. Reliability tests would also need to be carried out using the amended scale to ensure the measure is consistent over time. Future

research using psychometrically tested measures of support-seeking might provide evidence for a role of support-seeking in the current model.

In Chapters Three and Four, the relationship between emotional suppression and quality of life in IBS was mediated by beliefs about the unacceptability of emotions. It was suggested this might be reflective of processes outlined by Gillis et al. (2006) who argued that expressive behaviour can influence outcomes through changes in cognitions. However, Gillis et al. suggested this based on findings in patients with FMS and the tested mediation effect was not supported in the current study which also tested participants with FMS. It is possible therefore that other cognitive factors might mediate this relationship between increased emotional expression and improved outcomes in FMS in line with what Gillis et al. suggested. Research exploring mechanisms of change in trials of written emotional disclosure would best address this research question as there are differences between written emotional disclosure and other forms of emotional expression (such as talking with others incurring a risk of judgement and stigma that is not present when writing). Furthermore the timing of the changes in the mediator are crucial when attempting to explain delayed health benefits and thus experimental evidence is essential in answering this research question.

Evidence of a slight bias can be found in the overrepresentation of women and Caucasian participants in the current study particularly in the FMS group (though Chi Square analyses on ethnicity may not be considered robust in this instance). This may be due to online recruitment sources (e.g. FMS forums and Facebook groups) appealing to these particular demographics. The generalisability of these findings to non-Caucasian and male participants with FMS may therefore be questioned. Further research should explore differences between subgroups of participants with FMS, especially in the light of evidence that black and minority ethnic participants with CFS

differ from white British participants with CFS in terms of damage beliefs, catastrophizing, all-or-nothing behaviour, avoidance/resting behaviour and embarrassment avoidance (Ingman, Ali, Bhui, & Chalder, 2016). However, the large differences in sample sizes between the ethnic groups studied by Ingman et al., and the failure to apply corrections for multiple testing, question the reliability of the findings, suggesting more research on diverse ethnic groups is needed in order to apply the current study's findings more widely.

The current study found support for emotional suppression and affective distress as mediators of the relationship between beliefs about emotions and global impact, despite the direct relationship being non-significant. Further research should explore this model using experimental methods to understand the value of these variables within the context of intervention. Support-seeking did not significantly mediate the relationship between beliefs about the unacceptability of emotions and global impact in FMS or in IBS. This finding is unexpected and support-seeking should perhaps be explored further with regards to different cognitions and outcomes.

6. Chapter Six: Validating a new measure of beliefs about sharing illness experiences

6.1. Introduction

The previous chapter found that the relationship between beliefs about emotions and global impact was serially mediated by emotional suppression and then affective distress in individuals with FMS. However, this relationship was not mediated by support-seeking. Furthermore, the direct relationship between beliefs about emotions and global impact was not significant.

Studies to this point in the thesis have explored the role of beliefs about the unacceptability of experiencing and sharing emotions with others. It was then hypothesised that this would be related to support-seeking based on cognitive behavioural models of persistent physical symptoms, which suggest that if one believes that emotions are unacceptable, they may try to hide their emotions and not ask for help, which can in turn lead to increased distress and physiological symptoms such as fatigue, pain (Ali et al., 2000; Rimes & Chalder, 2010; Surawy et al., 1995). However it can be argued that there is an important distinction between sharing emotional experiences and sharing experiences regarding one's illness in that discussing illness experiences may be more relevant to support-seeking intentions compared with openness to disclosing emotional experiences, for example, when considering stigma related to a disorder (McInnis, McQuaid, Bombay, Matheson, & Anisman, 2015).

There are barriers to sharing illness experiences for those with persistent physical symptoms, especially when there is no clear medical explanation, which may include fear of people's judgements. McInnis et al. (2015) have argued that in conditions that lack clear medical explanations (for example FMS and CFS) there is

stigma which results in increased secrecy about the condition. This secrecy may then result in the individual trying to appear as though they are not struggling with their condition to others and this may then be related to a reduction in social support (McInnis et al., 2015). Evidence for this relation between stigma and perceived support has also been found in patients with mental health conditions. In a Dutch sample of participants with mental health diagnoses, it was found that there were significant, though small, relationships between stigma, disclosure and social support (Bos et al., 2009).

One way in which stigma in relation to non-disclosure of illness can be damaging to an individual is if they then internalise prejudice (Corrigan et al., 2010). This has been termed internalised stigma or self-stigma, where individuals believe the stereotypes that exist among the community. Regarding mental health for example “Because I have a mental illness, I am dangerous” and “Nobody would be interested in getting close to me because I have a mental illness” are internalised stigma beliefs (Corrigan et al., 2012; Ritsher, Otilingam, & Grajales, 2003). This internalised/self-stigma has been studied in relation to mental health conditions and the stigma surrounding them. In a study of 87 participants with mental health conditions, it was found that the relationship between self-stigma and quality of life was mediated by the benefits of disclosing one’s mental health status to others (Corrigan et al., 2010).

The effects of having a strong and supportive social network are well documented in health psychology research, with reduced social ties being linked to increased morbidity and mortality (Uchino, 2013). There is evidence in FMS and other pain populations that suggests social support is related to better outcomes. For example, low social support in the workplace is considered a risk factor for developing chronic low back pain (Hoogendoorn, Vanpoppel, Bongers, Koes, & Bouter, 2000).

And in rheumatoid arthritis, it has been found that disappointment with social support is associated with maladaptive coping and that social support measured at the time of diagnosis predicted long-term functional disability (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003; Holtzman, Newth, & Delongis, 2004).

One study has looked both quantitatively and qualitatively at social support in FMS and CFS, combining the two patient groups. With 46 participants who had either or both FMS and CFS, it was found that perceived support from family and friends, and not support from health care providers, was significantly related to quality of life, with large effect sizes ($r=.509$ and $.610$ respectively). During an interview with 16 of these participants, it was noted that individuals with CFS and FMS tend to report low levels of social support (Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004). However, these results were found in a small sample that consisted of individuals with CFS and FMS when there may be important distinctions between these two patient groups. Additionally, reporting low levels of social support in an interview is not sufficient evidence. Comparisons would need to be made with other groups to confirm whether social support is perceived to be lower in these individuals compared with others.

It has been suggested that there are different kinds of social support and that some may be more helpful than others. For example, Sherbourne and Stewart (1991) distinguished between tangible support (defined as behavioural and material assistance and emotional support (referring to attachment or affect). In a study looking at 94 adults who had been diagnosed with juvenile FMS, perceived social support and social network size significantly predicted physical functioning and depressive symptoms after controlling for pain intensity and condition (i.e. FMS or healthy control) (Lynch-Jordan, Sil, Bromberg, Ting, & Kashikar-Zuck, 2015). The study also

found that compared with 33 healthy controls, perceived tangible support, perceived emotional support, social network size and positive social interactions were all significantly lower in the FMS than the healthy control group. While the authors acknowledged issues with unequal samples and addressed these by adjusting their alpha level, there were no corrections for multiple comparisons indicating an increased risk of Type I error.

Though specific facets of social support were not tested as predictors in Lynch-Jordan et al.'s study, when looking at correlations, emotional support and positive social interaction were related to physical functioning, while tangible support and affectionate support were not. All four facets of perceived social support (i.e. emotional, tangible and affectionate support, and positive social interaction) however were related to depression symptoms. The authors concluded (though based on a small sample specifically with juvenile FMS) that social support has a relationship with physical functioning that is not explained by greater pain intensity (i.e. those with more pain need more support).

The above evidence on the relation between social support and outcomes in chronic pain and in FMS suggests there may be a link between social support and outcomes in FMS, but the quality of evidence to date is poor. Furthermore, the evidence suggests that different kinds of support may be more or less related to outcomes around physical functioning. The above evidence also appears to suggest a trend in that there is less social support perceived in individuals with FMS. Since support-seeking did not mediate the relationship between beliefs about the expression of emotions and global impact in the previous study (Chapter Five), exploration of other beliefs that may be more relevant to social support (such as beliefs about sharing the experiences of one's illness) is warranted. By doing so it may be possible to

uncover a potential maintaining cycle similar to that found in Chapters Four and Five with regards to beliefs about emotions and emotional suppression. In this cycle, it may be that unhelpful beliefs about sharing illness experiences relate to reduced support-seeking and greater symptoms and/or reduced function. Based on research described above, it is suggested then that the consequent struggles with symptoms and poorer functioning will again not receive support from one's social network so as to maintain symptoms and disability.

Another way in which fear of stigma and social judgements surrounding sharing one's illness experiences might relate to outcomes is by individuals trying to appear well to others (McInnis et al., 2015), which may alter their level of activity. Activity pacing is often a target of pain management programmes for a range of chronic pain conditions (Andrews, Professor-Strong, Meredith, 2012). Both avoidance of activity due to fear of symptoms and confrontation/persistence of activity with a disregard for symptoms have been associated with the maintenance of chronic pain, where in particular a pattern has been described where excessive persistence cannot be sustained which then results in an increase in symptoms and consequently enforced rest (Antcliff, Keeley, Campbell, Woby & McGowen, 2015).

Previous research into behavioural responses to illness has investigated the role of all-or-nothing and limiting behaviour. All-or-nothing behaviour is a cycle of over-activity and a consequent need to rest, while limiting behaviour refers to individuals resting and limiting activity in the response to illness. As described in Chapter One, research has shown that all-or-nothing and limiting behaviour predicted the onset of IBS following *Campylobacter* infection, suggesting that this boom-and-bust activity pattern and inadequately limiting activity when faced with illness works as part of a maintaining cycle in IBS (Spence & Moss-Morris, 2007; Spence, Moss-

Morris, & Chalder, 2005). With regards to FMS physical activity is considered a key component in the maintenance of FMS symptoms (Steiner, Bigatti, & Ang, 2015), and although there is little evidence of this all-or-nothing cycle in research focusing on people with FMS, evidence can be drawn from research focusing on chronic pain.

A recent study, using qualitative methods, argues that boom-and-bust activity patterns may work to maintain symptoms of FMS (Antcliff, Keeley, Campbell, Woby, & McGowan, 2015). This was based on interview data from 16 individuals diagnosed with either CFS (n=2), FMS (n=5) or chronic low back pain (n=9). Similarly, in a study of 132 individuals with musculoskeletal pain, all-or-nothing behaviour was related to pain and to disability (Kindermans et al., 2011). Together, this evidence suggests that all-or-nothing/boom-and-bust cycles of behaviour may play a role in maintaining symptoms of pain, though further evidence on samples specifically diagnosed with FMS are warranted.

Spence, Moss-Morris and Chalder (Spence & Moss-Morris, 2007; Spence, Moss-Morris, & Chalder, 2005) found that initially limiting behaviour at the onset of illness was beneficial and predicted not developing later IBS, although ongoing limiting behaviour is unhelpful. This in part is consistent with the fear-avoidance model of pain that argues that fear of pain results in limiting activity and this limited activity over a longer period of time then results in greater disability through deconditioning (Lethem et al., 1983).

It is proposed that helpful beliefs about sharing illness experiences may enable individuals to engage in a level of activity that is helpful for them (e.g. graded return to activity after a period of acute illness or fatigue), as this enables greater understanding from others of the particular needs of that person at that time.

In summary, based on previous research described above, it is proposed that in response to the fear of social judgements when sharing illness experiences, and the resulting need to appear as though one is not struggling (McInnis et al., 2015), individuals with FMS may overexert themselves, which forces them into periods of prolonged rest, or they may avoid activities. This may, in turn, result in deconditioning and greater pain and/or disability. Similarly, these beliefs about social judgements of sharing illness experiences might result in a reduction in the intention to seek support. This reduction in social support may in turn relate to poorer outcomes.

Based on the above evidence, it would be useful to identify and measure cognitions that relate to talking about one's illness experiences however such a tool was not identified by the author in the existing literature. This tool may be useful, not only as an instrument in research, but also in clinical practice. The current studies presented in this chapter therefore validated a measure named the Beliefs about Sharing Illness Experiences scale (BASIE) that was developed by the academic supervisor of this project. The second study in this chapter tested hypothesised mediation models using this measure.

6.2. Study One: Validating the BASIE

6.2.1. Hypothesis

It is hypothesised that the measure will demonstrate a clear factor structure and will be internally consistent. When comparing individuals with FMS to healthy controls, it is expected that those with FMS will score higher. It is also hypothesised that the new tool will correlate with similar constructs and with outcomes in FMS.

The BASIE is expected to have large negative correlations with the two support-seeking scales (personal/emotional and symptom-related) and moderate positive

correlations with all-or-nothing behaviour, limiting behaviour and self-sacrifice schema.

6.2.2. Methods

6.2.2.1. Participants and procedure

All participants provided informed consent before taking part in online questionnaires. Participants with FMS (n=147) were recruited online through social networking FMS communities (for example on Reddit and Facebook) in addition to online FMS forums (FMAUK and UK Fibromyalgia). Ninety-five was the target sample size for this study. The BASIE was considered similar in content and structure to the BES (Rimes & Chalder, 2010). The validity of the BES was evaluated by correlating scores with similar constructs and the coefficients of the significant correlations of Rimes and Chalder's validation study ranged from .25 to .73. Using the minimum effect size of this study, 95 was calculated to be the sample size required to achieve statistical power at .8. Of the participants who took part, 16 did not meet the LFESSQ criteria for FMS and were excluded from the analysis. Nine participants did not respond to a sufficient number of items (less than 80%) of the BASIE and were therefore excluded from all further analyses.

Of the remaining 122 participants, if more than 20% of data was missing for any given scale, the participant was not included in the analysis for that particular scale. For missing data less than 20% of a particular scale, estimation maximisation techniques were used to impute missing data (Shrive et al., 2006).

Healthy controls (n=47) were recruited online through participant recruitment webpages and social media and through word of mouth, employing snowballing methods. The desired sample size for this group (n=41) was calculated in the same

manner is the previous three studies, using the effect size of Rimes and Chalder's (2010) comparison between participants with and without CFS on the BES. Five participants met the criteria for FMS despite stating they do not have the disorder. Two of the remaining participants did not complete more than 80% of the BASIE and were excluded. Therefore, the final sample consisted of 122 participants with FMS and 40 controls.

6.2.2.2. Questionnaire Development

The questionnaire was developed by a Clinical Health Psychologist, working with people with persistent physical symptoms, including FMS. Items were developed based on the cognitions regarding beliefs about sharing illness experiences identified by clients with persistent physical symptoms (including FMS) during Cognitive Behavioural Therapy sessions as opposed to in formal cognitive interviews, for example "If I ask for help, then I have failed in some way" and "If people know about this condition, they will judge me". Several beliefs were discussed in depth with individuals with coeliac disease, lung condition and persistent pain, as well as individuals without persistent symptoms, to check that the questions were acceptable to participants, and that they understood them. Once a draft questionnaire had been developed, this was shared with other clinical psychologists and subsequent amendments were made. No statistical analyses (including factor analysis) had been conducted prior to the current study. The scale was therefore developed outside of the current study. However, this draft measure, with 26 items, was then used in the current study to examine the reliability and validity of the scale. The questionnaire was named the Beliefs about Sharing Illness Experiences questionnaire (BASIE). The full questionnaire as it appeared online can be found in Appendix G. The response scale

was designed to be 11 points initially however when adding the questionnaire to the online platform, it was decided to use a slider scale which was from zero to 100 as this appeared to be more user-friendly and avoids issues with individual differences in interpreting the differences or intervals between responses (e.g. the difference between very much disagree and totally disagree).

Participants were asked to rate from totally disagree to totally agree (on a slider scale from zero to 100) with each statement. The questionnaire covers both positively and negatively focused beliefs about illness disclosure and therefore the positively worded items (items 21 to 26) were reverse scored to create a total score on this measure. This meant that high scores indicated more negative beliefs about sharing illness experiences.

The instructions given to the participants with FMS instructs participants to reflect on how they think most of the time: “Please move the slider to a position that best describes how you think. Please note that because people are different, there are no right or wrong answers to these statements. The way you think about these things might vary depending on who you are talking to, but try focus on how you tend to think in general.”

However, for the purpose of recruiting healthy controls as a comparison group, participants who do not have FMS were instructed to reflect on a time when they have experienced “significant pain or fatigue”, which might have been due to illness or injury: “For these questions, you will need to think of a time when you have experienced significant pain or fatigue. This might have been due to an illness or due to an injury. When we refer to condition in these questions, we are referring to the pain or fatigue experience you have chosen to think about.” For these participants, there was a question asking them to describe the experience they chose to reflect on. This

response was not analysed, but used to ensure participants saw the instruction to consider a specific time when they experienced pain or fatigue.

6.2.2.3. Measures

To test the construct validity of the BASIE, similar constructs to the BASIE were selected to be measured. In addition, the FIQR and the HADS were measured as outcomes (current study Cronbach's alphas=.927 and .856 respectively). These two outcome measures are described in detail in Chapter Two of this thesis (sections 2.2.3 and 2.3.2). The measures which are specific to the current study and the details of these which are not described earlier in the thesis are described below.

6.2.2.3.1. Self-Sacrifice Schema Scale

In order to test convergent validity, it was proposed to use a questionnaire that measured similar beliefs to that of the proposed questionnaire. However, a questionnaire specifically measuring beliefs about sharing illness experiences could not be found. The closest questionnaire, which measures beliefs about receiving and giving support to others, is The Self-Sacrifice Schema Scale (SSSS), a subscale of Young's Schema Questionnaire (Young, 1998). It consists of 17 items with responses rated on a six-point scale (from 'completely untrue of me' to 'describes me perfectly'). These items measure schemas pertaining to helping others even at the expense of one's own needs or wants (e.g. "I give more to other people than I get back in return"). The subscales of Young's Schema Questionnaire have been supported using factor analysis (Saariaho, Saariaho, Karila, & Joukamaa, 2009; Welburn, Cristine, Dagg, Pontefract, & Jordan, 2002). Total scores have a maximum score of 35 and a minimum score of 5, where higher scores demonstrate a stronger presence of self-sacrifice schemas.

In 271 Finnish patients with pain, internal consistency was good (Cronbach's alpha=.83) (Saariaho et al., 2009). Waller, Meyer, & Ohanian (2001) evaluated the Schema Questionnaire and found that all subscales (including Self Schema) had a Cronbach's alpha greater than .80 for both participants with bulimia and the female non-bulimic comparison group. When comparing bulimics with the comparison group, bulimics scored higher. The Self-Sacrifice subscale was not however related to bingeing or purging behaviours in the bulimic group. In the current study, the SSSS had excellent internal consistency (Cronbach's alpha=.901).

6.2.2.3.2. *GHSQ*

In order to test convergent validity further, additional scales were used, that measures behaviours associated with beliefs about sharing illness experiences. As explained in the introduction to this chapter, relevant behaviours include support-seeking, as individuals who believe there are negative consequences to sharing these experiences are expected to be less likely to seek social support. The GHSQ was used to measure support-seeking. The GHSQ was modified as in Chapter Five to create two scores measuring personal/emotional support-seeking and symptom-related support-seeking separately. For more details on this measure refer to Chapter Two: Methods (page 53) and Section 5.2.2.1 (page 127). Internal consistency for personal/emotional (Cronbach's alpha=.602) and symptom-related support seeking (Cronbach's alpha=.630) in the current study was questionable.

6.2.2.3.3. *Behavioural Response to Illness Questionnaire (BRIQ)*

The BRIQ was developed in order to measure behavioural responses to acute illness and how these relate to the development of persistent physical symptoms for

which there is no known medical explanation (Spence et al., 2005). The scale has four subscales, all-or-nothing behaviour, limiting behaviour, emotional support-seeking and practical support-seeking. While emotional and practical support-seeking appear relevant for the current study, an author of the measure has stated that both these subscales of the questionnaires are problematic and advised against using them in the current study (R. Moss-Morris, June 1st, 2015). In a study validating the measure, practical support-seeking and emotional support-seeking did not predict later cases of IBS in a sample of 580 participants with *Campylobacter* (Spence et al., 2005). This finding has been used to argue that these two subscales are not valid. The all-or-nothing and limiting behaviour subscales were therefore used. These were only used with participants with FMS and not healthy controls as they measure behavioural responses to illness.

6.2.2.3.4. *All-or-nothing behaviour*

All-or-nothing behaviour is a pattern of activity characterised by periods of over-exertion and periods of excessive resting, often viewed as a ‘boom-and-bust’ cycle of activity (Surawy, 1995). This subscale of the BRIQ uses six items to address all-or-nothing activity patterns in participants with physical symptoms. In the current study, internal consistency was good (Cronbach’s alpha= .847).

In response to each statement, participants are asked to rate the frequency with which it applies to their life on a five-point scale from ‘not at all’ to ‘everyday’. Structural validity was evident in the validation of this measure with all six items loading onto the same factor, and the scale was found to be internally consistent (Cronbach’s alpha=.81). In a sample of 758 participants with *campylobacter*, the authors of the scale correlated all-or-nothing behaviour with symptoms of

campylobacter and with days off work. However, these correlations, though significant, were only small. It might be that all-or-nothing behaviour shows only a small (negative) relationship with days off work because participants scoring highly on this measure are more likely to persist with work during the ‘boom’ phase of the cycle. Additionally, these all-or-nothing behaviours might not relate strongly with symptoms of infection, but may still relate to symptoms of later IBS.

In a prospective study of 580 individuals with Campylobacter, it was found that all-or-nothing behaviour predicted later onset of IBS (n=99) (Spence et al., 2005). It would be expected that individuals who do not disclose their illness experiences may instead persist with activity (Griffith & Ryan, 2015), which may then result in forced periods of rest.

6.2.2.3.5. *Limiting behaviour*

The limiting subscale of the BRIQ comprises items measuring the avoidance of activities due to one’s illness (e.g. “I would put parts of my life on hold”). This subscale contains seven items which are rated in the same way as the all-or-nothing subscale described above. This subscale was deemed internally consistent (Cronbach’s alpha=.89) and was correlated positively with days off work and with Campylobacter symptoms suggesting it is a valid measure. In the current study, internal consistency was questionable (Cronbach’s alpha= .671). In the initial study validating the measure, limiting behaviour did not significantly predict the onset of later IBS following infection with Campylobacter, though there was a trend in the expected direction (p=.105) (Spence et al., 2005). However, in a later study with 581 participants with Campylobacter, limiting behaviour was a significant predictor of the onset of IBS, with those who exhibit more limiting behaviour after infection less likely

to develop IBS. Again, it may be that those who feel the need to continue with activity as a means of avoiding sharing illness experiences (Griffith & Ryan, 2015) may engage in less protective limiting behaviour.

6.2.2.4. Design and statistical analysis

The current study employed a correlational and cross-sectional design. In order to assess the psychometric properties of the BASIE, Cronbach's Alpha was used for internal consistency and exploratory factor analysis using direct oblimin rotation to test dimensionality (thereby allowing for correlations between factors).

To evaluate construct validity, participants with FMS were compared to participants without FMS on the BASIE using a randomly selected 40 participants with FMS so as to avoid the influence of unequal sample sizes on statistical power. A one-way MANCOVA compared groups on the BASIE and its two factors while controlling for affective distress and demographic features found to be significantly different between the two groups.

Convergent validity was examined using partial correlations controlling for affective distress (using HADS scores) with all participants with FMS to determine whether the BASIE correlates with other scales measuring similar constructs (GHSQ, SSSS, and the BRIQ all-or-nothing behaviour and limiting behaviour subscales). Affective distress was controlled for as there is strong evidence for greater negative affect in individuals with FMS and chronic conditions more generally (Deary et al., 2007; Moss-Morris, 2013; van Middendorp et al., 2008) and this might explain the relation between these measured variables over and above the scales measuring similar constructs. Bivariate correlations were also used to test for relationships between the BASIE and outcomes (HADS and FIQR).

6.2.3. Results

6.2.3.1. Sample characteristics

Demographic information about the participants was analysed using chi-square tests of association and significant associations were broken down using standardised residuals (i.e. if the standardised residual is greater than 2, it was considered significantly different from chance). Demographic information for each group is presented in Table 6.1.

There was no significant difference between groups in age ($t(158) = .199$, $p = .343$) or sex ($\chi^2 = 1.441$, $df = 1$, $p = .230$). There were more participants in the healthy control group who were employed full-time than expected by chance ($\chi^2 = 10.571$, $df = 1$, $p = .001$) and fewer participants in this group who were unemployed ($\chi^2 = 9.032$, $df = 1$, $p = .003$). This difference in employment could be explained by those with FMS being unable to work full-time or perhaps being unable to work at all due to their disorder.

There were significantly different distributions of ethnicity across the two groups than would be expected by chance ($\chi^2 = 17.10$, $df = 8$, $p = .029$), however 83.3% of expected values were less than 5 so the chi-square test cannot be considered robust in this instance.

There were more participants in the healthy control group with post-graduate education than expected by chance and more participants in the FMS group whose highest level of education was secondary school (up to 16 years) ($\chi^2 = 20.363$, $df = 3$, $p < .001$). This education difference might be explained by recruitment methods. Participants in the control group were in part recruited through word of mouth, thus the two researchers were perhaps more likely to reach out to people who also have

completed post-graduate education. The higher rate of education finishing at secondary level in the FMS group could be explained by symptoms preventing participants from completing education past what is compulsory.

No other demographic variables showed differences in frequencies across the two groups. The variables which did show differences (i.e. education and employment) were entered as covariates in tests of group differences so as to account for any differences in BASIE scores which might be explained by these characteristics. Means and standard deviations for all measured variables are presented in Table 6.2.

Table 6.1 Demographic information for both groups.

| Characteristics [n(%)] | FMS (n=122) | | Healthy (n=40) | |
|--------------------------|-------------|---------|----------------|---------|
| Age [M(SD)] | 44.19 | (11.32) | 42.23 | (11.39) |
| Sex | | | | |
| Female | 114 | (87.5) | 35 | (93.4) |
| Employment status | | | | |
| Full-time employed | 28 | (23.0) | 20 | (50.0) |
| Part-time employed | 22 | (18.0) | 12 | (30.0) |
| Full-time study | 3 | (2.5) | 1 | (2.5) |
| Part-time study | 1 | (0.8) | 1 | (2.5) |
| Self-employed | 5 | (4.1) | 3 | (7.5) |
| Unemployed | 29 | (23.8) | 7 | (2.5) |
| Retired | 15 | (12.3) | 1 | (2.5) |
| Chosen not to work | 6 | (4.9) | 0 | (0.0) |
| Home maker | 19 | (15.6) | 3 | (7.5) |
| Ethnicity | | | | |
| Caucasian | 119 | (97.5) | 34 | (85.0) |
| Pakistani | 0 | (0.0) | 1 | (2.5) |
| Bangladeshi | 0 | (0.0) | 1 | (2.5) |
| Indian | 1 | (0.8) | 2 | (5.0) |
| Chinese | 0 | (0.0) | 1 | (2.5) |
| Other Asian ethnic group | 1 | (0.8) | 1 | (2.5) |
| Other mixed ethnic group | 1 | (0.8) | 0 | (0.0) |
| Nationality at birth | | | | |
| United Kingdom | 107 | (87.7) | 30 | (75.0) |
| North America | 10 | (8.2) | 3 | (7.5) |
| Other Europe | 2 | (1.6) | 5 | (12.5) |
| Australasia | 1 | (0.8) | 1 | (2.5) |
| Asia | 0 | (0.0) | 1 | (2.5) |
| Africa | 2 | (1.6) | 0 | (0.0) |
| Education | | | | |
| Secondary school | 33 | (27.7) | 3 | (7.5) |
| Sixth form | 37 | (31.1) | 7 | (17.5) |
| Undergraduate | 35 | (29.4) | 14 | (35.0) |
| Post-graduate | 15 | (11.8) | 16 | (40.0) |

Table 6.2 Means and standard deviations for all measured variables.

| | FMS | | Healthy Controls | |
|-----------------------------|---------|--------|------------------|--------|
| | Mean | SD | Mean | SD |
| BASIE total | 1257.21 | 427.19 | 620.69 | 430.81 |
| BASIE factor 1 | 460.22 | 208.91 | 238.20 | 199.66 |
| BASIE factor 2 | 335.87 | 127.75 | 203.81 | 112.98 |
| BASIE factor 3 | 457.00 | 155.17 | 183.98 | 156.64 |
| SSSS | 75.67 | 14.21 | 63.74 | 11.76 |
| GHSQ: Personal/Emotional | 3.27 | 1.21 | 4.24 | 1.08 |
| GHSQ: Symptoms | 3.25 | 1.23 | 4.03 | 1.08 |
| HADS total | 23.56 | 7.25 | 11.26 | 7.23 |
| FIQr | 75.26 | 15.99 | - | - |

6.2.3.2. Dimensionality

Principal components analysis was conducted to explore the factor structure of the BASIE. Direct Oblimin rotation was used to allow for correlations between the factors. The Kaiser-Meyer-Olkin test indicated sampling adequacy (KMO=.895) and Bartlett's test of sphericity demonstrates sufficient correlations among items for factor analysis ($\chi^2=3086.060$, $df=325$, $p<.001$).

There was evidence of multicollinearity in the data (determinant=.000000000009544). Examination of the inter-item correlations table revealed 11 inter-item correlation coefficients greater than .8 (see Appendix H). Removing high inter-item correlations can reduce multi-collinearity between items. The removal of these items with high correlations (items 3, 6, 7, 11, 17) did improve the determinant (determinant =.0000000197). The fewest possible number of items

were removed in order to eliminate inter-item correlations greater than .8. This determinant was still below the desired value (.00001) despite removing the most highly correlated items, but was much closer to this value after items were removed. Further analysis was therefore based on this solution, however there is still some issue with regards to multicollinearity. After the removal of items, there was evidence of sampling adequacy (KMO=.893) well above the acceptable limit of .5 (Fields, 2011) and sufficient correlations between items ($\chi^2=2007.924$, $df=210$, $p<.001$).

In this final factor analysis, three factors were extracted based on factor loadings greater than .4 with Eigenvalues greater than 1 being considered factors (factor one Eigenvalue=10.048, factor two Eigenvalue=2.756, factor three Eigenvalue=1.246). Factors one and two explain a total of 60.97% of the variance, with factor three only explaining an additional 5.9%.

Three items (items 12, 20 and 23) loaded onto both factor three (with factor loadings of .53, .44 and .50 respectively) and either factor one or two. These items were assigned to either factor one or two, depending on which factor they loaded onto (see Table 6.3). No other items loaded onto more than one factor. Item 14 only loaded onto factor three (factor loading=.52) and was therefore removed from the scale. Item 15 did not load onto any item and was also removed from the questionnaire.

Table 6.3 Factor loadings and communality for each item onto each factor

| Item | Factor one | Factor two | Communality |
|---|------------|------------|-------------|
| 1 If people know that I am struggling in any way (physically or emotionally) with this condition, they will think I am a weak person | .78 | | .64 |
| 2 If people know that I am struggling in any way (physically or emotionally) with this condition, then I am a weak person | .97 | | .78 |
| 4 If people know that I am struggling in any way (physically or emotionally) with this condition, then I have failed in some way | .95 | | .81 |
| 5 If people know that I am struggling in any way (physically or emotionally) with this condition, they will think I have failed in some way | .78 | | .72 |
| 8 If I ask for help, then I am letting people down | .89 | | .81 |
| 9 If I have difficulties with this condition, I should not admit it to others | .79 | | .65 |
| 10 It is shameful to be struggling in any way (physically or emotionally) with this condition | .71 | | .64 |
| 12 Experiencing symptoms of this condition in front of others is embarrassing | .42 | | .63 |
| 13 With respect to living with my condition, I should put on a brave face in front of others | .68 | | .62 |
| 14 If people know about this condition, they will judge me | | | .61 |
| 15 If people know about this condition, they will treat me like a different person | | | .52 |
| 16 I should keep this condition a secret from most people I know | .56 | | .65 |
| 18 People will not want to be friends with me if they know I have difficulties with my condition | | .58 | .65 |

| | | | |
|----|--|-----|-----|
| 19 | To be acceptable to others, I should keep my condition mainly to myself | .51 | .75 |
| 20 | Others will expect me to manage this condition without support from them | .45 | .60 |
| 21 | If I tell people about my condition, they will support me | .81 | .65 |
| 22 | If people know about my condition, they will still treat me like “me” | .83 | .69 |
| 23 | It would be helpful for people to know | .47 | .45 |
| 24 | People will not judge me for having this condition | .87 | .68 |
| 25 | If I talk to people about my condition, they will feel pleased that I have shared this with them | .85 | .73 |
| 26 | Telling friends about my condition would strengthen our friendship | .89 | .79 |

It was therefore thought that the overall scale consists of two subscales. Subscales were labelled based on discussion with the PhD student and academic supervisor regarding the content of the items. The first factor was named the Beliefs about Sharing Struggles subscale and the second factor the Benefits of Sharing Illness Experiences subscale.

The two subscales were significantly correlated with each other and with overall scores on the BASIE with all three correlations significant at $p < .001$ (see Table 6.4).

Table 6.4 Correlation coefficients between the BASIE and its two scales.

| | Overall BASIE | Factor 1 |
|-----------------------------|---------------|----------|
| BASIE – Sharing Struggles | .936 | - |
| BASIE – Benefits of sharing | .807 | .548 |

6.2.3.3. Internal consistency

Internal consistency was analysed using Cronbach's alpha. The overall scale with the highly-correlated items, and items 14 and 15 removed demonstrates excellent internal consistency (Cronbach's alpha=.939). The removal of item 23 would improve the alpha to .942 but as this is only a minor improvement and since the level of internal consistency is already excellent, this item was not removed.

Reliability analyses were then conducted for each of the extracted factors. For the Beliefs about Sharing Struggles scale, internal consistency was excellent (Cronbach's alpha=.943). The Benefits of Sharing Illness Experiences scale also had very good internal consistency (Cronbach's alpha=.886). The deletion of item 23 would have increased the alpha to .903 for this scale. However, the internal consistency is already very good and the improvement made by deleting this item is only small. Therefore, the item was not deleted.

6.2.3.4. Group differences

A one-way MANCOVA was conducted on BASIE scores to compare healthy controls with a randomly selected sample of 40 participants with FMS³ whilst accounting for distress (measured using HADS) and demographic variables which are significantly different between groups (namely being employed full time, being unemployed, highest level of education up to 16 years and highest level of education post-graduate). A random sample of 40 was chosen to account for problems with unequal sample sizes.

³ These results were comparable to group comparisons using entire sample of individuals with FMS, which can be found in Appendix I.

Due to missing data on the demographic items entered into the model, there were 38 healthy controls and 40 participants with FMS included in this analysis. Homogeneity of variance was assumed for overall BASIE scores ($F(1,76)=.002$, $p=.969$), factor one ($F(1,76)=.699$, $p=.406$) and factor two ($F(1,77)=.090$, $p=.764$).

Distress was a significant confound in overall BASIE scores ($F(1,71)=10.362$, $p=.002$) and in the Beliefs about Sharing Struggles scale ($F(1,71)=10.857$, $p=.002$) and the Benefits of Sharing Illness Experiences scale ($F(1,71)=5.196$, $p=.026$). Having a post-graduate qualification was not a significant confound for overall BASIE scores ($F(1,71)=.017$, $p=.896$), Beliefs about Sharing Struggles ($F(1,71)=.766$, $p=.384$) or the Benefits of Sharing Illness Experiences scale ($F(1,71)=1.356$, $p=.248$). Neither was being educated up to secondary school level (total $F(1,71)=1.402$, $p=.240$), Beliefs about Sharing Struggles $F(1,71)=.988$, $p=.324$), Benefits of Sharing Illness Experiences $F(1,71)=1.459$, $p=.231$), being unemployed (total $F(1,71)=.009$, $p=.924$), Beliefs about Sharing Struggles $F(1,71)=.646$, $p=.424$), Benefits of Sharing Illness Experiences $F(1,71)=.092$, $p=.762$), or being employed full-time (total $F(1,71)=.009$, $p=.924$), Beliefs about Sharing Struggles $F(1,71)=.002$, $p=.967$), Benefits of Sharing Illness Experiences $F(1,71)=.928$, $p=.339$).

After controlling for affective distress and for demographic variables, participants with FMS scored significantly higher on overall BASIE scores and scores on the two subscales compared to healthy controls (see Table 6.5 for estimates, F statistics and effect sizes).

Table 6.5 Estimated marginal means, standard errors, F statistics and effect sizes for overall BASIE scores and its two factors after controlling for distress and demographic variables

| | FMS n=40 | | Healthy Controls n=38 | | F statistic | η^2 |
|----------------------|----------|-------|--------------------------|-------|-------------------------------|----------|
| | EMM | SE | EMM | SE | | |
| BASIE total | 1028.22 | 64.02 | 587.43 | 66.12 | F(1,71)=1 8.335, p<.001 | .205 |
| Sharing Struggles | 590.275 | 44.42 | 316.69 | 45.87 | F(1,71)=1 4.675, p<.001 | .171 |
| Benefits | 437.941 | 26.20 | 270.75 | 27.06 | F(1,71)=1 5.751, p<.001 | .182 |

6.2.3.5. Convergent validity

Correlations using Pearson's R were calculated for the FMS sample among overall BASIE scores, the two subscales, personal/emotional support-seeking, symptom-related support-seeking, two subscales of the BRIQ (all-or-nothing behaviour and limiting behaviour), and self-sacrificing schemas (see Table 6.6).

Overall BASIE scores and its two subscales were moderately positively related to self-sacrifice and the BRIQ subscale all-or-nothing behaviour, and were negatively to personal/emotional support-seeking and symptom support-seeking.

Table 6.6 Correlations between overall BASIE scores, its factors, and measures of related behaviours and cognitions after controlling for affective distress.

| | Overall BASIE | | Sharing Struggles | | Benefits | |
|--|---------------|-------|----------------------|-------|----------|-------|
| | r | p | r | p | r | p |
| Personal Emotional support- seeking | -.471 | <.001 | -.400 | <.001 | -.443 | <.001 |
| Symptom-related support- seeking | -.447 | <.001 | -.355 | <.001 | -.462 | <.001 |
| BRIQ- All or Nothing | .489 | <.001 | .401 | <.001 | .485 | <.001 |
| BRIQ – Limiting | -.007 | .940 | -.052 | .595 | .067 | .493 |
| Self-Sacrifice Schema Scale | .362 | <.001 | .325 | <.001 | .312 | <.001 |

6.2.3.6. Relations to outcomes

A second correlation analysis was conducted correlating the overall BASIE scores and its two subscales with affective distress and global impact.

Overall scores on the BASIE, and scores on the two subscales were significantly correlated with global impact. Affective distress was significantly correlated with overall BASIE scores and scores on the two subscales (see Table 6.7 for coefficients).

Table 6.7 Correlations between overall BASIE scores and its two factors, and outcome measures.

| | Overall BASIE | | Factor One | | Factor Two | |
|--------------------|---------------|-------|------------|-------|------------|-------|
| | r | p | r | p | r | P |
| Global impact | .231 | .010 | .184 | .042 | .241 | .008 |
| Affective distress | .329 | <.001 | .358 | <.001 | .241 | <.001 |

6.3. Study Two: Exploring mediators of the relationship between beliefs about sharing illness experiences and global impact.

Using the same sample of individuals with FMS, mediation analyses were conducted in line with research from Chapter Five of this thesis. It was expected that the relationship between beliefs about sharing illness experiences and global impact would be mediated by the behaviours found to correlate with the BASIE in study one of this chapter (Section 6.2.3.5, on page 170), that is support-seeking (personal/emotional and symptom-related), all-or-nothing behaviour and limiting behaviour. This analysis was conducted based on the finding that support-seeking did not significantly mediate the relationship between beliefs about the unacceptability of expressing emotions and global impact. The current study therefore sought to investigate beliefs about sharing illness experiences, as opposed to beliefs about the unacceptability of expressing and experiencing emotions in relation to support-seeking and global impact.

6.3.1. Hypothesis

It was predicted that the relationship between beliefs about sharing illness experiences and global impact would be mediated in parallel by all-or-nothing behaviour, limiting behaviour, personal/emotional support-seeking and symptom-related support-seeking.

6.3.2. Methods

6.3.2.1. Participants and procedure

The same sample from the above validation study was used for the current study. Refer to section 6.2.3.1 (page 161) for sample characteristics. For this study, only participants with FMS are considered. The questionnaires included are the BASIE, the two BRIQ subscales (all-or-nothing behaviour and limiting behaviour), personal/emotional support-seeking, symptom-related support-seeking and the FIQR. For details on these measures refer to section 6.2.2.3 (page 156) of this chapter.

6.3.2.2. Design and statistical analysis

Process model 4 was used (Preacher & Hayes, 2004). In this model, beliefs about sharing illness experiences was the predictor and global impact the outcome. The four mediators were the behaviours found to correlate with beliefs about sharing illness experiences, namely all-or-nothing behaviour, limiting behaviour, personal/emotional support-seeking and symptom-related support-seeking. These mediators were tested in parallel.

6.3.3. Results

Of the four mediators tested, all-or-nothing behaviour and personal/emotional support-seeking were the only significant mediators. The all-or-nothing subscale of the BRIQ (standardised indirect effect= .0987) and personal/emotional support-seeking (standardised indirect effect= .1627) positively mediated the relationship between beliefs about sharing illness experiences and global impact indicating that more negative beliefs about sharing illness experiences is related to greater impact of the disorder through these two mediators. The bootstrapped unstandardized indirect effect for all-or-nothing behaviour was .0038 (95% CI [.0006, .0080]) and for personal emotional support-seeking was .0063 (95% CI [.0010, .0132]).

Limiting behaviour was not a significant mediator of the relationship between beliefs about sharing illness experiences and global impact (standardised indirect effect=.0399). The unstandardized indirect effect was .0001 (95% CI [-.0001, .0003]). Similarly, symptom-related support seeking was not a significant mediator (standardised indirect effect=-.0770). The unstandardized indirect effect was -.0002 (95% CI [-.0006, .0002]). See Figure 6.1 for coefficients.

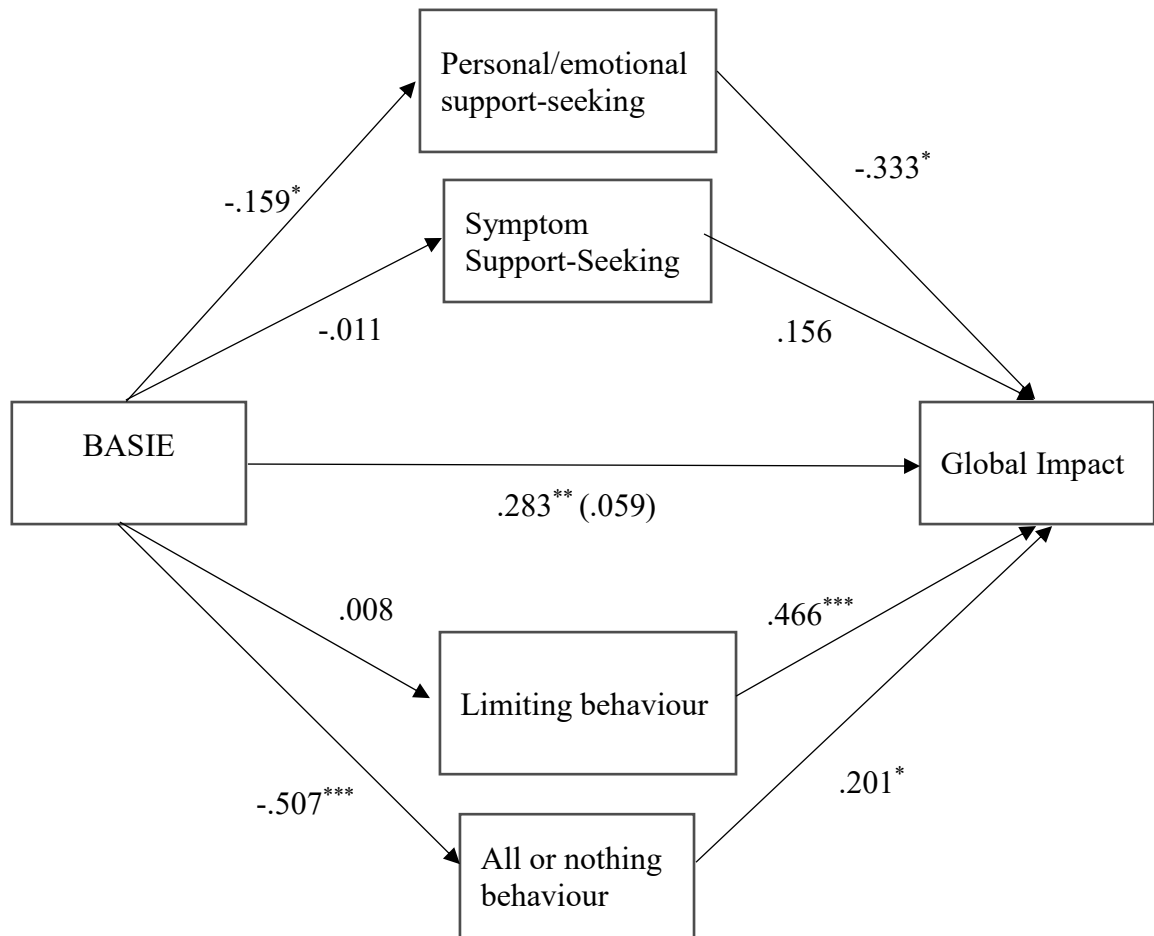


Figure 6.1. Standardised regression coefficients for the mediation model where the BASIE is the predictor, global impact is the outcome and the four parallel mediators are symptom support-seeking, personal/emotional support-seeking, limiting behaviour and all-or-nothing behaviour. For each path, the parallel mediators are included as control variables.

Note: * $p < .050$, ** $p < .010$, *** $p < .001$

6.4. Discussion

The current study aimed to validate a questionnaire that measures beliefs about sharing illness experiences. The questionnaire was administered online to participants with FMS. Due to issues with multicollinearity five items were removed from the questionnaire resulting in a total of 21 items. Factor analysis of these 21 items revealed two factors: Beliefs about sharing struggles and benefits of sharing illness experiences.

The overall scale and the two subscales were internally consistent and were significantly correlated with scales measuring similar cognitive and behavioural constructs. The sizes and the directions of the correlations largely supported hypotheses with the correlation coefficients for support-seeking approaching large (defined as $>.5$ (Fields, 2011)) and the correlations for all-or-nothing behaviour and self-sacrifice schema being moderate and positive. However, there was no significant correlation between the BASIE and limiting behaviour despite a moderate positive correlation being expected.

This, in addition to finding higher scores in the FMS group compared to controls, suggests good construct validity for the measure. The sample size was smaller than most recommendations suggest for factor analysis (Maccallum, Widaman, Zhang, & Hong, 1999) meaning it may have been underpowered. However, the KMO indicates excellent sampling adequacy. Thus, despite evidence of some multicollinearity in the factor analysis and the small sample, the findings of the current study largely suggest the scale is reliable and valid, though further psychometric testing is needed.

There were group differences in sociodemographic features of the healthy controls and participants with FMS regarding employment status, ethnicity and education. These were therefore entered in the ANCOVA when comparing groups on the BASIE. However none of these were found to significantly confound the differences between the two groups in BASIE overall scores or the scores of the two subscales.

Beliefs about sharing illness experiences (both as an overall measure and as two subscales) were correlated with affective distress and global impact as outcome measures in FMS. The relation between beliefs about sharing illness experiences and

outcomes suggest that these beliefs may be particularly important in a therapeutic context. This measure may therefore be considered for use in clinical practice in order to identify potential unhelpful beliefs about sharing illness experiences in clients which could be useful in cognitive behavioural interventions. However, the questionnaire and its subscales require further testing in its final form (with only the final included items) in order to validly examine the relationship between beliefs about sharing illness experiences and global impact in FMS.

This measure may be valuable in future research. As biopsychosocial and cognitive behavioural models of persistent physical symptoms are still under investigation, it might be that this measure can open a new avenue of research into psychosocial factors that contribute to the maintenance and possibly development of FMS. In particular, future prospective research testing beliefs about sharing illness experiences as a predictor of the onset of FMS in individuals at risk of the disorder would be valuable.

All-or-nothing behaviour and seeking support for personal/emotional problems significantly mediated the relationship between beliefs about sharing illness experiences and global impact, in that holding more unhelpful beliefs about sharing illness experiences was related to greater impact of the disorder via reductions in all-or-nothing behaviour and personal/emotional support-seeking. It could be that believing that sharing illness experiences can lead to forms of social rejection/judgement which might result in overexertion in order to ‘put on a brave face,’ as suggested by McInnis et al. (2015). This overexertion might worsen symptoms.

The finding that personal/emotional support-seeking and not symptom related support-seeking was a mediator of the relationship between beliefs about sharing

illness experiences and global impact is unexpected (though the internal consistency of these scales is questionable and future research with stronger measures of support seeking is warranted). While the two measures of support-seeking did differentiate between seeking-support for emotional problems and for symptoms, it does not distinguish between emotional problems that are caused by FMS and emotional problems that are distinct from the experience of FMS. Future research may want to distinguish between seeking support for general emotional difficulties and seeking support for emotional difficulties that arise as a result of living with FMS in order to determine whether both, or just seeking support for symptom-related emotional difficulties are related to unhelpful beliefs about sharing illness experiences in line with evidence that there are different kinds of support (Lynch-Jordan et al., 2015; Matos, Bernardes, Goubert, & Carvalho, 2015).

A similar line of research has argued that different kinds of social support can promote functional autonomy or functional dependence. It is argued that this is particularly important with regards to individuals with chronic pain who may engage in activity avoidance as a result of receiving support which promotes functional dependence as opposed to support which promotes functional autonomy (Matos et al., 2015). As such, support which promotes dependence was found to be related to worse physical function while support which promotes autonomy was found to be related to greater physical functioning in elderly participants with chronic pain (Matos et al., 2015).

With regards to the current finding that personal/emotional support-seeking and not symptom-related support-seeking was a significant mediator, it could be that symptom-related support-seeking relates to more practical forms of support and such practical support may include completing physical activities (e.g. household chores)

on behalf of an individual with FMS. This may mean that this symptom-related support-seeking could be confounded by the difference between promoting autonomy or dependence in relation to outcomes, while personal/emotional support-seeking may not be so greatly influenced by this confound. As such, the presence of the conflicting positive and negative correlations of support-seeking promoting autonomy and support-seeking promoting dependence with outcomes may have resulted in a non-significant mediation effect when looking at symptom-related support-seeking. However, for personal/emotional support-seeking, these conflicting relationships were not present and therefore did not mask the mediation effect.

These mediation findings suggest potential mechanisms through which cognitive behavioural interventions may help those with FMS, in particular those who hold beliefs about the unacceptability of sharing their illness experiences with others. Cognitive Behavioural Therapy, which is supported as a treatment for FMS (Glombiewski et al., 2010), focuses on understanding maintaining cycles of beliefs and behaviours in order to improve outcomes. The current study's finding that beliefs about sharing illness experiences relates to global impact of FMS via all-or-nothing behaviour and support-seeking for personal/emotional problems therefore indicates that these beliefs and behaviours should be investigated as process variables in cognitive behavioural treatment for FMS.

Chapter Five of this thesis (page 121) found that the relationship between beliefs about the unacceptability of expressing emotions and global impact was not significantly mediated by support-seeking (neither personal/emotional nor symptom-related). Similarly, in Chapter Five, it was found that the direct relationship between beliefs about the unacceptability of emotions and global impact was not significant. In the current study however, beliefs about sharing illness experiences was directly

related to global impact. The current findings suggest that beliefs about sharing illness experiences as opposed to beliefs about the unacceptability of expressing emotions, may be more relevant with regards to the relationship between support-seeking (specifically for personal/emotional problems) and global impact in FMS and further research into support-seeking in FMS should include this measure of beliefs about sharing illness experiences.

The current study has produced a scale that from current analyses can be considered reliable and valid. However further tests are warranted in order to fully determine the reliability, validity and acceptability of the BASIE. For example, future research in a second sample of individuals with FMS could test the correlations between scores at two time points, within-participants to measure test-retest reliability. The current study did not examine the factor structure beyond principle components analysis. Therefore (using a new sample) the factor structure found in the current study should be tested using confirmatory factor analysis to see if the factor structure is a good fit in a new data set with the removed items excluded. Further research testing the BASIE's sensitivity to change would especially be useful given the implications for use in clinical practice.

The current study validated the BASIE with participants with FMS. However, the questionnaire is designed in such a way that means it can be used with individuals with any health condition. There are a number of health conditions where individuals experience stigma, such as obesity, HIV, mental health problems and diabetes (Hackler, Cornish, & Vogel, 2016; Kato et al., 2016; Latner, 2016; Lokko & Stone, 2016). It may therefore be useful to validate this measure in other conditions in order to explore unhelpful beliefs about sharing illness experiences in individuals with a range of health problems. Further research comparing individuals with FMS to individuals with

other health conditions would also be useful in determining the specificity of the mediation models supported in the current study.

While the current study and Chapters Three, Four and Five have provided valuable insight into the relationships between particular beliefs relating to sharing illness experiences and emotional experience, and outcomes in IBS and FMS, these relationships cannot fully support a direction of causality. For example, in the current study, it could be that those who are impacted more greatly by their disorder will seek more emotional support. They may then shape beliefs about sharing these experiences based on negative interactions with their support network when the individual has approached them for support. Further experimental evidence is needed where measures are taken at multiple time points to establish a direction of causality for these models.

7. Chapter Seven: Examining beliefs about emotions and emotional suppression in patients attending therapy for fibromyalgia

7.1. Introduction

Chapter Five investigated the role of beliefs about emotions and emotional suppression in people with FMS in an online sample. This study found that there was a significant indirect effect whereby the relationship between beliefs about the unacceptability of emotions and global impact of FMS was mediated by emotional suppression and then affective distress. It was argued that this linear path may reflect ironic processing effects (Wenzlaff & Wegner, 2000) in that believing it to be unacceptable to express one's emotions was related to more emotional suppression. This emotional suppression was then related to an increase in affective distress which in turn was related to a greater impact of the disorder on a person's life. This was found using online samples as opposed to clinical samples who have been diagnosed and referred for treatment by a clinician. Given previous research has highlighted problems in collecting data online (see Chapter Two, section 2.5, page 73), it was noted that replication in a clinical sample would be beneficial.

The role of emotional suppression in FMS is supported by studies evaluating written emotional disclosure interventions. Two studies discussed in Chapter One found that written emotional disclosure (compared to neutral writing) resulted in improvements in physical symptoms (i.e. pain and fatigue) and in global impact (Broderick et al., 2005; Gillis et al., 2006). This limited evidence indicates that changes in emotional expression may lead to improvements for individuals with FMS. It is possible therefore (based on this evidence alongside the mediation findings of Chapter Five) that beliefs about the unacceptability of emotions and emotional suppression could be of interest when investigating psychological therapies for FMS.

The findings from Chapter Five support evidence in IBS (Chapters Three and Four), which also found this significant indirect effect where believing emotions to be unacceptable was related to greater emotional suppression and in turn greater affective distress which was then related to poorer quality of life. In FMS, the direct relationship between beliefs about the unacceptability of emotions and global impact was not significant (the direct relationship in IBS was however significant). It was suggested that while the indirect effect tested in Chapter Five was significant, there may also be an indirect effect in the opposing direction which was not measured. For example, it might be that for some individuals with FMS, believing it is unacceptable to express emotions results in acting 'normal' and less avoidance of activity. This might then lead to better outcomes. Due to the contradicting nature of the role of beliefs about the unacceptability of emotions in FMS, further research into their role within a therapeutic context is warranted to understand whether emotional expression is believed to be more acceptable following psychological intervention and whether this change is related to improvements in outcomes.

Evidence-based guidelines recommend psychological approaches, as part of multimodal approaches including pharmacological, psychological and exercise treatments in FMS (Häuser et al., 2008; Lami et al., 2013). A meta-analysis of 23 studies demonstrated small short-term reductions in pain and small-to-medium sized long-term reductions in pain following psychological treatment for FMS. These studies use second and third wave CBT approaches, all of which aim to help the individual to understand the relationship between thoughts, feelings, behaviours and pain, and support individuals to make changes in a way that is helpful for them (Mccracken & Morley, 2014). The techniques used to support behaviour change may

however vary between these approaches, and any of the approaches may focus more or less on beliefs and behaviours around emotional expression.

In a meta-analysis, CBT was associated with greater short-term pain reductions when compared to all other psychological interventions included (i.e. mindfulness-based treatment, education, behavioural intervention, relaxation and biofeedback) (Glombiewski et al., 2010). However, across the literature on psychological treatments for FMS, studies are generally of poor quality (Bernardy, Klose, Busch, Choy, & Häuser, 2013; Lauche, Cramer, Dobos, Langhorst, & Schmidt, 2013; Turk, Okifuji, Sinclair, & Starz, 1996). A Cochrane review of randomised control trials found benefits of CBT as a treatment in FMS (Bernardy et al., 2013). Twenty-three studies were reviewed and found that there was a reduction in pain (SMD=-.30), negative mood (SMD=-.34) and disability (SMD=-.31) in the CBT arms of studies compared to control conditions, though this evidence was considered of low quality and these effects were small. Similar findings have emerged from a systematic review and meta-analysis of six trials of mindfulness-based stress reduction in FMS, with small improvements in quality of life (SMD=-.35) and pain (SMD=-.23) when compared to usual care or an active control conditions (i.e. education, support, relaxation, stretching and discussion) (Lauche et al., 2013).

While there is yet to be a systematic review of acceptance and commitment based interventions in FMS specifically, there is evidence that ACT is a beneficial treatment for chronic pain conditions (Hann & McCracken, 2014). In a review of ten randomised control trials with small sample sizes (n ranging from 16 to 156 across the ten studies), ACT was considered to be an effective treatment for chronic pain when compared to waitlist controls, treatment as usual and pharmacological controls, with pain and distress as outcome measures. When compared with CBT however, there were no

differences, suggesting an advantage for psychological therapy over non-psychological therapy though there appeared to be no difference overall between different psychological therapies.

There is evidence for the use of ACT compared to wait list controls specifically in FMS: In a randomised control trial of ACT with 40 participants with FMS, participants in the ACT condition showed moderate to large improvements in quality of life, self-efficacy, depression, anxiety and psychological flexibility (Wicksell et al., 2013). A later randomised control trial with a larger sample (n=156) comparing ACT to waitlist controls and to recommended pharmacological treatment also found that group ACT was an effective intervention for FMS, eliciting large improvements in global impact (Cohen's $d=2.35$) (Luciano et al., 2014). Again, this indicates that psychological treatment is beneficial when compared with non-psychological treatment for FMS, though it does not indicate if this treatment is comparable to the effects of treatment with other psychological approaches. In this study, acceptance did not mediate the treatment effect, suggesting other possible psychological variables might mediate the effect of psychological treatment on outcomes in FMS which warrants further investigation.

The small effect sizes in these studies suggest that while these psychological interventions may be useful in helping those with FMS, there is a need to improve the treatments. Furthermore, while two randomised control trials have reported moderate to large effect sizes for ACT, further research, and further meta-analyses are need to examine the potential benefits of ACT as an intervention in FMS.

Whilst it is widely accepted that psychological approaches are a key part of treatment of FMS, the particular psychological approach and the mechanisms of change through the psychological interventions are not clear (Lami et al., 2013). In

addition to the need for improved quality of evidence, Lami et al. therefore recommended that research on psychological treatments for FMS should focus in particular on which components of treatment are effective, and for whom. Perhaps by understanding the mechanisms of treatment, it would be possible to design interventions that better target mechanisms of change which may result in larger improvements following treatment.

In an uncontrolled trial (n=72), a psychological intervention was developed and tested which aimed to specifically target emotional awareness and expression in adults with musculoskeletal pain (Burger et al., 2016). In this study, it was found that emotional awareness, emotional approach coping (defined as the understanding, validating and acknowledge of emotions as well as valuing the expression of emotions) and alexithymia all changed significantly from baseline to post-intervention suggesting that this intervention did influence change in these variables. However, Burger et al. did not control for changes in affective distress when measuring changes in emotional approach and emotional awareness. It may be that the intervention simply reduced distressed which resulted in fewer unpleasant or difficult emotions needing to be aware of or expressed.

Furthermore, increases in emotional awareness were related to decreases in measures of pain at post-treatment and at follow-up. Increases in emotional approach were related to decreases in depressive symptoms and psychological distress at post-treatment, though not at follow-up. All effect sizes were small, ranging from .24 to .35 and this study did not have a control condition. However, this evidence seems to suggest emotional variables as mediators in treatment for FMS and it is possible that these emotional variables are addressed in existing group therapies. The role of these potential process variables has not been tested in current third-wave treatments for

FMS. Research on NHS prescribed interventions in relation to emotional expression is therefore needed.

Given the prior mediation evidence on the role of emotional suppression and beliefs about emotions in FMS and the evidence that psychological therapies may be beneficial to individuals with FMS, the current study aimed to assess the extent to which changes in these particular beliefs and behaviours, from before to after psychological intervention, are associated with changes in outcome, thus potentially being a mechanism of change for people with FMS.

Beliefs about emotions, emotional suppression, affective distress and global impact were therefore measured before, immediately after and 12 weeks after individuals with FMS received psychological treatment in the NHS. The particular psychological intervention used was not the focus of the study, as each cognitive behavioural approach could focus to a greater or less extent on beliefs and/or behaviours related to emotional suppression. The focus of the study was on the association between changes in beliefs and behaviours and outcomes. It is also worth noting that the psychological interventions were all group-based, and as such, afford the opportunity for individuals to express thoughts and feelings to others. It is thus possible that the group processes may also result in changes in beliefs about emotions and emotional suppression even if this is not a specific focus of the intervention.

Furthermore, the study aimed to replicate the mediation findings of Chapter Five in a clinical sample, based on evidence that emotional suppression can result in an ‘ironic’ increase in distressing emotions (Wenzlaff & Wegner, 2000). It was found in Chapter Five that beliefs about emotions was related to more emotional suppression, which was in turn related to an increase in affective distress which was related to higher impact of FMS on a person’s life. This indirect effect was therefore tested in

the current study (using data from only the first time point) in order to uncover whether this finding can be replicated in a clinical sample.

7.1.1. Hypotheses

1. The relationship between beliefs about emotions and global impact will be mediated by emotional suppression and then affective distress (all measured at the first time point).

2. There will be a significant reduction in beliefs about the unacceptability of emotions and emotional suppression following the intervention. This reduction will be maintained at 12 weeks' follow-up.

3. Changes in beliefs about the unacceptability of emotions and changes in emotional suppression will be related to changes in affective distress and changes in global impact.

4. Change scores between pre-treatment and post-treatment in beliefs about emotions, emotional suppression and affective distress will significantly predict changes in global impact from pre-treatment to follow-up.

7.2. Methods

7.2.1. Participants

In total, 79 participants (mean age=47.50, SD=11.01; 66 females) were recruited from NHS trusts in the south of England. Participants were patients referred to a clinical psychologist for psychological treatment for FMS. To be eligible for the study, participants must have had a diagnosis of FMS from either their GP or a rheumatologist.

Sample size calculations to detect changes in process variables over time were conducted using the effect size from Burger et al.'s (2016) uncontrolled trial measuring changes in emotional awareness and expression (Cohen's $d=.28$ for changes in emotional approach coping from baseline to follow-up). Using G Power calculations for this comparison between two means (as Burger et al. did not report sufficient information for the calculation of main effect sizes) a sample size of 81 participants is recommended to achieve .8 power.

Sample size calculations for correlations between changes were based on the correlation coefficient from Burger et al.'s correlation between changes in emotional approach coping and changes in psychological distress ($r=-.27$). Using G power with the desired power level set to .8, 81 participants were recommended. The current study therefore aimed to recruit 81 participants to achieve statistical power.

7.2.2. Treatment

Participants underwent a pain management group programme as part of their standard care after referral to an NHS pain management team. The particular content of the pain management programme varied across NHS sites, and the details of the psychological approach was determined, using current evidence-base, by the clinical psychologist and their team. Participants were not randomised into treatment groups and treatment groups were not compared for the purpose of the current study.

There were four collaborators on this project who recruited participants for this study. This meant participants received four variations of psychological therapy. All groups were jointly run by a clinical health psychologist and a specialist pain physiotherapist. All psychological interventions were in a group setting and used second and third wave CBT. Three of the collaborators used an integrative approach

while one primarily used ACT and MBCT. Two of the pain management programmes used in this research were offered specifically to participants with FMS, while the other two were for patients with chronic pain more broadly. The number of sessions ranged from six to nine with the lengths of sessions being two or three hours each. Group sizes varied with the smallest group containing four patients and larger groups containing ten patients.

All four variations of the therapies discussed mindfulness, goal-setting, values, boom-and-bust or pacing activity, education about pain and how it is processed, managing unhelpful thoughts, advice on exercise and sleep. One group also covered communication and self-compassion. Another was geared more towards mindfulness compared with other groups. Two of the groups included discussions and information about medication.

7.2.3. Procedure

Participants were notified of the study by post in advance of their first session of the pain management programme. Participants were informed of their right to withdraw and that doing so would have no impact on their treatment with the service. This experiment received ethical approval from the psychology departmental ethics committee at Royal Holloway and from the NHS Research Ethics Committee (REC ref: 14/WM/1003).

Participants were given a questionnaire pack by their therapist either before or during their first session of the intervention, at the final session of the intervention and then again 12 weeks after the intervention either at a follow-up meeting, by post or online. The questionnaire pack included an information sheet, consent form, demographic questions, the BES, CECS, HADS and FIQR (see section 2.2, page 59

for details on these measures). Internal consistency of the four scales was examined and found the BES (Cronbach's alpha=.909) and FIQR (Cronbach's alpha=.909) has excellent internal consistency, while the CECS (Cronbach's alpha=.800) and HADS (Cronbach's alpha=.881) had good internal consistency. Participants were asked demographic questions regarding sex, age, nationality, education level, employment status and ethnicity. Questionnaires were given either by the researcher, the clinical psychologist leading the group or by the physiotherapist at the group.

7.2.4. Design and Statistical Analysis

This quasi-experimental design compared scores across three time points in individuals who were allocated non-randomly to treatment. The independent factor was therefore time and there were four dependent variables: beliefs about the unacceptability of emotions, emotional suppression, affective distress and global impact.

Hypothesis one was an attempt to replicate the cross-sectional mediation model of Chapter Five and was tested using model six in Process to test a mediation model with serial mediators in one path (Preacher & Hayes, 2004). As in Chapter Five, the predictor was beliefs about emotions and the outcome was global impact. The two mediators were emotional suppression and affective distress, in that particular order. All measures for this model were taken from the first time point which had the largest number of participants.

Before correlating changes in measures, it was first tested whether beliefs about emotions and emotional suppression changed significantly during the interventions. Hypothesis two was therefore tested using a linear mixed model to test the main effect of a repeated measures factor whilst accounting for a covariate. This method was

chosen over a one-way repeated MANOVA due to missing data across different time points. By using linear mixed modelling, all participants are analysed, even if they did not complete all time points. It uses all observed data by allowing varying intercepts and slopes for each individual participant and does not require imputation of missing data (Muth et al., 2016; Peters et al., 2012). This improved the power of the current study despite the inability to reach the desired sample size across all three time points.

The repeated measures fixed factor in the linear mixed model was time with three levels (pre-intervention, post-intervention and follow-up). The dependent variables were beliefs about the unacceptability of emotions and emotional suppression. Individuals' affective distress scores across each time point were entered as a covariate in order to explore changes in beliefs about emotions and emotional suppression that are not explained by a reduction in affective distress. Due to testing multiple dependent variables individually as opposed to in one MANOVA, Bonferroni corrections were applied and the alpha level for this particular test for the main effects was therefore set to .025 (.050/2).

For this linear mixed model, the covariance type was set to compound symmetry as this covariance type is suitable for repeated measures due to the greater likelihood of equal variances and covariances. Furthermore, it retains power compared to other covariance types due to its larger degrees of freedom (Jennrich & Schluchter, 1986; Littell, Pendergast, & Natarajan, 2000). Significant main effects were broken down using Bonferroni post-hoc comparisons as planned comparisons were not available in linear mixed modelling in SPSS.

To test hypothesis three, change scores were calculated for all four dependent variables. These scores were the difference between the first and second time point.

The change scores were then entered into a bivariate correlation matrix using Pearson's correlation.

A hierarchical regression model was used to test hypothesis four. Change scores calculated as the difference between pre- and post-treatment for beliefs about emotions, emotional suppression and affective distress were entered as predictors. In block one, beliefs about emotions was the sole predictor, emotional suppression was added in block two and affective distress in block three. The outcome variable was the change in global impact scores between pre-treatment and follow-up.

7.3. Results

7.3.1. Sample Characteristics

Sample characteristics as measured by these questions are presented in Table 7.1. Of the 79 participants who took part, only 21 completed questionnaires at all 3 time points (see Figure 7.1 for attrition rates). One participant was excluded from the analysis as this participant's global impact score worsened by 28 points (out of a total score of 100 on the FIQR) over the course of the study to the extent that the calculated difference between pre-treatment and follow-up was two standard deviations above the mean difference score. Means and standard deviations for all variables are presented in Table 7.2.

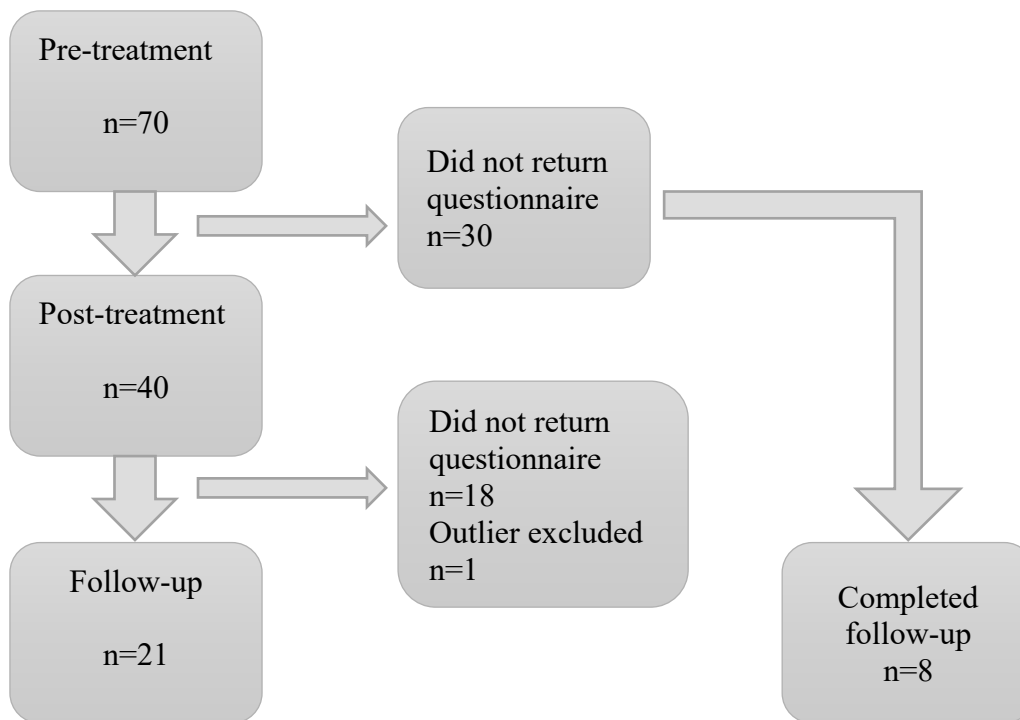


Figure 7.1 Flow chart of participation throughout the study

Table 7.1 Sample characteristics

| Variable | N | (%) |
|------------------------------------|-------|---------|
| Age: Mean years (S.D) | 47.50 | (11.01) |
| Sex | | |
| Female | 64 | (91.4) |
| Ethnicity | | |
| Caucasian | 60 | (85.7) |
| Mixed White and Black Caribbean | 1 | (1.4) |
| Mixed White and Black African | 1 | (1.4) |
| Indian | 2 | (2.9) |
| Black/African/Caribbean | 1 | (1.4) |
| Any other ethnic group | 1 | (1.4) |
| Highest education level | | |
| Senior/secondary school (up to 16) | 23 | (32.9) |
| Sixth form/college (up to 18) | 28 | (40.0) |
| University undergraduate | 8 | (11.4) |
| University postgraduate | 9 | (12.9) |
| Employment | | |
| Full time employee | 12 | (17.1) |
| Part time employee | 12 | (17.1) |
| Full time student | 0 | (0.0) |
| Part time student | 1 | (1.4) |
| Self-employed | 5 | (7.1) |
| Unemployed | 38 | (54.3) |

Table 7.2 Means and standard deviations for beliefs about emotions, emotional suppression, affective distress and global impact

| | Pre-treatment | | Post-treatment | | Follow-up | |
|------------------------|---------------|-------|----------------|-------|-----------|-------|
| | M | SD | M | SD | M | SD |
| Beliefs about emotions | 45.36 | 13.72 | 40.44 | 15.18 | 38.40 | 16.53 |
| Emotional suppression | 55.83 | 11.85 | 55.23 | 14.75 | 52.52 | 11.18 |
| Affective distress | 22.36 | 8.13 | 20.58 | 6.28 | 19.10 | 9.00 |
| Global impact | 69.23 | 14.04 | 62.34 | 17.13 | 62.98 | 18.55 |

Participants who completed all three time points' baseline scores were compared with participants who completed two time points and those who completed just one. None of the groups were significantly different on baseline measures. Descriptive statistics can be found in Table 7.3.

Table 7.3 Descriptive statistics of baseline scores for participants who completed one, two and three of the three time points.

| | Completed all three time points | | Completed two time points | | Completed one time point | |
|------------------------|---------------------------------|-------|---------------------------|-------|--------------------------|-------|
| | M | SD | M | SD | M | SD |
| Beliefs about emotions | 43.31 | 17.65 | 45.72 | 12.90 | 45.78 | 12.48 |
| Emotional suppression | 58.40 | 13.44 | 55.83 | 12.26 | 52.60 | 11.19 |
| Affective distress | 21.31 | 6.38 | 22.71 | 8.24 | 23.18 | 8.98 |
| Global impact | 66.41 | 13.18 | 70.01 | 16.08 | 72.55 | 11.97 |

7.3.2. Hypothesis one: Mediation

Using the Process plug-in for SPSS, a serial mediation model was tested using model six using data from all participants in the first time point (the pre-treatment phase). Emotional suppression and affective distress did not serially mediate the

relationship between beliefs about emotions and global impact before the intervention (standardised indirect effect = .0288). The indirect effect was .0271 and was not significant (95% CI [-.0051, .1205]) (see Figure 7.2 for coefficients).

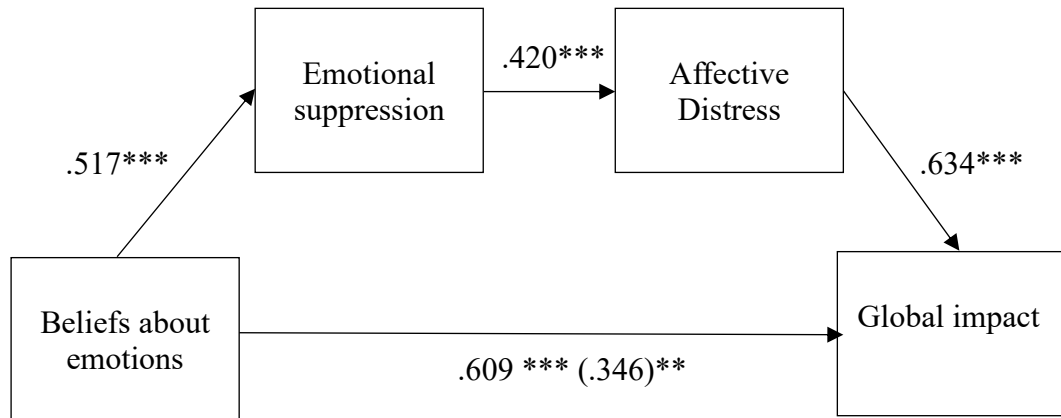


Figure 7.2 Standardised coefficients for paths in the serial mediation model

Note: * $p < .050$, ** $p < .010$, *** $p < .001$

7.3.3. Hypothesis two: Changes over time

Four linear mixed models were tested using repeated measures. The within-participants fixed factor was time and the four dependent variables were beliefs about emotions, emotional suppression, affective distress and global impact.

There was a significant main effect of time on beliefs about emotions after controlling for affective distress ($F(2, 82.390) = 5.941, p = .004$) where beliefs about emotions decreased after the intervention ($p = .011$) and did not change from post-intervention to follow-up ($p = 1.000$). The difference between pre-treatment and follow-up was also significant ($p = .034$). See Table 7.4 for descriptive statistics. There was however no significant effect of time on emotional suppression scores after controlling for affective distress ($F(2, 67.146) = 1.784, p = .176$).

7.3.4. Hypothesis three: Changes in processes are related to changes in outcomes

Before correlating changes in beliefs about emotional suppression and affective distress with outcomes, linear mixed modelling was used (as for hypothesis two) to determine whether affective distress and global impact did significantly change during the study.

Affective distress scores significantly changed over time ($F(2, 42.371)=4.771, p=.010$). There was a decrease in affective distress after the intervention compared to pre-treatment scores ($p=.018$). Comparisons between pre-treatment and follow-up were not significant ($p=.085$) though were approaching significance with a trend towards lower scores at follow-up compared with pre-treatment. There was no significant change in affective distress from post-treatment to follow-up ($p=1.000$).

Global impact scores significantly reduced over time ($F(2, 72.337)=8.307, p=.001$), with scores being significantly lower at post-treatment ($p=.001$) and follow-up ($p=.040$) compared with pre-treatment. The difference between post-treatment and follow-up was not significant ($p=1.000$).

Table 7.4 Estimated marginal means and standard error for the three treatment times for each of the four measures.

| | BES | | CECS | | HADS | | FIQr | |
|----------------|-------|------|-------|------|-------|------|-------|------|
| | M | SE | M | SE | M | SE | M | SE |
| Pre-treatment | 45.09 | 1.75 | 56.47 | 1.68 | 22.44 | 0.95 | 69.57 | 1.81 |
| Post treatment | 38.96 | 2.13 | 54.55 | 1.81 | 20.16 | 1.07 | 63.77 | 2.03 |
| Follow-up | 39.09 | 2.40 | 53.79 | 1.95 | 20.40 | 1.16 | 65.28 | 2.18 |

Change scores for each dependent variable were calculated in SPSS based on subtracting the pre-intervention scores from the post-intervention scores (see Table

7.5 for means and standard deviations of change scores). The difference between pre-intervention and post-intervention scores (n=40) were chosen over follow-up scores (n=30) due to the high attrition rate meaning a reduction in power when using the later time point.

Table 7.5 Mean and standard deviation of the change scores for each measured variable.

| | Mean | SD |
|------------------------|-------|-------|
| Beliefs about emotions | -5.43 | 15.19 |
| Emotional suppression | -1.98 | 7.99 |
| Affective distress | -2.17 | 5.19 |
| Global impact | -5.36 | 10.42 |

Changes in beliefs about emotions were significantly positively related to changes in emotional suppression but not affective distress (though this was approaching significance) or global impact. Emotional suppression was not related to changes in global impact, but was related to changes in affective distress. Changes in affective distress were strongly related to changes in global impact. See Table 7.6 for correlation coefficients and p values.

Table 7.6 Correlations between change scores for each variable comparing pre- and post-treatment

| | CECS | | HADS | | FIQ | |
|------|------|------|------|------|------|-------|
| | r | p | r | p | r | p |
| BES | .378 | .019 | .307 | .054 | .061 | .714 |
| CECS | - | - | .334 | .041 | .105 | .538 |
| HADS | - | - | - | - | .543 | <.001 |

7.3.5. Hypothesis Three: Predicting later global impact

A hierarchical regression model was tested where changes between pre-treatment and post-treatment in beliefs about emotions (block one), emotional suppression (block two) and affective distress (block three) were predictors of changes in global impact between pre-treatment and follow-up. This hierarchical model was used to investigate the individual contribution of each variable included in Chapter Five's mediation model before and after accounting for the next variable in the model. Due to attrition rates and missing data, only 20 participants were tested in this model.

There was no evidence of multicollinearity in the model (BES tolerance=.592, VIF=1.69; CECS tolerance=.69, VIF=2.709; HADS tolerance=.535, 1.871) (see Table 7.7 for zero order correlations between predictors and the outcome). Residuals were roughly randomly distributed across the continuum and were normally distributed. No outliers of the model were identified.

Model one, where changes in beliefs about emotions from pre-treatment to post-treatment is the sole predictor, was not significant ($F(1,18)=.769$, $p=.392$) and explained 0% of the variance in changes in global impact from before treatment to follow-up. Adding changes in emotional suppression to the model did not significantly improve the model (F change $(1,17)=1.262$, $p=.277$) with the model not significantly predicting changes in global impact from pre-treatment to follow-up ($F(2,17)=1.021$, $p=.381$), explaining 0.2% of the variance in changes in global impact.

Adding changes in affective distress between pre-treatment and post-treatment as a predictor in the model did not significantly improve the model (F change $(1,16)=1.736$, $p=.206$). The overall model with all three predictors was not significant ($F(3,16)=1.290$, $p=.312$) explaining 4.4% of the variance in the changes in global

impact from pre-treatment to follow-up. Unstandardized coefficients are presented in Table 7.8.

Table 7.7 Correlations between predictors and outcomes for participants included in the model

| | CECS | | HADS | | FIQ | |
|------|------|------|------|------|------|------|
| | r | p | r | p | r | p |
| BES | .639 | .001 | .395 | .054 | .217 | .179 |
| CECS | - | - | .689 | .001 | .107 | .327 |
| HADS | - | - | - | - | .038 | .437 |

Table 7.8 Unstandardized regression coefficients for individual predictors for each block of the model.

| Block | Variable | B | t | p |
|-------|----------|-------|--------|------|
| 1 | BES | .126 | 0.877 | .392 |
| 2 | BES | .257 | 1.395 | .181 |
| | CECS | -.342 | -1.123 | .277 |
| 3 | BES | .287 | 1.566 | .137 |
| | CECS | -.652 | -1.718 | .105 |
| | HADS | .601 | 1.319 | .206 |

7.4. Discussion

The current study aimed to investigate beliefs about emotions, emotional suppression, affective distress and global impact before and after psychological treatment for FMS. The current study did not find support for the mediation model evidenced in Chapter Five, finding that the relationship between beliefs about emotions and global impact was not mediated by emotional suppression and affective distress, all measured before treatment.

Beliefs about emotions were significantly lower after the intervention compared to pre-treatment and stayed significantly lower at follow-up. However emotional suppression scores did not change. Changes in beliefs were correlated with changes in emotional suppression and there was a marginally significant correlation with changes in affective distress. Emotional suppression changes were correlated with changes in affective distress, which in turn was correlated with changes in global impact. However, changes in beliefs about emotions, emotional suppression and affective distress from pre-treatment to post-treatment did not predict changes from pre-treatment to follow-up in global impact.

Using only the questionnaires taken before treatment, the mediation model found in Chapter Five was tested in the current sample. The current study did not find support for this model with the relationship between beliefs about emotions and global impact having no significant indirect effect via emotional suppression and affective distress. This suggests that perhaps there is something distinct about this clinical sample which is different from the previous online sample where those attending secondary care do not show evidence of this ironic processing path. Instead they may show a different pattern with regards to the relationship between beliefs about emotions and global impact.

It is possible that those who are receiving psychological treatment for FMS may be struggling more than those recruited online and as such, the relation between beliefs about emotions and global impact may be different. Interestingly, there was a significant direct positive relationship between beliefs about emotions and global impact in this sample (see Figure 7.2) which this was not found in Chapter Five. Again, it appears that this clinical group are different from the online sample regarding the role of beliefs about emotions. This may reflect possible subgroups within the wider

FMS population where for some emotional suppression is related to more negative affect, while for others this is not the case (López-Cicheri et al., 2013). The exact implications of these differing relationships for each subgroup should be investigated further with regards to treatment as it appears there may be other mediators of this direct relationship between beliefs about emotions and global impact.

Alternatively, it may be that the current study lacked statistical power due to the small sample size and therefore was unable to detect the significant mediation (which has a small effect size) but was sufficiently powered to detect the direct relationship.

There were significant reductions in beliefs about emotions immediately after treatment which were maintained at follow-up after controlling for affective distress. This suggests that there were changes in these beliefs beyond just experiencing less distress and thereby being more willing to express and experience this lower level of distress. This supports Burger et al.'s finding that valuing emotional expression can change during intervention and further demonstrates that this change may be independent of changes in affective distress. This finding indicates firstly that beliefs about emotions may be changed through psychological group interventions and secondly that existing interventions are modulating these beliefs (though comparison with a control group to rule out any significant changes over time not attributable to treatment is necessary).

On the basis of this research, it is difficult to draw conclusions regarding what may have led to changes in beliefs about emotions due to the integrative and varied nature of the psychological interventions. One possible explanation for this is that these psychological group therapies all involve an element of sharing thoughts and feelings within a group, which provides an opportunity for individuals to be more expressive and receive positive or helpful responses to this expression, which then

modulate beliefs about the unacceptability of expressing emotions. Beliefs may therefore change as a result of practicing being more expressive in these group settings. However, if this were the case, emotional expression would have been expected to also change. Either beliefs were not changed through this mechanism, or somehow despite beliefs changing, this did not translate into behavioural changes outside of the context of treatment.

Alternatively, the content of these interventions did in part revolve around the idea of acceptance. While the focus in some cases may have been more on the acceptance of pain, mindfulness and ACT based discussions around acceptance of emotions in relation to pain also may have been discussed. This may have then influenced patients' beliefs about the unacceptability of expressing emotions through encouraging the acceptance of emotions. The second wave CBT aspects of the psychological intervention focuses on unhelpful behaviours around the experience of emotions (e.g. emotional avoidance), and individuals may have focused on beliefs about suppressing emotions. In one group, time was spent discussing 'communication', which may also have resulted in changes in beliefs about sharing emotions.

Emotional suppression did not change during or after the intervention which is unexpected, especially given that beliefs about the unacceptability of expressing emotions did change. As previously stated, it could be that patients were willing to be more emotionally expressive within the context of the group (and this may have influenced beliefs) but this did not extend beyond the group sessions and therefore was not reflected in the questionnaire which asks how one behaves most of the time. Alternatively, if greater acceptance more generally explains the changes in beliefs about emotions, it is possible that emotional suppression was not influenced and

instead only beliefs about this changed. In this case, other factors which may influence emotional suppression beyond beliefs about the unacceptability of expressing emotions should be explored in future research. Furthermore, given that changes in emotional suppression were significantly related to changes in affective distress, research on treatments which encourage emotional expression in addition to addressing beliefs may result in longer term improvements in distress, which was not found in this study.

The changes in each variable from pre-treatment to post-treatment were tested for bivariate correlations to test the extent to which changes in beliefs about emotions and emotional suppression were related to changes in affective distress and global impact. Changes in beliefs about emotions and emotional suppression were related which suggests that as beliefs change, so might behaviour (though emotional suppression did not significantly change in the current study). Changes in emotional suppression were correlated with both changes in affective distress and changes in beliefs about emotions. Changes in beliefs about emotions showed a trend that was approaching significance where changes in beliefs were related to changes in affective distress. This is in line with Burger et al. (2016) who found that changes in emotional approach coping were related to changes in psychological distress but not pain in an intervention aimed at addressing emotional awareness and coping. Interestingly, Burger et al. found that changes in emotional awareness and alexithymia were related to changes in pain. Perhaps future research should measure awareness of emotions and alexithymia as process variables in NHS psychological treatments for FMS as these may be related to changes in global impact, while beliefs about emotions and emotional suppression were not.

Changes in emotional suppression related to changes in affective distress and changes in affective distress related to changes in global impact. These correlational findings support the expected relationships of the mediation model outlined in Chapters Four and Five. However, these correlations were bivariate and therefore each correlation did not account for variance explained by other variables included in the correlation matrix. This would need to be explored using mediation analyses to fully test the proposed effects of beliefs about emotions on global impact via emotional suppression and affective distress. The current study's high attrition rate however meant that the sample size was insufficient for tests of mediation across the three time points.

Before testing the correlations between changes from pre-treatment to post-treatment between processes and outcomes, the current study tested whether the outcomes (affective distress and global impact) significantly changed with treatment. Global impact, like beliefs about the unacceptability of emotions, significantly improved (i.e. reduced) during the intervention and was still significantly lower at follow-up which suggests that the treatments provided lasting improvements to the individuals' lives (though a control group would be useful in ruling out any effects not directly related to the psychological intervention, such as group processes). This supports previous research that psychological interventions are beneficial to individuals with FMS (Bernardy et al., 2013; Hann & McCracken, 2014; Lauche et al., 2013; Luciano et al., 2014). Affective distress significantly reduced during the intervention, though this difference was not maintained at follow-up (but it was approaching significance). This suggests that perhaps there was a slight worsening for some participants during the follow-up period to the extent that the difference between pre-treatment and follow-up did not reach significance: The small sample size of this

study and the high attrition rate might have meant that the test was underpowered when testing for the significance of the difference between pre-treatment and follow-up and therefore may have been more affected by a slight worsening during the follow-up period than if there had been a larger sample. Looking at the estimated marginal means, the worsening from pre-treatment compared to post-treatment is very small which indicates that statistical power was a key issue as opposed to there being a substantial worsening in affective distress.

Regardless, the difference between pre-treatment and follow-up is not statistically significant, therefore it would be useful to explore the possible factors which may lead to worse outcomes following an intervention. For example, it might be that some individuals revert back to previous ways of thinking and/or behaving following the intervention. Alternatively, other factors external to the intervention such as stressful life events may result in more distress. Changing beliefs about the unacceptability of emotions may work to buffer the effects of distress on a person's life, thus while distress did not remain significantly reduced at follow-up, global impact remained lower, and beliefs about emotions were still significantly lower at follow-up.

A regression model was also tested in which changes in beliefs about emotions, emotional suppression and affective distress between pre-treatment and post-treatment were predictors and changes in global impact from pre-treatment to follow-up was the outcome variable. This was conducted to test whether earlier changes in predicted processes can predict later changes in global impact. By implementing a clear timeline (using earlier changes to predict later changes), it is possible to further evaluate the proposed direction of causality put forward in this thesis.

It was expected that changes in beliefs about emotions, emotional suppression and affective distress would predict later changes in global impact. However, none of the predictors were significant. It is likely that only having 21 participants who had scores at all three time points meant this test was under powered. Further investigation is needed in a study where fewer participants drop out of the study. It may be useful in future to control for baseline scores on the outcome measure (i.e. the FIQR) to account for individual differences in the severity of the condition.

A substantial issue with the current study is the low sample size. This was in part due to issues during the recruitment and data collection at certain sites and also due to attrition of participants throughout the study. While some attrition was expected, the number of participants with data at all time points was not expected to be less than 50% of the sample. In the current study, it was 27%. This does not appear to be due to characteristics of the participants (at least with regards to those measured in the current study). Many of the participants were invited to take questionnaires home and return them by post for the post-treatment and follow-up time points, which may have meant participants were likely to forget to complete the questionnaire and also forget to post it. This meant that many questionnaires were not returned to the researcher. There were no set guidelines given to therapists regarding reminding participants to complete their questionnaires either by post or online. While some therapists did send email reminders or contact participants by phone, others did not, which may explain why many participants did not complete questionnaires at the second and third time points⁴. The number of completers therefore differs between therapists, meaning

⁴ The number of 'completers' varied between the therapists at the different sites: 5.6%, 40.9%, 25% and 80% of the participants completed all of the questionnaires in each therapist group.

therapist effects should be investigated in future research where the sample size is sufficient.

A better method would have been to collect questionnaires in person at the therapy sessions, however this was not always feasible within the timeframe allocated to each therapy session. To address this issue, participants later in the study were offered the option to complete the questionnaire online as it was thought this would be less demanding of the participant and more convenient than posting a questionnaire. This method however was rarely used by participants and therefore did not adequately address the attrition rates.

Linear mixed modelling meant that the differences between the different time-points were still sufficiently powered as participants were not excluded on the basis of having missing data. However, correlation and regression analyses could not account for this issue and were therefore likely underpowered. The current study therefore has not supported the proposed model whereby changes in beliefs about emotions result in reduced global impact via a reduction in emotional suppression and consequent affective distress. Further research with much larger samples to account for attrition would need to be conducted.

It may also be of interest for future research to account for or even explore the effects of different interventions. With a larger sample, it would have been possible to explore the four intervention groups as a second independent variable to see if perhaps one intervention elicits greater changes in beliefs about emotions and emotional suppression compared to others and to account for therapist effects. In future research exploring this model, it may be useful to also include the BASIE given that Chapter Six has shown this to be related to outcomes in FMS. The BASIE was however not

fully developed or validated at the time of data collection in the current study and was therefore not included.

The current study did not find evidence that changes in beliefs about emotions and emotional suppression are related to changes in affective distress and global impact, meaning that the findings do not support the role of emotional suppression and beliefs about emotions as processes of change in psychological therapy for FMS. However, the lack of power in the correlational analyses might explain why the correlational findings of the current study were not significant yet beliefs about emotions did change during the intervention and maintain lower at follow-up. This indicates the value in continuing to explore these beliefs in relation to treatment.

8. Chapter Eight: An intervention addressing beliefs about emotions and emotional suppression: A single case series

8.1. Introduction

Throughout this thesis, a role of emotional suppression in IBS has been evidenced in previous as well as the current studies. Ali et al. (2000) found in a small sample that individuals with IBS (n=25) scored higher on a measure of self-silencing compared to a reference value (which aimed to represent the general population) and compared with individuals with IBD (n=25). In the current thesis (see Chapter Three and Four, pages 83 and 96), emotional suppression was not found to be different between those with IBS and healthy controls or those with IBD.

Emotional expression has been used as a therapeutic technique in persistent physical symptoms such as FMS. As discussed in Chapter One (Section 1.4, page 44), asking participants with FMS to write emotively (compared to controls who wrote about neutral topics) has been shown to elicit improvements in symptoms and quality of life (Broderick et al., 2005; Gillis et al., 2006).

This finding has been replicated in an uncontrolled pilot study in 103 participants with IBS (Halpert et al., 2010). While the pilot study did not use a control group, individuals who completed the intervention (n=82) were compared to those who did not complete the intervention (n=21). These comparisons revealed a difference between the two groups with regards to changes from baseline to three-month follow-up. However, these group differences were only found in measures of functional bowel disease cognitions and symptom severity – although the writing group showed improvements in quality of life at three-month follow-up, and the non-

writers showed no improvements, the difference between groups was not statistically significant.

Overall, these three studies on written emotional disclosure support the idea that interventions encouraging more emotional expression could be beneficial to participants with IBS, though more rigorous testing with a larger sample and a control group is warranted. Furthermore, these studies did not measure changes in beliefs surrounding emotional expression even though it has been suggested that changes in beliefs may play a role in the influence of emotional expression on outcomes (Gillis et al., 2006; see Chapter Three of this thesis, page 78).

Previous research in this thesis (See Chapter Four, page 96) found that individuals with IBS report more belief that expressing emotions is unacceptable when compared with healthy controls (though not when compared to individuals with IBD) and that this difference is no longer statistically significant after accounting for affective distress. Though this suggests that affective distress might explain this group difference in beliefs about the unacceptability of emotion, the initial finding that these beliefs are more prevalent in IBS, along with evidence from this thesis that these beliefs are related to poorer outcomes, suggests a need to explore these beliefs as a target in interventions for IBS.

Further to this, Chapter Four demonstrated evidence that the relationship between beliefs about emotions and quality of life in IBS is mediated serially by emotional suppression and affective distress in that particular order. This finding supports a proposed model in which believing the expression and experience of emotions to be unacceptable is related to an increase in actual emotional suppression. This in turn is associated with an increase in affective distress and subsequently a decrease in quality of life.

While this proposed model posits a causal direction, the previous evidence in this thesis has used correlational methods. To fully evaluate this proposed direction of causality, an experimental method with a timeline is necessary. Furthermore, given the need to understand the role of these beliefs about emotions and emotional suppression within the context of psychological interventions, it is paramount to investigate whether targeting these variables using cognitive behavioural techniques results in improvements in distress and quality of life for those with IBS.

The current study aimed to test whether beliefs about emotions and emotional suppression could be adapted and whether efforts to adapt these would result in changes in distress and quality of life. A cognitive behavioural approach was chosen as there is a body of evidence on psychological interventions in IBS, with more evidence for CBT than other therapies: A systematic review of 15 randomised control trials testing psychological treatments for IBS found moderate to large improvements in quality of life (as well as symptom severity) across a range of treatments, with seven of the included studies looking at CBT, two studies examining cognitive therapy, two behavioural therapy, and four further studies looking at stress-management, psychodynamic therapy, mindfulness and psychoeducation (Altayar et al., 2015). When comparing findings of studies that evaluated CBT with studies that evaluated other psychological interventions, there was no significant difference in treatment effects. Thus, this suggests that the use of psychological intervention, with more studies reported for cognitive behavioural therapy (CBT), may be beneficial for those with IBS.

In the previous chapter (Chapter Seven) it was found that beliefs about the unacceptability of emotions reduced following psychological treatment for FMS, suggesting these beliefs can be addressed therapeutically, even when the focus on the

intervention was not specifically on beliefs and behaviours around emotional expression. It was argued in the previous discussion that addressing emotionally suppressive tendencies (which did not change in the treatment for FMS) in addition to beliefs about expressing emotions might result in longer lasting reductions in distress on a person's life.

The current study therefore explores the effects of an intervention using cognitive behavioural techniques aimed at reducing emotional suppression through addressing beliefs about the unacceptability of expressing emotions and emotionally suppressive behaviours. This intervention focuses more specifically on these factors so as to test the model which to this point has been supported using cross-sectional correlational designs. Further to this, the current study will explore changes not just in outcome measures (namely quality of life) but will also investigate changes in the proposed mechanisms of beliefs about the unacceptability of emotions, emotional suppression and affective distress.

8.1.1. Hypotheses

The current study therefore evaluated a group-based cognitive behavioural intervention designed to address beliefs about the unacceptability of expressing and experiencing emotions and emotional suppression. Based on the above evidence four hypotheses can be proposed:

1. There will be a significant reduction in beliefs that expressing and experiencing emotions is unacceptable following the intervention.
2. There will be a significant reduction in emotional suppression following the intervention.

3. There will be a significant reduction in affective distress following the intervention.

4. There will be a significant improvement (i.e. an increase in scores) in quality of life following the intervention.

8.2. Methods

8.2.1. Participants

Eleven participants were recruited online through campus webpages, local online forums and IBS-focussed forums and social media. Five of those participants responded to the recruitment email providing further information about the study. One of those five withdrew from the study early in the pre-treatment phase. This resulted in a sample of four female participants (mean age=45.5, SD= 9.75) all of whom had been diagnosed with IBS by a clinician and met three or more of the Manning Criteria for Irritable Bowel. Only results from these four participants are discussed.

The idea of selecting participants who scored highly on the BES and CECS was discussed however once recruitment had started, it was realised that the response rate was low. Thus, the four participants who responded and consented to take part were involved in the current study.

Participants had symptoms of IBS for a mean of 19.75 years (SD=6.60) and had been diagnosed on average 18.25 years prior to the study (SD=6.50). Participants' age ranged from 31 to 52. One participant was Indian (with regards to both ethnicity and nationality) while the other three were White British and English. Education level ranged from sixth form/college in one participant to post-graduate in another participant. The remaining two participants were educated to undergraduate level.

8.2.2. Materials

Participants were initially given full copies of the BES, CECS, HADS and IBS-QoL (see section 2.2, page 59 for more details on these measures). The questionnaires were adapted to be idiographic measures in that they are designed to be used for a particular respondent (Haynes, Mumma, & Pinson, 2009). These idiographic questionnaires were created in order to reduce the burden on the participant who would be completing the questionnaire bi-weekly throughout the intervention and for up to eight weeks' follow-up. One of the methods for creating an ideographic measure is to select a subset of items from an existing standardised questionnaire. Given that an idiographic measure is designed to increase the relevance of an instrument to a particular individual (Haynes et al., 2009), after completing the full measures at the first time point, these questionnaires were reduced to include only the highest scoring items for that participant. As there is no set guideline for selecting items which will comprise an idiographic measure, it was decided (between the clinical health psychologist, a second clinical psychologist with experience in idiographic measures and myself) that higher scoring items on each measure reflect particular thoughts, feelings and behaviours that are problematic for that individual and as such, selecting these items would increase the relevance of the measure.

All items for which a participant scored the maximum possible score were included in their idiographic shortened questionnaire. For example, all items of the BES to which the participant responded "Totally agree" were included in their ideographic version of the BES. This meant participants completed variations of the questionnaires that varied in their number of items. For participants who either did not score any item at the maximum, or only scored one item at the maximum, the next

highest score was used. For example, for a participant who did not say “Totally agree” to any item on the BES, all items to which they responded “Very much agree” were used in their version of the BES.

8.2.3. Procedure

A five- session course was designed with an accompanying booklet (see Appendix G for full booklet). The key components of the course were developed in conjunction with the clinical health psychologist supervising the project.

This course aimed to address beliefs about emotions and emotional suppression in five 60-90 minute group CBT sessions, using CBT skills including Socratic questioning, identifying maintaining cycles considering helpful and unhelpful aspects of identified thoughts and behaviours, and testing out making changes. Session one provided an introduction to the course with brief education on IBS and an introduction to the relationship between stress and IBS symptoms, introducing the idea of a ‘vicious cycle’ between stress and symptoms. Session two focussed on the consequences of suppressing emotions as a long-term emotion regulation strategy, focussing on ironic processing effects, reduced social support and increased tension. Session three focussed on thought challenging and involved a discussion of the potential benefits to sharing emotions with others and asked participants to set goals. In this session, participants raised the issue of how one can cope with difficult emotions, if not avoid them and asked about relaxation techniques. As such, in this session relaxation techniques were briefly discussed. The goals set in session three were revisited in session four and the role of anxiety and avoidance in IBS was discussed. In this session participants were presented a ‘vicious cycle’ within the context of emotional suppression and beliefs about emotions (see Figure 8.1). This

session discussed acceptance of emotions and used exercises that are popular in ACT (i.e. Passengers on a Bus and The Unwelcome Party Guest) to encourage the acceptance of emotion. Session five provided a review of the course and covered managing setbacks and plans for the future (including setting more long term goals).

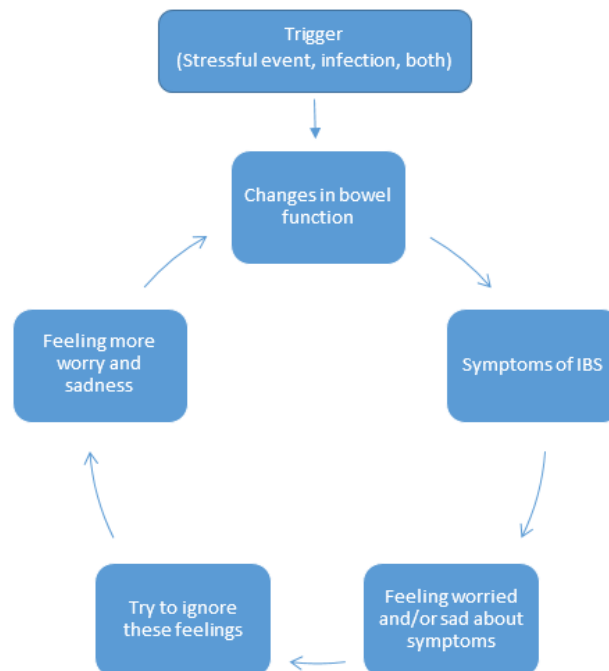


Figure 8.1 ‘Vicious cycle’ presented to participants in the fourth session

In addition to the weekly group sessions, each week participants were set home tasks that were designed to support their learning during the intervention.

It should also be noted that, as it was a group session, with significant participation from all of the individuals, the focus of the group work was not rigidly on beliefs and behaviours around emotional expression when participants raised other, related issues. For example, when individuals discussed expression of emotion to friends, this led to a discussion about letting friends/family know about the foods they could eat. These discussions, which were deemed helpful, were not ended in order not

to interrupt the flow and peer support from the group, but were steered back to beliefs and behaviours about emotional expression as appropriate.

Participants were reminded to complete the questionnaire twice per week across all three phases of the studies, though they did not always respond to this reminder. As such the number of data points and the length of time for each phase varied for each individual. The length of the baseline phase was also influenced by the date on which the individual started the study. Participants were paid for the completion of questionnaires. In order to encourage the completion of questionnaires, participants were paid £10 for every phase (of the three-phase experiment) for which they had completed all questionnaires.

At the end of the study, three of the four participants met for a semi-structured group interview (see Appendix L for transcript). The aim of the interview was to uncover the feasibility of the intervention and to find out if participants felt that they had improved as a result. The interview was conducted by the PhD student.

8.2.4. Design and Analysis

This study used an AB single case series design, where phase A is the pre-treatment phase and phase B is the treatment phase (Kratochwill et al., 2013). The pre-treatment or baseline phase consisted of five data points for three participants and four data points for one participant. This phase ranged from a duration of one week and one day to two weeks and two days due to some participants missing questionnaires at the beginning of this phase. The treatment phase consisted of two parts. Phase B1 was during the intervention and phase B2 was after treatment. Phase B1 comprised of between nine and thirteen data points across participants spread over nine weeks, while B2 comprised nine to twelve data points over a period ranging from seven weeks

and four days to eight weeks and four days depending on the participant completing their questionnaires on schedule.

The data were analysed using Tau-U non-overlap analysis to determine differences in levels and trends between phases by considering the proportion of data that is non-overlapping between phases. This analysis is specifically designed for single case research and uses all data points as opposed to averages (Willson et al., 2016). Comparisons were made for each participant individually (A vs B1 and B1 vs B2) for each of the four variables. Corrections for baseline trends were applied when a significant baseline trend was present. Weighted averages were then calculated for each of the four variables (weighted by the inverse of the variance of the Tau statistic) which reflects the overall non-overlapping data across all four cases. Significance was determined through examination of confidence intervals of the effect, where confidence intervals that do not contain zero indicate a significant proportion of non-overlap between phases.

Thematic analysis was conducted on interview data identifying themes after reading and coding the qualitative data. A research assistant also read, coded and identified themes in the data. The research assistant was kept blind to the aims of the research so as to avoid any potential bias. The research assistant and I then discussed and agreed upon themes found in the data.

8.3. Results

8.3.1. Attendance

All of the participants missed at least one session, which may be due to timetabling during working hours. If a session was missed, the participant(s) was caught up in person or by phone. The handbooks given to each participant covered the content of the sessions and therefore also supported those who missed a session. In

this sense, none of the participants missed any of the information given during the intervention.

8.3.2. Beliefs about emotions

Looking at the weighted average across participants, there was a significant reduction in BES scores during the intervention period (i.e. when comparing phase A with phase B1) and during follow-up (comparing phase B1 with B2). Confidence intervals and Tau statistics are presented in Table 8.1. Only one of the participants (case B) showed a decrease in BES scores when comparing phase A and phase B1 and this was maintained during follow-up (phase B2). However, cases A and C did show a reduction in BES scores during the follow-up period (phase B1 compared to phase B2). Case D showed no improvements from phase A to phase B1 and unexpectedly showed an increase in BES scores in the follow-up period (phase B1 compared to B2). See Figure 8.2 for participant scores over time.

Table 8.1 Tau statistics and confidence intervals for BES scores

| | Tau | SD Tau | <i>p</i> value | 85% CI |
|------------------|---------|--------|----------------|-------------------|
| Case A | | | | |
| A vs B1 | -0.4063 | 0.3680 | 0.2696 | -0.936 <> 0.124 |
| B1 vs B2 | -0.9219 | 0.2976 | 0.0019 | -1.350 <> -0.493* |
| Case B | | | | |
| A vs B1 | -0.5111 | 0.3333 | 0.1252 | -0.991 <> -0.031* |
| B1 vs B2 | -0.3457 | 0.2796 | 0.2164 | -0.748 <> 0.057 |
| Case C | | | | |
| A vs B1 | -0.3500 | 0.3162 | 0.2684 | -0.805 <> 0.105 |
| B1 vs b2 | -0.6429 | 0.2817 | 0.0225 | -1.049 <> -0.237* |
| Case D | | | | |
| A vs B1 | -0.4600 | 0.3266 | 0.1590 | -0.930 <> 0.010 |
| B1 vs B2 | 0.5545 | 0.2582 | 0.0317 | 0.183 <> 0.926* |
| Weighted Average | | | | |
| A vs B1 | -.4315 | | 0.0104 | -0.674 <> -0.189* |
| B1 vs B2 | -0.3112 | | 0.0260 | -0.513 <> -0.110* |



Figure 8.2 Beliefs about emotions over time for each case.

Note. Scores were converted to be on a scale from 0 to 100 so as to compare across cases.

8.3.3. Emotional suppression

Across the four cases there was a significant reduction in emotional suppression (as measured using the CECS) during the intervention (phase A compared with B1) and during the follow-up period (phase B1 compared with B2) (see Table 8.2 for Tau statistics and confidence intervals). As with beliefs about emotions, only one participant (case C) showed a reduction in CECS scores during the intervention (phase A compared with phase B). This continued to decrease during the follow-up phase (phase B1 compared with B2). For cases A and B, changes were not observed until the follow-up period where there was a significant reduction in CECS scores. Case D did not change on this measure of emotional suppression during the intervention or during follow-up. See Figure 8.3 for CECS scores over time for each case.

Table 8.2 Tau statistics and confidence intervals for CECS scores

| Case | Tau | SD Tau | <i>p</i> value | 85% CI |
|------------------|---------|--------|----------------|--------------------------------------|
| A | | | | |
| A vs B1 | -0.3438 | 0.3680 | 0.3502 | -0.874 \diamond 0.186 |
| B1 vs B2 | -1.0000 | 0.2976 | 0.0008 | -1.428 \diamond -0.572* |
| B | | | | |
| A vs B1† | -0.3556 | 0.3333 | 0.2861 | -0.836 \diamond 0.124 |
| B1 vs B2 | -0.5309 | 0.2796 | 0.0576 | -0.934 \diamond -0.128* |
| C | | | | |
| A vs B1 | -0.5833 | 0.3162 | 0.0651 | -1.039 \diamond -0.128* |
| B1 vs b2 | -0.7262 | 0.2817 | 0.0099 | -1.132 \diamond -0.321* |
| D | | | | |
| A vs B1 | 0.1600 | 0.3266 | 0.6242 | -0.310 \diamond 0.630 |
| B1 vs B2 | -0.1818 | 0.2582 | 0.4813 | -0.554 \diamond 0.190 |
| Weighted Average | | | | |
| A vs B1 | -0.3498 | | 0.0950 | -0.523 \diamond -0.039* |
| B1 vs B2 | -0.5507 | | 0.0000 | -0.796 \diamond -0.394* |

Note. †Indicates a correction for baseline trends



Figure 8.3 Emotional suppression over time for each case.

Note. Scores were converted to be on a scale from 0 to 100 so as to compare across cases.

8.3.4. Affective distress

The weighted average across the four cases shows that there was no change in affective distress (as measured by HADS scores) during the intervention phase compared to baseline (phase B1 compared to phase A). However, there was a significant reduction in HADS scores during the follow-up phase (phase B2 compared to phase B1) (see Table 8.3 for Tau statistics and confidence intervals). Looking at the individual cases, only one participant (case B) showed a reduction in HADS scores when comparing phase B1 (intervention) to phase A (baseline). This continued to decrease during the follow-up period. Cases A and B showed a reduction in HADS scores during the follow-up phase only, while case C showed no changes in HADS scores throughout. Scores for each participant over time are presented in Figure 8.4.

Table 8.3 Tau statistics and confidence intervals for HADS scores

| Case | Tau | SD Tau | <i>p</i> value | 85% CI |
|-------------------------|---------|--------|----------------|---------------------------|
| A | | | | |
| A vs B1 | .1563 | .368 | .6711 | -0.374 \diamond 0.686 |
| B1 vs B2 | -1.0000 | .2976 | .0008 | -1.428 \diamond -0.572* |
| B | | | | |
| A vs B1† | -.5778 | .3333 | .0830 | -1.058 \diamond -0.098* |
| B1 vs B2 | -.7778 | .2976 | .0054 | -1.180 \diamond -0.375* |
| C | | | | |
| A vs B1 | -.2500 | .3162 | .4292 | -0.705 \diamond 0.205 |
| B1 vs b2 | -.3571 | .2817 | .2049 | -0.763 \diamond 0.049 |
| D | | | | |
| A vs B1 | .1800 | .3266 | .5815 | -0.290 \diamond 0.650 |
| B1 vs B2 | -.7091 | .2582 | .0060 | -1.081 \diamond -0.337* |
| Weighted Average | | | | |
| A vs B1 | -.2219 | | .1872 | -0.464 \diamond 0.020 |
| B1 vs B2 | -.7073 | | .0000 | -0.909 \diamond -0.506* |

Note. †Indicates a correction for baseline trends.



Figure 8.4 Affective distress over time for each case.

Note. Scores were converted to be on a scale from 0 to 100 so as to compare across cases.

8.3.5. Quality of life

Using the weighted average across all cases, there was no immediate improvement in quality of life (measured using the IBS-QOL) during the treatment phase compared to baseline (phase B1 compared with phase A). Tau statistics and confidence intervals are presented in Table 8.4. However, there was a significant increase in IBS-QOL scores indicating improvement during the follow-up phase compared to baseline (phase B2 compared to phase A). As with the other measures, only one participant (case B) showed improvements during the treatment phase. This improvement continued into follow-up. For the remaining three participants (cases A, C and D) there were improvements in IBS-QOL scores during the follow-up period only. Scores across this measure for each participant are presented in Figure 8.5.

Table 8.4 Tau statistics and confidence intervals for IBS-QoL scores.

| Case | Tau | SD Tau | <i>p</i> value | 85% CI |
|-------------------------|--------|--------|----------------|----------------|
| A | | | | |
| A vs B1 | 0.0000 | .3680 | 1.0000 | -0.530 < 0.530 |
| B1 vs B2 | 1.0000 | .2976 | .0008 | 0.572 < 1.428* |
| B | | | | |
| A vs B1 | .7556 | .3333 | .0234 | 0.276 < 1.236* |
| B1 vs B2 | .5926 | .2796 | .0341 | 0.190 < 0.995* |
| C | | | | |
| A vs B1 | -.3167 | .3162 | .3166 | -0.077 < 0.139 |
| B1 vs b2 | .7967 | .2817 | .0046 | 0.395 < 1.203* |
| D | | | | |
| A vs B1† | -.4600 | .3266 | .1590 | -0.930 < 0.010 |
| B1 vs B2 | .6273 | .2582 | .0151 | 0.255 < 0.999* |
| Weighted Average | | | | |
| A vs B1 | .1624 | | .3347 | -0.080 < 0.405 |
| B1 vs B2 | .7480 | | .0000 | 0.547 < 0.949* |

†Indicates a correction for baseline trends.



Figure 8.5 Quality of life over time for each case

Note. Scores were converted to be on a scale from 0 to 100 so as to compare across cases.

8.3.6. Qualitative analysis

Two researchers analysed the qualitative data independently and then combined themes (see Appendix L for a full transcript of the interview). The qualitative analysis supported the quantitative findings in that there were themes surrounding sharing feelings with others and improvements in their thoughts and behaviours.

Sharing

The theme ‘Sharing’ was identified which indicated that in particular identifying and sharing thoughts and feelings with others was beneficial. Within this theme, it was found that participants felt uncomfortable talking to others.

Case C: Because it isn't one of those things that you're happy to talk about like you might talk about a broken ankle or something to somebody you're not going to sort of raise it in normal day to day conversation.

They felt that keeping their IBS and their feelings about their IBS a secret was a burden and that it was a relief to discuss these issues with others.

Case B: And for me talking about it to my partner and a close friend is like, it was like a pressure released that you didn't even realise was there because you live with it.

Reassurance in identifying with others

In particular, it was noted that meeting with other individuals who have IBS was beneficial. A theme named ‘Reassurance in identifying with others’ was identified

where participants reported feeling less lonely and feeling understood. There was a sense that participants' thoughts and feelings were normalised through identifying with others who also have IBS.

Case B: My solution to this problem would be doing this which is quite normal in my world but you would never dream of telling anyone else, and then you find out that "yeah that's my solution to that problem as well". It's reassuring and enlightening really.

Changes/improvements in cognition, emotion and behaviour

Within the theme of 'Changes/improvements in cognition, emotion and behaviour', participants noted a shift in their perception of talking with others, in particular, with one individual (Case D) reporting feeling 'less awful' about talking about her IBS.

Case D: I'd already shared things with family and work and things so I didn't need to change that. But it did make me feel less awful about it. Less like I was some kind of problem.

Similarly, in this theme, there appeared to be a shift in behaviour with regards to making an effort to see friends and to talk about IBS. The reporting of these changes are particularly interesting given that the participants reported feeling as though the questionnaires had not changed despite reporting changes in cognitions and behaviours.

Case B: *We were given challenges. It made you rethink your whole situation but we weren't given challenges to deal with other people or change our our normal routine of just saying no we don't want to go to dinner, we don't want to do this, or I'm not going to tell anyone about it. It actually challenged me and the others too to do something new.*

Avoidance

There was also evidence of avoidance prior to attending the intervention noted by participants. Participants reported that previously they had been avoiding activity (e.g. avoiding going out to dinner) and avoiding thinking about their IBS.

Case C: *I refused to sort of...either not dealing with it not trying to think about it ignore it*

Changes/improvements in the perception and understanding of IBS

Analysis revealed that there was a shift in participants' perception of their IBS in that they now understood the relation between stress and symptoms and had also learned to 'draw a line' separating the two.

Case D: *when it happens when you have a bad bout it's so easy to get more and more and more stressed about what's happening once it once it kicks off once you feel the first like..., mm..., and then to just worry about it and it gets worse and worse and then it gets worse and worse and worse and it's a bit sort of self—perpetuating to think— to try and sort of relax about it if you can which isn't that easy but to sort of draw a line where the pain starts I suppose*

How other people view IBS

Participants also explained their understanding of other people's perceptions of IBS. In particular, they spoke of the lack of support from their GP, the marginalisation of the disorder and expressed appreciation for the fact that this research was being conducted on IBS.

Case D: *I know I also thought when I saw it on the college intranet I sort of thought 'thank God somebody's doing something that looks at this' because nobody— it's like we said in the sessions, like nobody really seems to sort of — it's quite marginalised. I thought "somebody's actually looking at it!" You know it's like you say the GPs don't just tell you you've got it and don't really., that's it.*

Acceptance

There were additional themes identified which were not directly related to the current aims. Acceptance was identified as a theme where participants note the value of accepting their IBS, and acknowledge that symptoms are only temporary.

Case D: *It's definitely made me accept that it happens to other people therefore it's nothing to be you know. It's just one of those things. Not a very nice thing, but one of those.*

Within this theme, it was also noted that relaxation was seen as a useful coping tool in dealing with IBS.

Case B: *We did learn some techniques to relax which I do find useful especially when it is bad or it does — I said it's frustrating it's annoying it gets you down.*

For some acceptance of the symptoms resembled a mindful approach.

Case C: *Quite often you sort of get this feeling it is never going to end. And what are you going to do, how are you going to manage. And then you have to keep reminding myself it will pass and I'll be ok again but just not at the moment.*

Practical comments

Participants made practical comments about the intervention. They felt that five meetings was a good amount to benefit from the intervention, but also felt that continuing to meet with each other as a means of support would be useful.

Case C: *[Five sessions is] Probably enough but it would be nice to sort of carry on.*

The questionnaires, while generally well received, were at times difficult to answer. In particular, one individual noted that the questions were not always well suited to reflect day-to-day changes.

Case C: *Some of the questions asked about your emotions in the last few days and I was thinking.., sort of feeling angry was one of them. And I found it hard to answer because if I didn't recall feeling angry in the last week*

One participant highlighted that the analogies used in the intervention (in relation to the idea of acceptance) were not useful for her.

Case C: I found that the sort of analogies like the playing tennis and the bus one. I didn't find they worked of me.

Overall, the qualitative data suggests that participants generally liked the intervention and felt as though there were a range of positive changes as a result.

8.4. Discussion

The current study tested a group-based intervention using a single case series with four participants. The intervention was specifically designed to target beliefs that expressing emotions is unacceptable and target actual emotional suppression, using cognitive behavioural techniques.

Looking at weighted averages across participants, there were significant improvements in beliefs about emotions and emotional suppression during the intervention phase of the experiment. These improvements were maintained during the follow-up period. Overall, affective distress and quality of life also improved, however these changes were not apparent until later during the follow-up phase of the experiment. It therefore appears that beliefs about emotions and suppressive behaviour changed initially and improvements in distress and quality of life occurred after these initial changes. The timing of these changes is consistent with a model in which beliefs about emotions and emotional suppression are potential process variables with a possible causal effect of changes in these beliefs and behaviours on the outcomes of affective distress and quality of life.

The particular order in which these mechanisms work (i.e. the relationship between beliefs about emotions and quality of life that is mediated serially by first emotional suppression and then affective distress) warrants further investigation in a larger sample using mediation analyses in an experimental design with a clear timeline. However, the current findings are in line with a model whereby improving beliefs about emotions may consequently reduce emotional suppression. This may then improve quality of life through a reduction in affective distress, which would not only improve coping but might directly influence symptoms in IBS (Blomhoff et al., 2000; Dancey et al., 1998). However, mediation models in CBT, psychoeducation and waitlist controls with IBS (n=147) has found that there is a direct effect of CBT on symptom improvement in IBS that is independent of distress (Lackner et al., 2009). This has not been explored in the current study, thus future research could better disentangle the separate influences of distress reduction and other treatment components on treatment outcomes.

Through finding that the designed intervention resulted in significant changes in beliefs about emotions and emotional suppression, the current study demonstrated that beliefs about emotions and emotional suppression can be influenced using cognitive behavioural techniques particularly targeted to these beliefs and behaviours which may be of value in treating individuals who may have difficulty expressing emotions.

Further to this, the current study showed that an intervention which aimed to specifically change beliefs about the unacceptability of emotions and emotional suppression may elicit changes in affective distress and quality of life. This is in line with the mediation model previously tested in this thesis (see Figure 4.1, page 106) in which the relationship between beliefs about emotions and quality of life is mediated

by emotional suppression and distress. While the current evidence supports this causal direction, further research with a control condition would be essential in ruling out the role of other factors eliciting influence on the outcomes measures.

The current study used mixed methodology. The qualitative data from the group interview supported the statistical findings of this study. Themes around the idea of sharing emotions were identified indicating that the intervention did successfully address beliefs about emotions and emotional suppression. The overall view of the intervention was positive and the treatment was well-received by the participants.

However, it should be acknowledged that for the purpose of this PhD thesis, the interviews were conducted by the PhD student which may have caused participants to answer in a socially desirable manner. While the bias of the PhD student was accounted for in analysis (by having a second researcher, blind to the aims, code the qualitative data) it is possible that there was experimenter bias in the data collection process.

The qualitative analysis revealed that participants perceived benefits of the intervention that were not part of the current aims, such as a reduction in avoidance of activities, acceptance of the disorder, viewing symptoms as temporary and coping by using relaxation techniques. While the intervention discussed acceptance of emotions, it is possible that these discussions also encouraged acceptance more broadly which then resulted in participants being more accepting of having IBS. Similarly, when talking about problems with avoiding talking about one's feelings, participants may have also reflected on avoidance more generally, leading to less avoidance of activity.

Relaxation techniques were reported as being useful by some of the participants. Though relaxation was not a key component planned in the intervention, there was discussion around relaxation techniques as participants specifically asked about

relaxation. As such, it seems that this discussion was useful as participants reported using relaxation techniques to deal with the stress that comes with IBS. Interestingly, there was no explicit discussion regarding viewing symptoms as temporary as a coping technique, however participants reported finding this useful. This shift in the perception of symptoms is surprising and indicates that although particular coping strategies are not taught, individuals may generalise learned skills and adopt new coping strategies as a result of intervention. This demonstrates the value of using a mixed methods design with an inductive approach in that there may be processes that are beneficial to participants that may not be detected when measuring only hypothesised variables.

While the overall changes across participants support the hypotheses, the changes were not consistent across all four cases. For example, with BES scores, whilst all participants made improvements, changes across the intervention stage were only significant in one participant, with the rest of the participants showing significant changes during the follow-up period. However, the weighted average across participants seems to suggest that while the changes were not so great as to achieve statistical significance in a single participant, once weighted with other cases, there were significant improvements.

Conversely, Case D unexpectedly showed an increase in their beliefs about the unacceptability of emotions. This might be explained by a marked decrease in scores for the last two data points during the intervention phase (see Figure 8.2) as opposed to an overall worsening since the intervention started. This is further supported with evidence that there was no significant difference between the baseline and the follow-

up phase⁵. This seems to indicate there was no change in beliefs about emotions as opposed to a worsening of these beliefs. This lack of change fits with the participant's reporting that she considered herself to be quite open with others emotionally during the interview, stating "I'd already shared things with family and work and things, so I didn't need to change that". However, she went on to say "But [the intervention] did make me feel less awful about it, less like I was some kind of problem," which seems to suggest that while her emotional suppression may not have changed, her beliefs about expressing emotions might have. The particular belief that one is a 'problem' or burden for sharing emotions is not directly addressed in the beliefs about emotions scale, which may explain why this change was not detected in the statistical analysis.

There was a similar pattern with emotional suppression as in beliefs about emotions regarding individual changes in that only one participant showed significant improvements in emotional suppression during the intervention phase. However as before, the overall improvements as seen in the weighted averages may reflect small changes within each case. Case D did not change in emotional suppression during the intervention or follow-up phases of the experiment. However as previously stated, this participant reported already being able to express feelings with family and work colleagues which may be why there was no change.

For affective distress, case B showed improvements early on compared to the rest of the group who did not show improvements until the follow-up phase. These early changes for case B in affective distress and beliefs about emotions could be reflective of her making significant changes in her behaviour during the intervention: "And for me talking about it to my partner and a close friend is like – it was like a

⁵ For case D, phase A and phase B2 were not significantly different (Tau=-0.0545, SD Tau=0.3210, 85% CI [-0.517, 0.408]).

pressured released that you didn't even realise was there because you live with it." It could be that this participant in particular benefited the most from a targeted intervention as she particularly struggled with talking about her feelings and her IBS to even her partner and close friend until she attended the intervention.

Case C surprisingly showed no improvements in affective distress however this participant had much lower levels of distress at the start of the intervention, resulting in only two items on her idiographic measure which perhaps limited variance to the extent that changes would not be detected if they had occurred. These floor effects may therefore explain the lack of change in affective distress for Case C.

The findings for quality of life were more consistent, with all four participants improving during the follow-up period. Case B again also improved during the intervention phase though this was not reflected in the averages across participants. Perhaps the changes for this participant are again reflective of her particularly closed nature and her earlier improvements in affective distress.

It is perhaps unexpected that case D showed improvements in quality of life and affective distress given that there were no changes in emotional expression or beliefs about emotions. This may be indicative of other mechanisms at play in the intervention that may have benefitted the participant. For example, during the interview this participant reported the value in understanding the relation between stress and symptoms, relaxation techniques and viewing the symptoms as temporary as a means to manage living with IBS. She also highlighted that discussing IBS with a group of people who understood the condition was very helpful. It may be these factors which resulted in improvements in affective distress and quality of life as opposed to beliefs about the unacceptability of emotions and emotional suppression. Had the current study selected participants only with high BES and CECS scores during recruitment,

it may not have been possible to learn that an individual who reports being emotionally expressive can still benefit from this intervention through other mechanisms.

By using a single case experimental design, it is possible to explore the effects of the intervention on each individual participant as opposed to looking across participants at the average scores. This method, along with using qualitative data, has allowed exploration of the intervention on an individual level, for example finding that there may be other processes at play for Case D compared with Cases A, B and C. This raises questions for future research which may find differential responses to treatment. In larger samples, analyses of subgroups (or clusters) may be beneficial.

Using idiographic measures lightened the work-load for participants by asking them to complete fewer items, which is beneficial when asking participants to complete two questionnaires per week for several months. However these measures have only previously been validated as constructs with all items and have not been validated as shortened constructs. They therefore may measure slightly different latent variables for each individual. For example, when measuring emotional suppression, one participant may only be answering items related to anger suppression which means that the suppression of other emotions is not being measured. Furthermore, these items may have been selected in the first instance simply because the individual was feeling (for example) angry at the time of completing the first questionnaire. It may be that different emotions arose during the intervention (e.g. sadness) and that the suppression of these emotions was not being measured by the idiographic questionnaire. Future research investigating this intervention in a larger sample would allow for questionnaires to be completed less frequently which would mean the full validated versions of questionnaires could be used.

The current study took a flexible approach in that topics deemed helpful by participants which arose in discussions were not ended. In addition when participants requested information about relaxation techniques as a means of dealing with distress in an alternate way this was not discouraged. While this flexible and individualised approach to treatment is beneficial, introducing relaxation as a means of coping with emotional difficulties may have confounded the current study.

A systematic review and meta-analysis of eight studies looking at the effects of relaxation therapy in IBS found that relaxation treatments elicit improvements in quality of life, symptom severity and anxiety (Park, Han, & Kang, 2014). Given the qualitative evidence that relaxation was useful, it is possible that relaxation played some part in improving quality of life and affective distress in the current study. However, the findings regarding statistically significant changes in beliefs about the unacceptability of emotions and in emotional suppression, along with qualitative evidence that sharing feelings with others was a beneficial change following the intervention, seem to suggest that beliefs about emotions and emotional suppression are still key mechanisms of the intervention, even if changes in relaxation did explain some of the improvements in affective distress and quality of life.

Despite participants' reporting satisfaction with the intervention, attendance to the meetings could have been improved. All four participants missed at least one group meeting. However, participants were met with individually to cover the session that they missed, meaning they did not miss any of the content of the intervention. Given that participants were generally happy with the intervention, it may be that extraneous factors (such as scheduling the meetings during work hours) influenced attendance. Data on reasons for missing sessions was not collected, but would have provided further insight into the feasibility of the intervention.

The current study has found early support for an intervention targeting beliefs about emotions and emotional suppression in IBS. However, this was only tested with four participants and no control group. It might be that other participants with IBS who do not hold unhelpful beliefs about the expression of emotions may not benefit from such intervention. Case D reported that she was emotionally expressive before the intervention and thereby did not change with respect to beliefs about emotions and emotional suppression. However, quality of life and distress did improve for this participant regardless. Similarly, for the participant who reported low levels of distress prior to intervention (Case C), though distress did not change, quality of life did. It may therefore be that different mechanisms of treatment are useful for different individuals and thus larger samples with subgroup analyses would be beneficial. Doing so would enable an individualised approach to interventions where treatment is based on individualised formulations (Hallam, 2013).

Further to this, a fully randomised control trial would be useful in accounting for any effects of other unmeasured mechanisms such as peer support, and time to talk about living with IBS. Additionally, using regularly used forms of CBT as a control condition compared with the same CBT with the addition of the current content on beliefs about emotions and emotional expression would be useful in determining the additive value of addressing beliefs about emotions and emotional expression in this sample.

9. Chapter Nine: General Discussion

The current thesis aimed to explore the role of psychosocial factors in persistent physical symptoms. By exploring cognitive and behavioural factors, the current thesis attempted to improve our understanding of beliefs and behaviours that are relevant to a potential maintaining cycle in people with persistent physical symptoms. The thesis focused on beliefs about emotions, emotional suppression, support-seeking, beliefs about sharing illness experiences and outcomes in people with FMS and IBS.

These aims were addressed using a range of research methods. Chapters Three, Four and Five used correlational and cross-sectional designs to explore differences between clinical groups and to investigate mediation models involving beliefs about emotions and emotional suppression. Chapter Six used similar online methods that incorporated mediation and group comparisons to validate a newly developed measure of beliefs about sharing illness experiences. Chapter Seven tested the role of beliefs about emotions and emotional suppression in existing psychological therapies for FMS, while Chapter Eight involved designing and testing an intervention that used cognitive behavioural techniques focusing on beliefs about emotions and emotional suppression with individuals with IBS, including following participants after the intervention to assess long-term changes.

The current chapter summarises the findings across all studies in this thesis before discussing possible conclusions in relation to beliefs about emotions and beliefs about sharing illness experiences in persistent physical symptoms. Implications and limitations of the current findings are then discussed.

9.1. Summary of findings

Chapters Three and Four both showed that individuals with IBS score higher on a measure of beliefs about the unacceptability of emotions compared to healthy controls (this finding was only approaching significance in Chapter Four), but do not differ on a measure of emotional suppression. Chapter Four examined whether the stronger belief that expressing emotions is unacceptable was specific to IBS or whether there is something more broadly about having persistent bowel symptoms that might be related to believing it is unacceptable to express one's emotions. A comparison between individuals with IBS, individuals with IBD and healthy controls was therefore conducted. In doing so, it appeared that those with IBS did not differ from those with IBD on measures of beliefs about emotions and emotional suppression. Interestingly, after controlling for affective distress (which is found to be higher in those with IBS compared to control groups (Deary et al., 2007; Muscatello et al., 2014)) the difference between those with IBS and healthy controls was no longer significant. In both Chapter Three and Four there were no differences in emotional suppression between the groups.

However in Chapter Five, looking at individuals with FMS, a different pattern emerged. When comparing individuals with FMS to those with psoriatic arthritis and to healthy controls, there were no differences in beliefs about the unacceptability of emotions. This may be explained by the healthy controls having stronger beliefs about emotions than previous healthy control groups in this thesis (see Section 5.4, page 138). However, those with FMS were more emotionally suppressive than healthy controls, though were not different from those with psoriatic arthritis. After controlling for affective distress, the difference between FMS and healthy controls became non-significant and the arthritis group scored significantly higher than those with FMS.

When testing mediation models, Chapters Three and Four found support for a model where the relationship between emotional suppression and quality of life is mediated by beliefs about emotions in IBS, suggesting that expressing one's emotions may modulate beliefs about emotions, which may then influence quality of life. This supports proposed mechanisms of change in written emotional disclosure interventions in FMS (Gillis et al., 2006), though further investigation with experimental methods is warranted. This model was not supported in FMS in Chapter Five however. Along with the mediation findings of Chapters Four and Five (where emotional suppression and affective distress mediated the relationship between beliefs about emotions and outcomes), this mediation effect of beliefs about emotions on the relationship between emotional suppression and quality of life in IBS may form part of a self-maintaining cycle where the relationship between beliefs and behaviours is reciprocal, fitting with Deary et al.'s (2007) description of autopeptic cycles in persistent physical symptoms.

Chapter Three tested a mediation model where the relationship between beliefs about emotions and quality of life was mediated by emotional suppression, however this was not found to be significant. It was noted in the discussion that this study (Chapter Three) did not measure affective distress which was suspected to play an important role in the relationship between beliefs about emotions and quality of life. In line with ironic processing theory (Wenzlaff & Wegner, 2000) it was proposed that beliefs about emotions would relate to poorer quality of life through an increase in emotional suppression which would then be associated with an 'ironic' increase in the emotions that were being suppressed. This increase in unpleasant emotions (measured as affective distress) was then expected to relate to poorer disorder-specific outcomes.

This proposed model was therefore tested in Chapters Four and Five by measuring affective distress. It was found that the relationship between beliefs about emotions and either quality of life (in IBS) or global impact (in FMS) was mediated serially by emotional suppression and then affective distress in that particular order. It was also expected that believing it is unacceptable to express one's emotions would relate to poorer outcomes through a reduction in seeking support. Support-seeking however was not a significant mediator of the relationship between beliefs about emotions and outcomes in IBS and FMS.

To investigate further the beliefs related to support-seeking, a new questionnaire measuring beliefs about sharing illness experiences was validated in a sample of individuals with FMS. This questionnaire was found to be reliable and valid and there was evidence that the scale consisted of two distinct factors: 'beliefs about sharing struggles' and 'benefits of sharing illness experiences'. Using this questionnaire as the predictor variable and global impact as the outcome, a mediation model was tested. This mediation model found that all-or-nothing behaviour and support-seeking for personal/emotional problems were significant mediators, while limiting behaviour and support-seeking for symptoms of FMS were not.

In Chapter Seven, beliefs about emotions, emotional suppression, affective distress and global impact were measured before and after NHS treatment for individuals with FMS. This chapter found that changes in beliefs about emotions over the course of treatment were positively correlated with changes in emotional suppression. However, the relationship between changes in beliefs and changes in affective distress was only marginally significant and was non-significant for global impact. Changes in emotional suppression from pre-treatment to post-treatment were

related to changes in affective distress and changes in affective distress were correlated with changes in global impact.

These individual relationships appear to provide support for beliefs about emotions and emotional suppression relating to global impact via the path laid out in the serial mediation model tested in Chapters Four and Five of this thesis. However, beliefs about emotions and emotional suppression were not directly related to global impact, which would be expected in a test of bivariate correlations given that shared variance is not accounted for. However, these correlations were conducted only on those who had complete both pre-treatment and post-treatment measures ($n=39$) which may have been too small a sample to detect these relationships. Furthermore, evidence from Chapter Five suggests that while the direct relationship between beliefs about emotions and global impact is not significant, there is still an indirect effect through which they relate. Thus, it is possible that there is an indirect effect, despite the lack of significant relationship between beliefs about emotions and emotional suppression.

Beliefs about emotions did significantly reduce over the period of treatment and remained lower at 12-week follow-up. Emotional suppression however did not change. This suggests that while beliefs about emotions may be a key process in the given interventions (though the correlational evidence cannot support this), emotional suppression does not appear to be influenced by the treatments in this study. It may be that changes in beliefs about emotions are sufficient for lasting improvements in global impact (which were evident in this chapter), though it is also possible that a reduction in emotional suppression may provide greater benefit to patients.

Based on the mediation models supported in Chapters Three, Four and Five, the final study of this thesis, presented in Chapter Eight, designed and tested a brief group

intervention specifically aimed at addressing beliefs about emotions and emotional suppression in IBS to test the notion that there is a causal relation between beliefs about emotions and quality of life in IBS. It was hypothesised that the intervention, which used cognitive behavioural techniques, would support individuals in making helpful changes in beliefs and behaviours around emotional expression and would result in improvements in quality of life.

In four individuals with IBS it was found that quality of life improved after the intervention. There was also a significant reduction in affective distress during the follow-up period for three of the four participants. Three of the participants showed significant reductions in unhelpful beliefs about emotions and in emotional suppression and weighted averages show the changes in these two variables to be significant during treatment with no significant overall change at follow-up. Qualitative evidence from this experiment highlighted expressing emotions as a potential mechanism of treatment along with other possible mechanisms, such as acceptance. From the interviews, it was evident that participants liked the interventions and felt that it had benefitted them.

Across these studies, support has been provided for the proposal that beliefs about emotions and emotional suppression may play a role in a maintaining cycle of symptoms in IBS and in FMS. There is also evidence that support-seeking for personal/emotional problems, all-or-nothing behaviour and beliefs about sharing illness experiences may too play a role in maintaining symptoms in FMS, though further evidence with a clear timeline is needed.

9.2. Beliefs about emotions and their role in persistent physical symptoms

The findings in this thesis support previous research suggesting that beliefs about emotions may be relevant to the cognitive behavioural model of persistent physical symptoms. This research has demonstrated this association in both IBS and FMS. In IBS beliefs about the unacceptability of emotions were related to poorer outcomes, such that greater beliefs were associated with poorer quality of life. The causality of this model is in part supported by the non-significant alternate model in Chapter Four and by the changes evidenced following a cognitive behavioural intervention focusing on beliefs about emotions and emotional suppression in Chapter Eight. Further experimental testing comparing changes in beliefs and behaviours with a control group who receive cognitive behavioural therapy that does not focus on beliefs and behaviours around emotions would help support this hypothesised causality.

In FMS however, beliefs about the unacceptability of emotions were not directly related to global impact, despite there being a significant indirect effect. The non-significant direct relationship in Chapter Five was argued to be potentially caused by either an unmeasured moderator or mediator having an influence on the relationship between beliefs about emotions and global impact. There is early evidence, using cluster analysis, that emotion processing varies across subgroups of individuals with FMS, in particular, in participants who were categorised as ‘interpersonally distressed’ emotional suppression was related to more negative affect and less positive affect. This was not found for individuals classified as ‘dysfunctional’ or ‘adaptive copers’ though the ‘dysfunctional’ patients showed the highest levels of emotional

suppression (López-Cichei et al., 2013). This could mean that there are differential relationships between beliefs about emotions and outcomes across different subgroups of individuals with FMS, which should be explored in future research as they may explain finding an indirect effect with no direct relation between the predictor and outcome.

In Chapter Seven when this model was tested, the indirect effect was not significant while the direct relationship between beliefs about emotions and global impact was. It is possible that those who are referred for psychological treatment are more likely to be from a particular subgroup identified by López-Cichei et al. (though it is unclear from the cluster analysis which of these particular subgroups most likely fit the findings of Chapter Seven). Conversely, using an online sample in Chapter Five might have meant participants reflected more than one of these subgroups which might explain why the direct relationship was not significant in Chapter Five. It therefore appears that while beliefs about the unacceptability of emotions are of interest in FMS, its relation to outcomes is more varied across participants than in IBS.

9.3. Distress and its role in persistent physical symptoms

In Chapters Four and Five, support was found for emotional suppression and affective distress as key variables explaining the relationship between beliefs about emotions and outcomes. Distress in particular was a key mechanism explored in this thesis as the mediation model in Chapter Three was non-significant when emotional suppression alone was tested as a mediator. Based on these studies it therefore appears that greater beliefs about the unacceptability of emotions is related to lower emotional suppression which in turn results in an increase in affective distress. The findings suggest that the increase in affective distress results in poorer outcomes as opposed to

emotional suppression being directly related to outcomes. This is in line with ironic processing explanations which suggest that emotional suppression results in an ‘ironic’ increase in the emotion being suppressed (Wenzlaff & Wegner, 2000) and with evidence linking distress with physical symptoms (Blomhoff et al., 2000; Dancy et al., 1998; Lee et al., 2013; Montgomery et al., 2010; van Koulil et al., 2007).

Some might argue based on this evidence that existing interventions targeting affective distress are sufficient in that they address this specific aspect of the model which relates to disorder-specific outcomes. Effective therapy for reducing distress focuses on identifying and adapting cognitions and behaviours which are related to the experience of depression/anxiety (which may encompass emotion regulation strategies such as emotional expression), while interventions addressing these affective symptoms alone (i.e. through the use of antidepressant medication) are less effective and less cost-effective (Dobson, Hollon, Schmaling, Kohlenberg, & Gallop, 2008; Koeser, Donisi, Goldberg, & McCrone, 2015). Evidence in treatments for individuals with chronic pain and depression have shown that stepped care (i.e. antidepressant treatment followed by a self-management pain program) results in clinically significant improvements in only 26% of patients (Kroenke et al., 2007). Additionally, beliefs and cognitions of participants predicted response to treatment (Ang et al., 2010), suggesting a need to focus on maladaptive cognitions that might relate to distress.

Given that beliefs can affect the response to treatment, it is imperative to investigate cognitions and behaviours that relate to the experience of distress, as opposed to focussing solely on the symptoms of distress, in order to improve response to treatment. This is especially prudent as in Chapter Seven there were significant changes in beliefs about the unacceptability of emotions during psychological

treatment for FMS after controlling for affective distress, suggesting these beliefs are addressed independently of reductions in distress.

9.4. Support-seeking and its role in persistent physical symptoms

Support-seeking was not found to be a significant mediator of the relationship between beliefs about emotions and outcomes in IBS and FMS. This was surprising given that cognitive behavioural models of persistent physical symptoms proposed that beliefs about unacceptability of emotions lead people to not ask for help, which in turn leads to a reduction in social support and poorer outcomes in terms of distress and physical symptoms such as fatigue and bowel disturbance (Ali et al., 2000; Rimes & Chalder, 2010; Surawy et al., 1995). This finding was, however, in line with one previous study which found that the relationship between beliefs about emotions and fatigue was not mediated by support-seeking in healthy individuals (Sydenham et al., 2016).

The current study measured support-seeking as opposed to support received. While support-seeking was related to beliefs about emotions it was not related to outcome measures in Chapters Four and Five. It may be that believing that emotions are unacceptable does lead to less support-seeking, but this does not necessarily lead to a helpful form of support being received, in that the support received may be inadequate. This could be particularly an issue when considering evidence that those with IBS and FMS tend to also score highly on measures of alexithymia (Huber, Suman, Biasi, & Carli, 2009; Phillips et al., 2013; Porcelli, De Carne, & Leandro, 2014; van Middendorp et al., 2008). Consequently, it may be that despite expressing emotions and then seeking support, individuals may be inaccurately or ineffectively expressing emotions due to an inability to understand and describe one's emotions.

This would mean that although one might express emotions and seek support for this, they may not receive the support that would be beneficial.

Based on previous evidence on stigma and secrecy in these conditions and the relationship between stigma, social support and outcomes (Frohlich, 2014; McInnis et al., 2015) (see sections 1.1.2, 4.1 and 5.1 on pages 22, 96 and 121), it was argued that concerns about stigma and social judgements of others regarding the condition would be more relevant than beliefs about sharing emotions (see section 4.4 and 5.4 on pages 115 and 138). A measure of beliefs about sharing illness experiences was therefore developed. Support-seeking was found to mediate the relationship between beliefs about sharing illness experiences and global impact. It could be therefore that beliefs about sharing illness experiences leads to receiving more helpful and appropriate support, perhaps because illness experiences may be more easily understood and described than emotional experiences for those who are alexithymic. This then means that support-seeking mediates the relationship between beliefs about sharing illness experiences and global impact.

9.5. Beliefs about sharing illness experiences and their role in persistent physical symptoms

An academic supervisor of this PhD project had previously developed a measure of beliefs about sharing illness experiences. This measure was then evaluated in Chapter Six of this thesis in participants with FMS and found to be a reliable and valid measure with two underlying factors (beliefs about sharing struggles and benefits of sharing illness experiences). This research found that unhelpful beliefs about sharing illness experiences were related to poorer outcomes (i.e. greater impact of the disorder and greater affective distress).

Further mediation analyses revealed that seeking support for personal/emotional problems was a significant mediator of the relationship between beliefs about sharing illness experiences and global impact while support-seeking for problems relating to symptoms was not. It therefore seems that greater negative judgements and perceived negative judgements of others in relation to sharing illness experiences, the less likely they are to seek emotional support, which then results in a greater impact of the disorder on their lives.

Practical support-seeking however was not a significant mediator of this relationship. It may be that this kind of support-seeking is more influenced by the distinction between social support for autonomy which is beneficial and social support for dependence which can be detrimental (Matos et al., 2015) (discussed in more detail in section 9.9): Being dependent on practical or physical support may be more detrimental than being dependent in terms of emotional support. When others are completing physical tasks on a person's behalf, that person is thereby avoiding activity and perhaps there is a degree of physical deconditioning (Vlaeyen & Linton, 2000), which may then influence outcomes. Furthermore, the question of the practical support-seeking measure was modified from the original GHSQ whereas the personal/emotional measure was not. It may be that this modification resulted in a reduction in validity/reliability resulting in an ability to capture support-seeking intentions in relation to FMS.

All-or-nothing behaviour was also found to mediate the relationship between beliefs about sharing illness experiences and global impact in parallel with the mediation effect of personal/emotional support-seeking. This indicates that if one has greater negative judgements around sharing experiences about one's illness, they may overexert themselves in an effort to appear as though they are not struggling (McInnis

et al., 2015). It is possible this overexertion may then force them into periods of prolonged rest before re-engaging in overexertion to compensate for the prolonged rest period (Spence, Moss-Morris, & Chalder, 2005). This cycle of all-or-nothing behaviour then results in a greater impact of the disorder on the individual's life.

The current thesis has therefore found evidence for two potential mechanisms through which beliefs about sharing illness experiences might relate to outcomes in FMS. This evidence along with the validation of the questionnaire enables future research to further explore the role of beliefs about sharing illness experiences in other conditions.

9.6. Differences between those with FMS and IBS

Researchers have often used the term 'medically unexplained symptoms' by which they refer to conditions such as IBS and FMS (among others) that have no clear medical explanation for the physical symptoms that patients experience. Some researchers have aimed to develop biopsychosocial or cognitive behavioural models which aim to describe psychosocial features of persistent physical symptoms with uncertain aetiology, spanning the specific diagnoses (Deary et al., 2007; Salkovskis et al., 2016). Salkovskis notes similarities as well as differences within this broad category of so called 'medically unexplained symptoms'.

In the current thesis, there are subtle, but noteworthy differences between the findings of those with IBS and those with FMS. For example, in IBS, it was found across two studies that those with IBS hold stronger beliefs about the unacceptability of emotions compared with healthy controls, but that they do not differ with regards to the suppression of emotion. Interestingly in FMS, there were no differences in beliefs about emotions, but there were differences in emotional suppression. It is

possible therefore that these two variables play similar, but still different roles in these two conditions. It is worth noting however that the healthy controls in Chapter Five scored significantly higher than those in Chapter Four on the measure of beliefs about emotions, which might explain the lack of a significant difference when measuring beliefs about emotions in Chapter Five, suggesting that with regards to beliefs about emotions, those with FMS may still differ from healthy controls as did those with IBS.

It could be worth further investigating the role of embarrassment and stigma in IBS and FMS to understand these differences. For example, beliefs about the unacceptability of emotions (which focuses on social judgements in particular) may be higher in those with IBS due to the inherently embarrassing nature of bowel symptoms which is arguably less potent for symptoms of chronic pain and fatigue (Frohlich, 2014). However, in Chapter Six, it was found that those with FMS had greater negative judgements (of self and perceived judgements of others) around sharing illness experiences compared with healthy controls, suggesting that judgements about sharing more broadly might be higher than healthy controls in FMS as well as in IBS, despite the use of slightly different measures. Based on these findings in Chapter Six, a replication of Chapter Five with a different sample of healthy controls would be useful in determining whether the findings in beliefs about emotions were in fact a type II error.

Another noteworthy difference between the findings of Chapters Four and Five involves the direct relationship between beliefs about emotions and the disorder-specific outcome measure. In IBS (Chapter Four), beliefs about emotions were directly related to quality of life, while in FMS (Chapter Five), this relationship was not significant (despite finding a significant indirect effect). However, as described above, these findings were not supported in a clinical sample in Chapter Seven.

In line with previous research finding distinct subgroups of individuals with FMS that differ in their emotion processing (López-Chicheri et al., 2013), it could be that for those with FMS who are within the previously identified ‘interpersonally distressed’ subgroup (where emotional suppression was related to more negative and less positive affect), beliefs about emotions may result in poorer outcomes through emotional suppression and increased negative affect. Alternatively, for those who are ‘dysfunctional’ or coping adaptively, there may be other mediators of this relationship which may in fact result in a positive indirect effect. However, the findings of López-Chicheri et al. do not provide any clear evidence for this suggesting more research into subgroups of individuals with FMS is needed.

This early evidence of subgroups within a FMS sample with regards to emotion processing demonstrates a lack of homogeneity in FMS samples with regards to emotion regulation and its relation to distress. The differences between those with FMS and IBS may therefore be explained by individuals with IBS making up a more homogenous group in terms of their emotional suppression and beliefs about emotions, while samples of individuals with FMS are made up of distinct subgroups where beliefs about emotions relate differently to distress and outcomes for different subgroups. Investigations into the heterogeneity of samples of IBS with regards to emotion processing variables would be needed to further test this supposition.

Despite the subtle differences in emotional suppression and beliefs about emotions between samples with FMS and IBS, there is still consistent evidence in the online samples supporting the indirect relationship between beliefs about the unacceptability of emotions and outcomes via emotional suppression and affective distress.

9.7. Implications for clinical practice

Chapters Three, Four and Five provided the basis for developing an intervention that targeted beliefs about the unacceptability of emotions and emotional suppression in IBS. As beliefs about emotions were related to quality of life via emotional suppression and affective distress, it was hypothesised that if an individual could be supported, using cognitive behavioural techniques, in adapting their unhelpful beliefs about emotions to become more accepting of emotions, this would result in a reduction in emotional suppression (which may also be directly addressed through cognitive behavioural methods) which would then result in less affective distress and improved quality of life. The aim was therefore to attempt to disrupt a potential unhelpful maintaining cycle of beliefs, emotions and behaviours that may work to maintain poor quality of life in IBS by changing beliefs and behaviours.

Chapter Eight showed that an intervention addressing unhelpful beliefs about the unacceptability of emotions and emotional suppression may result in improvements in distress and quality of life in IBS. Firstly, this supports the notion that individuals with IBS can benefit from cognitive behavioural approaches, demonstrating the value of investigations into the particular features of this treatment approach. Secondly, the evidence from Chapter Eight suggests that targeting these particular beliefs about emotions may be useful in treating individuals with IBS. In order to investigate whether this evidence could be applied to clinical practice, further research should compare Chapter Eight's intervention with other CBT protocols for IBS (in addition to wait-list controls) in order to understand whether adding content on beliefs about emotions and emotional suppression contributes to greater improvements when compared to similar treatment methods that do not address these factors.

Given the evidence that psychological, and in particular cognitive behavioural intervention is useful for those with IBS, it is important to explore the potential mechanisms through which these treatments are effective. This may then allow for better targeted intervention and increased effectiveness. It has been argued that the research on CBT for IBS has too often focussed on whether CBT works and instead should investigate particular components of effective psychological treatment in order to understand better the aetiology and prognosis of the disorder and to refine and streamline CBT for IBS (Lackner et al., 2009). Therefore, by targeting change in specific theory driven beliefs and behaviours (in this case beliefs about emotions and emotional suppression) using cognitive behavioural techniques, and measuring their change during and after intervention, it is possible to begin exploring mechanisms of treatment in IBS.

In FMS, it has also been suggested that the mechanisms of psychological treatment are unclear and should be investigated further (Eccleston et al., 2009). It is possible that in NHS interventions for FMS which include an integrative CBT, ACT and mindfulness approach to pain management in a group setting, beliefs about emotions and emotional suppression are adapted due to discussions around emotion processing in these treatments.

It was found that beliefs about the unacceptability of emotions (though not emotional suppression) reduced during these NHS psychological treatments for FMS, which suggests that these psychological interventions do indeed modify beliefs about emotions. However, interestingly, in Chapter Seven, emotional suppression was not affected by these interventions, while in the intervention designed in Chapter Eight, emotional suppression did change over the intervention phase of the study. It could be that current interventions for FMS could benefit from directly addressing emotional

suppression since the qualitative findings in Chapter Eight seemed to indicate this was useful for individuals with IBS. Analyses of these interventions with a specific focus on beliefs about the unacceptability of emotions and emotional expression, compared to a control group that does not contain this aspect, would be vital.

It is important to note that different therapeutic models may consider emotional expression using different approaches. For example, second wave CBT may directly consider the role of behaviours and beliefs, and the consequences, including unintended consequences, of such beliefs and behaviours. Third wave therapy (e.g. ACT) may consider more directly the concept of ‘acceptance’, defined as “permitting the presence of experiences that are unwanted, such as feelings, physical sensations, memories and urges” (McCracken, 2011). Acceptance of emotions and symptoms was part of the NHS psychological interventions, as well as the use of second wave cognitive behavioural techniques (identifying and evaluating cognitions around emotions).

Acceptance of emotions (not of symptoms) was a focus of the intervention described in Chapter Eight. However, a theme that was highlighted during the qualitative analysis of Chapter Eight included acceptance of symptoms. It is likely, then, that each of the interventions in Chapters Seven and Eight encouraged acceptance in participants of both emotions and of their symptoms. It could be that individuals generalise the increased acceptance of the expression and experience of emotions to acceptance in other areas (such as acceptance of physical symptoms). As such, changes in beliefs about unacceptability of emotions may therefore have resulted in increasing levels of acceptance of emotions, and individuals generalised these skills in considering the experience of symptoms. However, the acceptance of emotion was not measured in this research and therefore this would require confirmation from

future research. This idea is however consistent with research that suggests that acceptance of symptoms increases through second wave CBT interventions; and beliefs about pain are adapted in third wave ACT interventions (Wetherell et al., 2011). It seems therefore that the mechanism of change around beliefs about emotions and acceptance could be somewhat overlapping. The particular mechanisms of change in terms of beliefs and behaviours around acceptance of emotions and acceptance of symptoms, should be investigated further as acceptance was not measured in the current studies.

It is however worth noting that the mediation effect sizes in the current study were generally small which indicates that this maintaining cycle surrounding beliefs about emotions and beliefs about sharing illness experiences plays a small part in a much bigger cycle of cognitions and behaviours. These beliefs and related mediating behaviours should be targeted in treatments alongside other cognitions and behaviours which have been evidenced in IBS and FMS.

The current thesis produced a valid and reliable measure of beliefs about sharing illness experiences and found these to be related to the impact of FMS on a person's life via support-seeking and all-or-nothing behaviour (see Chapter Six, page 146). Though this measure requires further validation in additional samples, it may prove useful in clinical settings. Such a measure may help clinicians identify barriers to sharing illness experiences with others. These unhelpful beliefs may then be addressed using CBT (though further evidence that these beliefs can be modified using CBT and that the BASIE is sensitive to change is needed). If CBT addressing these beliefs is successful, it may in turn reduce all-or-nothing behaviour and increase support-seeking for personal/emotional problems which may then result in FMS having less impact on the person's life. While further research is needed on the BASIE, this thesis

has provided valuable early evidence that beliefs about sharing illness experiences could be a useful construct to consider when working with clients with FMS. Furthermore, by creating a scale to measure these beliefs, clinicians can measure this construct in practice.

9.8. Relating these findings to other long term conditions

Chapters Four and Five compared individuals with IBS and FMS to individuals with IBD and arthritis. There were no differences between those with IBS and those with IBD with regards to emotional suppression or beliefs about emotions. Similarly, there were no differences between those with FMS and those with arthritis until after controlling for affective distress, in which case those with arthritis were marginally more emotionally suppressive. It is likely then that role of emotional suppression and beliefs about emotions in these particular conditions, with uncertainty surrounding the aetiology, could be extended to the consideration of conditions where the aetiology is known. It is possible that there is something about persistent physical symptoms more broadly which is related to beliefs about the unacceptability of emotions and emotional suppression.

Salkovskis et al. (2016) argue that furthering our understanding of so-called persistent physical symptoms will likely generalise to other long-term conditions as both involve the experience of psychological distress that is associated with living with a chronic condition. As an example, Salkovskis et al. describe the role of health anxiety and how it negatively impacts the perception of disability and quality of life in long-term conditions, regardless of whether there is a medical explanation. Similarly, since persistent physical symptoms (regardless of their aetiological explanations) are associated with distress about the condition (Moss-Morris, 2013;

Salkovskis et al., 2016), one may question the effect of the individual's response to that distress. For example, if both IBS and IBD are associated with distress about the symptoms, it is indeed possible that both conditions would be affected by emotional suppression and beliefs about the unacceptability of that distress. In fact there is evidence that emotional suppression and beliefs about emotions play a role in other psychological and physical conditions such as anxiety and mood disorders (Campbell-Sills et al., 2006), anorexia nervosa and CFS (Hambrook et al., 2011), depression (Liverant et al., 2008), breast cancer (Schlatter & Cameron, 2010), social anxiety (Spokas et al., 2009) and psoriasis (Kossakowska et al., 2010).

It was found in both Chapters Four and Five that after controlling for affective distress, previously found differences between those with FMS or IBS compared with healthy controls were no longer significant. This suggests that distress explains some of the variance in beliefs about emotions (for those with IBS) and emotional suppression (for individuals with FMS). However, in both studies, after controlling for affective distress, the clinical control groups (i.e. IBD and arthritis) were more emotionally suppressive than the groups with IBS and FMS. This suggests that while distress explains some of the variance in emotional suppression in IBS and FMS, this is not the case for IBD and psoriatic arthritis, which highlights a potential difference between persistent physical symptoms with and without a clear medical explanation with regards to the relation between distress and emotional suppression.

The current thesis did not test the mediation models of Chapters Four and Five in conditions where there is a clearer understanding of the aetiology (i.e. in arthritis and IBD), though this would be useful in generalising the findings of the current thesis to persistent physical symptoms beyond those which lack a clear medical explanation.

Future research using trans-diagnostic outcome measures would better be able to compare the mediation models in conditions with and without a clear aetiology.

It therefore appears that while some aspects of the current findings may be generalizable to other persistent physical symptoms with a clear aetiology, there are still potential differences between conditions with and without a medical explanation that need further investigation.

9.9. Limitations and directions for future research

The current studies relied on participants to self-report a diagnosis of either FMS or IBS, with the sample in Chapter Three including individuals who reported self-diagnosed IBS. From Chapter Four onwards, individuals who were self-diagnosed (as opposed to being diagnosed by a clinician) were excluded from the analysis. This may mean that the sample in Chapter Three reflects a broader group of individuals who may not have IBS as defined by clinicians, meaning the application of findings to IBS samples may be limited. However, the findings of Chapter Three were replicated in Chapter Four where the sample included only those who had received a diagnosis of IBS from a clinician, indicating that perhaps the inclusion of self-diagnosed individuals did not greatly influence the findings of the study in Chapter Three.

Research on IBS in the current thesis used the Manning Criteria for Irritable Bowel to support the self-reported diagnosis of IBS (Manning et al., 1978). While there is evidence that these criteria are comparable to more recent criteria (Saito et al., 2000), most recent research relies on the Rome criteria which are regularly evaluated and updated (Drossman, 2006; Drossman & Corazzi, 2000; Lacy et al., 2016). There may therefore be discrepancies between the categorisation of individuals in the current study and other studies using the Rome criteria.

The NICE guidelines for diagnosing IBS in UK clinical practice however differ from both the Rome and the Manning criteria. Given that participants report receiving a diagnosis from a clinician, it can be assumed that they meet the criteria set out by the NICE guidelines which state that diagnosing IBS should be considered if the person has abdominal pain or discomfort that is either relieved by defecation or is associated with a change in bowel frequency or stool form, and is accompanied by at least two of these symptoms: altered stool passage (straining, urgency, incomplete evacuation); abdominal bloating, distension, tension or hardness; symptoms made worse by eating; and passage of mucus.(NICE, 2016). While there is some overlap between the NICE guidelines and the Manning criteria (i.e. pain/discomfort relieved by defecation or associated with looser stools, abdominal distension, incomplete evacuation and passage of mucus), there are differences in the criteria set by NICE compared with Manning's criteria (e.g. symptoms being made worse by eating). This may result in less valid categorisations of individuals with IBS in the current thesis.

Similarly, the current study used the LFESSQ to support the self-reported diagnosis of FMS by a clinician, though many recent studies adopt the American College of Rheumatology classification. This may mean that there is some discordance between the samples of the current study and other research on FMS due to differing classifications. However, as stated in Chapter Two (see section 2.1.2, page 57) the LFESSQ has shown better sensitivity and specificity compared with the American College of Rheumatology criteria and the Fibromyalgia Rapid Screening Tool (Perrot et al., 2010; White et al., 1999; Wolfe et al., 1990), which is why it was used in Chapter Five of this thesis. Chapter Seven was not affected by the screening tool as participants were included based on their self-report of a clinician diagnosing

them with FMS and by their referral to group therapy by a rheumatologist or general practitioner for their FMS.

Chapters Three, Four, Five and Six recruited participants online. This was beneficial as it allows for large sample sizes to be collected more cost-effectively. In addition, individuals living with persistent physical symptoms may be particularly difficult to recruit in research due to their difficulty in leaving the house and avoidance of activities (Golden, 2007; Nijs et al., 2013). Therefore, these methods were beneficial in recruiting large enough sample sizes to achieve sufficient statistical power to test mediation models in these samples.

However there is some evidence that using online samples can result in bias with regards to financial motive, personality traits, self-esteem and the amount of missing data (Cantrell & Lupinacci, 2007; Goodman et al., 2012). There have been criticisms of this research that finds differences between pencil-and-paper and online participants in that many studies which make this comparison often have other differences between the two conditions which means differences cannot be solely attribute to online data collection (Weigold et al., 2013). Furthermore, when participants have been compared in a more controlled manner (i.e. where the only key difference between groups is that one sample is online and the other is pencil-and-paper), personality traits and social desirability (which have previously differed between conditions) were comparable (Weigold et al., 2013).

Despite the conflicting evidence on issues with online samples, online data collection and recruitment may be problematic for studies which aim to measure variables relating to emotional disclosure and sharing illness experiences. Many of the participants with clinical conditions were recruited from websites, forums and social media pages dedicated to that specific condition. As such, these individuals may be

more expressive than participants recruited through other means, that is, individuals who discuss their condition online may tend to be more open and expressive. This may mean that participants in these samples are biased with regards to their emotional expression, beliefs about emotions and beliefs about sharing illness experiences.

Healthy controls were also recruited online however this was done through participant recruitment webpages (e.g. Reddit's Sample Size page) and through snowball sampling via contacts of the experimenters. There is perhaps still an argument to be made that individuals who regularly take part in online research are likely to be more expressive than those who do not take part. Consequently, the samples in Chapters Three to Six may have underestimated the differences between groups and the relationships between variables. Alternatively, it is possible that the wording of the recruitment posts online might have influenced who chose to take part in the research, creating a bias in the healthy control groups. The recruitment posts stated that the study was interested in how the expression of emotions related to symptoms of IBS/FMS. It is possible that healthy controls reading this might assume that expression of emotion causes symptoms and therefore healthy individuals who are more suppressive may be more inclined to take part as they feel they would support the aims of the study. As such this might have resulted in the high BES scores of healthy controls, particularly in Chapter Five.

Similarly, participants in Chapter Seven were individuals who attended group psychological interventions. Consequently, this sample may have been biased to include more emotionally expressive individuals as only those who attended the intervention were included in the study. Individuals with FMS who are seen within secondary care may not be referred for or agree to attend these interventions if they are unwilling to express their emotions to others. It is possible then that emotional

suppression may have changed if tested in a sample which may not have been biased in this manner.

In Chapters Four, Five and Six, support-seeking intentions were measured using the GHSQ. This measure was chosen as it can be modified to address support-seeking with regards to specific struggles related to a particular disorder. However, this advantage of being adaptable for different struggles also means that the particular items used in the current studies have not been validated. The reliability of the two scales was evaluated using Cronbach's measure of internal consistency in IBS (see Chapter Four, section 4.2.2.1, page 103) and in FMS (see Chapter Five, section 5.2.2.1, page 127). While there was good internal consistency in the sample with FMS, in IBS the internal consistency of the two scales was poor and questionable. This may explain the non-significant indirect effect of support-seeking in the mediation model in IBS, however this does not explain why support-seeking was not a significant mediator in FMS.

It has been argued (based on evidence from 250 older participants with pain) that there are two forms of social support, support that promotes functional autonomy (which is beneficial to an individual) and support that promotes functional dependence (which is not beneficial). Based on mixed evidence on the relationship between social support and pain-related outcomes in older participants, Matos et al. (2015) argued that social support can encourage either activity avoidance (through support which promotes dependence on others) or activity engagement (if the social support promotes autonomy). A measure of social support was developed and Matos et al. found support for a two-factor structure that included social support promoting autonomy and social support promoting dependence as two distinct factors. In their validation study, there was a positive relationship between social support promoting

autonomy and physical functioning, and a negative relationship between physical functioning and social support promoting dependence.

This might explain the non-significant mediation effect of support-seeking in Chapter Five where the distinction between support promoting autonomy and dependence was not accounted for. It may be that those who score lower on the measure of beliefs about the unacceptability of emotions do engage more in support-seeking, and those who score highly seek support less frequently (which is supported by the significant negative relationship found between these two variables – see Chapter Four, Table 4.4, page 111 and Chapter Five, Table 5.4, page 135). However, those who seek support less frequently may have poorer outcomes due to a lack of social support which promotes autonomy, while those who score high on measures of support-seeking intentions may also have poorer outcomes due to greater social support which promotes dependence. Thus, while the relationship between beliefs about the unacceptability of emotions and support-seeking is linear, the relationship between support-seeking and global impact may not be. This may therefore explain the non-significant mediation effect of support-seeking in Chapters Four and Five.

A different pattern emerged however in Chapter Six when beliefs about sharing illness experiences were measured: Personal/emotional (and not symptom-related) support-seeking did in fact mediate the relationship between beliefs about sharing illness experiences and global impact. This inconsistency between the two types of support-seeking may be explained by a differential role of social support for dependence in relation to practical and personal/emotional support-seeking.

Other measures included in this thesis included the BES and the CECS. No items on the BES are reverse scored and therefore all items are worded so that expressing and experiencing emotions is considered unacceptable. It is possible that the

negatively worded items could prime participants to view the expression of emotion as unacceptable which may impact later responses on the measure. From Chapter Four onwards, the questionnaires were randomly ordered to avoid such order effects.

A possible limitation of the way that this measure is used in this research to test the relationship with emotional suppression is that that measure does not distinguish between beliefs about the unacceptability of experiencing versus expressing emotions. Arguably, one might be accepting of experiencing emotions yet not be accepting of expressing emotions such that only beliefs about the expression of emotions is associated with emotional expression. It is possible that the lack of distinction in the current thesis explains inconsistencies in group comparisons across the BES and CECS as the CECS only measures internal suppression (i.e. not experiencing emotions) in a single item. For example, differences were found in the BES between those with IBS and healthy controls, and not the CECS, which might be explained by those with IBS being less accepting of the experience emotions, but not less accepting of the expression of emotions. Future research should measure both internal and external suppression and perhaps explore any differences between the two with regards to comparing clinical groups and with regards to its relationship with distress.

Further to this, the non-significant mediation of the relationship between the BES and outcome measures by support-seeking might be explained by the BES measuring these two beliefs. Support-seeking may mediate the relationship between beliefs about expressing emotions and outcomes (external suppression), but may not mediate the relationship between beliefs about experiencing emotions and outcomes (internal suppression). Future research should aim to distinguish between individuals who hold beliefs about the unacceptability of experiencing emotions and those who hold beliefs about unacceptability of expressing emotions. It is worth noting however

that a factor analysis of the BES reliably extracted only one factor (in both those with CFS and healthy controls together, CFS patients alone and healthy controls alone) which explained more than 50% of the variance indicating that this questionnaire is measuring one overall construct. Despite a potential theoretical difference between the beliefs, it is likely that beliefs about internally experiencing and externally expressing emotions are strongly related.

The BES is a useful and novel measure however due to its novelty, more evidence is needed to demonstrate its reliability and stability in participants over time and warrants further testing in different samples.

The CECS has been used in research in clinical groups, however many studies use alternate measures of emotional suppression. This thesis selected the CECS as it does not contain measures of motivations or beliefs regarding suppression, instead focusing explicitly on whether particular emotions are expressed or not. It was considered advantageous that this measure highlighted specific emotions as opposed to speaking about emotions more generally as this would encourage participants to reflect on unpleasant emotions in particular. However, this questionnaire may be limited in that it may be influenced by the frequency with which one experiences a particular emotion listed: While talking broadly and not naming specific emotions may have limitations, this method does mean that if an individual has not recently or does not regularly experience an emotion, their emotion suppression score will not be impacted.

It is also possible that the wording may not have encompassed all unpleasant emotions felt by participants. For example, the word 'afraid' (used in the CECS) might indicate something different from 'anxiety' or 'worry' to different participants which might affect the validity of the measure. An individual may perceive the word 'afraid'

to be more extreme than 'worry' which may mean they indicate they would be more likely to express this emotion, but they may actually tend to suppress less intense feelings such as worry. It would be useful for future research to develop a questionnaire that measures emotional suppression separately from beliefs that focusses on unpleasant emotions but encompasses a range of terms corresponding to different emotions and emotional intensities.

The current study has explored the relationships between beliefs, behaviours and outcomes in FMS and IBS across a range of methodologies. Chapters Four and Five supported emotional suppression and affective distress as mediators of the relationship between beliefs about the unacceptability of emotions and disorder-specific outcomes. It was proposed that this supports ironic processing effects and a causal chain was put forward where beliefs influence suppression which in turn results in increased affective distress which then results in poorer outcomes. This causal chain was supported by the non-significant alternate model where the order of the two mediators was inverted. Similarly, in Chapter Six a causal model was posited based on finding all-or-nothing behaviour and personal/emotional support-seeking to mediate the relationship between beliefs about sharing illness experiences and global impact in FMS. However, all of these studies proposed causal models based on correlational findings.

Based on this evidence it is supposed that there is a causal path where believing it is unacceptable to express or experience one's emotions causes more distress and then poorer outcomes. However a reverse direction of causality cannot be ruled out based on the current evidence: It is possible that those who have poorer quality of life will thereby feel more distressed by their symptoms and their quality of life. This increased distress may result in a greater desire to suppress one's emotions.

Furthermore, the more distress a person experiences, the more likely they might be to have made previous attempts at sharing emotions. If these previous attempts have been met with criticism or were otherwise ill-received, this would then likely result in believing it is unacceptable to express or experience emotions.

To address issues with causality in these studies, Chapters Seven and Eight used experimental methods. Chapter Seven used a quasi-experimental design and measured variables from the models in Chapters Four and Five (i.e. beliefs about emotions, emotional suppression, affective distress and global impact) across three time points. By adopting a clear timeline, it was hoped that a direction of causality could be inferred. Regressions exploring changes from pre-treatment to post-treatment in beliefs about emotions, emotional suppression and affective distress as predictors of changes in global impact from pre-treatment to follow-up were not significant. However, the high attrition rate in Chapter Seven meant that there were only 21 participants with data at all three time points which is likely to leave the study under-powered meaning this study was unable to support the proposed causal relationships.

The final study of this thesis, presented in Chapter Eight, used a single case series experimental design. The intervention tested in Chapter Eight was specifically designed so as to target beliefs about the unacceptability of emotions and emotional suppression. These two variables did indeed change during the course of the intervention. Following these changes during the intervention, there were significant changes in quality of life and affective distress during the follow-up phase of the study. The timing of these changes supports a causal model where the intervention helped reduce unhelpful beliefs about emotions and reduce emotional suppression and then these reductions in beliefs and behaviours resulted in later changes in outcomes.

Due to the nature of single case designs, it was not possible to test the relationships between changes in earlier phases of the intervention and changes in outcomes during the follow-up period. This would have helped to support a causal relationship between these variables. Furthermore, without a control condition, it is possible that there were effects of the interventions that were not simply those of focus in the study. For example, participants attended a group setting, with people who share similar experiences, and received peer support. Such aspects could account for the changes, particularly when considering Case D, whose beliefs about emotions and emotional suppression did not change, but quality of life did. It would be important in future research to include a control group with a similar group setting, using cognitive behavioural techniques that do not focus on beliefs and behaviours around emotional expression. Furthermore, the different findings for Case D compared with other cases highlights the need for individualised formulations in order to offer the most appropriate and targeted therapeutic support (Hallam, 2013).

9.10. The cognitive behavioural model of persistent physical symptoms

Existing models of persistent physical symptoms have described self-perpetuating cycles of beliefs, behaviours and the consequences of these that work to maintain symptoms. It is believed that there is often a physiological or psychosocial trigger which activates this cycle, such as life events, abuse and illness (Deary et al., 2007). Once initial symptoms have been triggered, the individual's response to these symptoms is crucial in determining whether they are maintained and how much the individual's life will be impacted by the symptoms (see section 1.1.1, page 18).

The findings of the current thesis support research that places beliefs about the unacceptability of emotions and beliefs about sharing illness experiences within this

cycle. The current findings highlight the role of distress in this maintaining cycle. Once the symptoms have been initiated, individuals are likely to experience distress about their symptoms (Moss-Morris, 2013). The current thesis suggests that beliefs about sharing illness experiences and beliefs about the unacceptability of emotions may determine to what extent this distress about symptoms is likely to influence the person's life. For example, if an individual is distressed about their symptoms but they believe it is acceptable to experience and express their emotions and do not hold negative judgements surrounding sharing illness experiences, then this expected to be related to better outcomes.

The current thesis also found evidence to support potential mechanisms through which these beliefs relate to outcomes. Mediation models found support for stronger beliefs about emotions being related to poorer outcomes via an increase in emotional suppression followed by an increase in affective distress. This may be explained by ironic processing theory where the suppression of unpleasant emotions, when experiencing high levels of negative affect, can result in an 'ironic' increase in the unpleasant emotions being suppressed (Dalgleish et al., 2009; Wenzlaff & Wegner, 2000). However it may not just be the mechanisms described by Wenzlaff and Wegner through which beliefs about emotions and emotional suppression relate to an increase in distress. For example, as discussed in Chapter One of this thesis, the suppression of emotion may prevent more effective processing of an emotion-eliciting event (e.g. through cognitive reappraisal) (John & Gross, 2004). Furthermore, if one is avoiding the experience and the expression of a difficult emotion they may be less motivated to resolve the issue from which the emotion stems (Inzlight & Legault, 2012; Oatley & Johnson-laird, 1987) and they may be impaired in social interactions, resulting in isolation and therefore more distress (John & Gross, 2004).

In line with the cyclical nature described in models of persistent physical symptoms, it is then possible that this increased distress will then continue to be suppressed due to the individual's beliefs about the unacceptability of emotions, resulting in self-perpetuating cycle (see Figure 9.1). Furthermore, Chapters Three and Four found that the relationship between emotional suppression and quality of life in IBS was mediated by beliefs about emotions, suggesting that emotional suppression may in fact modulate or update beliefs about the unacceptability of emotions, further maintaining these unhelpful beliefs.

Similarly, the current thesis found evidence that the relationship between beliefs about sharing illness experiences and the impact of FMS on a person's life was mediated by seeking support and all-or-nothing behaviour. It was suggested that if an individual holds beliefs about negative judgements about sharing their illness experiences, they would therefore be less inclined to seek support from those around them and this lack of support would mean the disorder would have a greater impact on that person's life.

The all-or-nothing cycle of behaviour has previously been described in IBS (Spence & Moss-Morris, 2007; Spence et al., 2005). The current thesis found support for this behavioural cycle explaining the relationship between beliefs about sharing illness experiences and global impact in FMS. Similarly, it was argued that having unhelpful beliefs about sharing illness experiences means that an individual is also likely to persist in the face of symptoms in order to keep up appearances. This over-exertion would then result in forced periods of rest to which the individual will respond with more activity following the period of rest. The belief that there will be negative social evaluations regarding one's illness experiences may then work to perpetuate or maintain this all-or-nothing behaviour pattern.

Therefore, the variables measured across the current thesis appear to form part of a self-maintaining cycle, which may fit within broader existing cognitive behavioural models of persistent physical symptoms (e.g. Deary et al., 2007; Salkovskis et al., 2016; Spence & Moss-Morris, 2007).

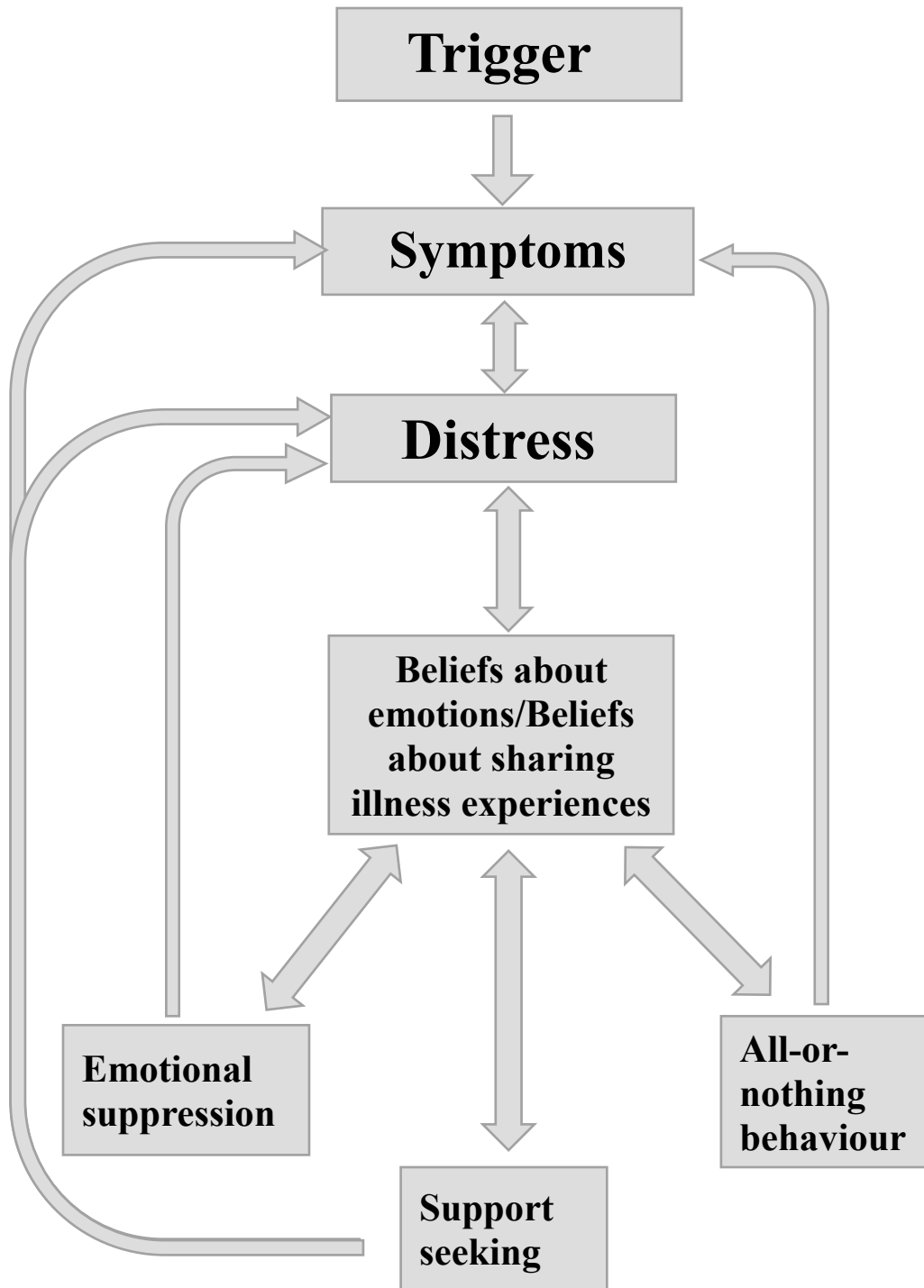


Figure 9.1 A self-maintaining cycle based on evidence from the current thesis.

9.11. Conclusions

This thesis aimed to investigate potential psychosocial features of persistent physical symptoms in line with cognitive behavioural theory, and an ironic processing model. Specifically, beliefs around the unacceptability of emotions and around sharing illness experiences were explored along with potential behavioural factors such as emotional suppression, support-seeking and all-or-nothing behaviour. By starting with correlational cross-sectional designs to explore the relationships between these variables, it was possible to later test the role of these factors in treatments for individuals with persistent physical symptoms.

A model has been proposed such that relevant beliefs and behaviours are added to existing cognitive models of persistent physical symptoms. In particular, beliefs about the unacceptability of experiencing and expressing emotions and beliefs about sharing illness experiences relate to poorer quality of life through emotional suppression and affective distress, all-or-nothing behaviour and support-seeking for personal and emotional problems. This model fits with previous cognitive behavioural models of persistent physical symptoms (Deary et al., 2007; Spence & Moss-Morris, 2007) and with evidence on ironic processing effects (Wenzlaff & Wegner, 2000).

Complete understanding of causal and maintaining factors in persistent physical symptoms in the absence of a clear medical explanation is complex task; one which the current thesis has not achieved, nor aimed to achieve. However, by investigating particular psychosocial factors related to outcomes in these samples, the current thesis has provided evidence that beliefs about the unacceptability of experiencing emotions, alongside emotional suppression, beliefs about sharing illness experiences, support-seeking, all-or-nothing behaviour, and distress, are important features of persistent

physical symptoms. These features fit within a much broader framework of understanding persistent physical symptoms.

Though the current thesis has not solved the complex issue of understanding the cause or maintenance of persistent physical symptoms, it has identified a small piece of the puzzle which fits into a much larger picture yet to be fully uncovered.

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10. Appendices

10.1. Appendix A: Beliefs about Emotions Scale

Please tick the column that best describes how you think. Please note that because people are different, there are no right or wrong answers to these statements. To decide whether a given answer is typical of your way of looking at things, simply keep in mind how you think most of the time.

| | Totally agree | Agree very much | Agree slightly | Neutral | Disagree slightly | Disagree very much | Totally disagree |
|---|---------------|-----------------|----------------|---------|-------------------|--------------------|------------------|
| It is a sign of weakness if I have miserable thoughts. | | | | | | | |
| If I have difficulties I should not admit them to others. | | | | | | | |
| If I lose control of my emotions in front of others, they will think less of me. | | | | | | | |
| I should be able to control my emotions. | | | | | | | |
| If I am having difficulties it is important to put on a brave face. | | | | | | | |
| If I show signs of weakness then others will reject me. | | | | | | | |
| I should not let myself give in to negative feelings. | | | | | | | |
| I should be able to cope with difficulties on my own without turning to others for support. | | | | | | | |
| To be acceptable to others, I must keep any difficulties or negative feelings to myself. | | | | | | | |
| It is stupid to have miserable thoughts. | | | | | | | |
| It would be a sign of weakness to show my emotions in public. | | | | | | | |
| Others expect me to always be in control of my emotions. | | | | | | | |

10.2. Appendix B: Courtauld Emotional Control Scale

Please read the following statements and tick the box to indicate how much each statement is true for you. Think about how you tend to act most of the time.

When I feel angry I keep quiet

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I refuse to argue or say anything

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I bottle it up

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I say what I feel

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I smother my feelings

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I avoid making a scene

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel angry I hide my annoyance

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I refuse to say anything about it

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I hide my unhappiness

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I put on a bold face

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I keep quiet

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I let others see how I feel

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I smother my feelings

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel unhappy I bottle it up

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I let others see how I feel

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I keep quiet

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I refuse to say anything about it

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I tell others about it

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I say what I feel

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I bottle it up

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

When I feel afraid I smother my feelings

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Almost never | Sometimes | Often | Almost Always |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10.3. Appendix C: Hospital Anxiety and Depression Scale

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

| | | |
|----------|---|------------------|
| A | I feel tense or 'wound up': Most of the time A lot of the time From time to time (occ.) Not at all | 3 2 1 0 |
| D | I still enjoy the things I used to enjoy: Definitely as much Not quite as much Only a little Hardly at all | 0 1 2 3 |
| A | I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all | 3 2 1 0 |
| D | I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all | 0 1 2 3 |
| A | Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time, but not often Only occasionally | 3 2 1 0 |
| D | I feel cheerful: Not at all Not often Sometimes Most of the time | 3 2 1 0 |
| A | I can sit at ease and feel relaxed: Definitely Usually Not often Not at all | 0 1 2 3 |

| | | |
|----------|---|------------------|
| D | I feel as if I am slowed down: Nearly all the time Very often Sometimes Not at all | 3 2 1 0 |
| A | I get a sort of frightened feeling like "butterflies" in the stomach: Not at all Occasionally Quite often Very often | 0 1 2 3 |
| D | I have lost interest in my appearance: Definitely I don't take as much care as I should I may not take quite as much care I take just as much care | 3 2 1 0 |
| A | I feel restless as I have to be on the move: Very much indeed Quite a lot Not very much Not at all | 3 2 1 0 |
| D | I look forward with enjoyment to things: As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all | 0 1 2 3 |
| A | I get sudden feelings of panic: Very often indeed Quite often Not very often Not at all | 3 2 1 0 |
| D | I can enjoy a good book or radio/TV program: Often Sometimes Not often Very seldom | 0 1 2 3 |

10.4. Appendix D: Irritable Bowel Syndrome Quality of Life questionnaire

- Q1. I feel helpless because of my bowel problems.
- Q2. I am embarrassed by the smell caused by my bowel problems.
- Q3. I am bothered by how much time I spend on the toilet.
- Q4. I feel vulnerable to other illnesses because of my bowel problems.
- Q5. I feel fat because of my bowel problems.
- Q6. I feel like I'm losing control of my life because of my bowel problems.
- Q7. I feel my life is less enjoyable because of my bowel problems.
- Q8. I feel uncomfortable when I talk about my bowel problems.
- Q9. I feel depressed about my bowel problems.
- Q10. I feel isolated from others because of my bowel problems.
- Q11. I have to watch the amount of food I eat because of my bowel problems.
- Q12. Because of my bowel problems, sexual activity is difficult for me.
- Q13. I feel angry that I have bowel problems.
- Q14. I feel like I irritate others because of my bowel problems.
- Q15. I worry that my bowel problems will get worse.
- Q16. I feel irritable because of my bowel problems.
- Q17. I worry that people think I exaggerate my bowel problems.
- Q18. I feel I get less done because of my bowel problems.
- Q19. I have to avoid stressful situations because of my bowel problems.
- Q20. My bowel problems reduce my sexual desire.
- Q21. My bowel problems limit what I can wear.
- Q22. I have to avoid strenuous activity because of my bowel problems.
- Q23. I have to watch the kind of food I eat because of my bowel problems.

Q24. Because of my bowel problems, I have difficulty being around people I do not know

Q25. I feel sluggish because of my bowel problems.

Q26. I feel unclean because of my bowel problems.

Q27. Long trips are difficult for me because of my bowel problems.

Q28. I feel frustrated that I cannot eat when I want because of my bowel problems.

Q29. It is important to be near a toilet because of my bowel problems.

Q30. My life revolves around my bowel problems.

Q31. I worry about losing control of my bowels.

Q32. I fear that I won't be able to have a bowel movement.

Q33. My bowel problems are affecting my closest relationships.

Q34. I feel that no one understands my bowel problems.

Items 1, 2, 4, 8-10, 12, 13, 16, 25-29, and 34 use the following response scale:

1 = not at all, 2 = slightly, 3 = moderately, 4 = quite a bit, 5 = extremely.

Items 3, 5-7, 11, 14, 15, 17-24, and 30-33 use the following response scale:

1 = not at all, 2 = slightly, 3 = moderately, 4 = quite a bit, 5 = a great deal.

10.5. Appendix E: Revised Fibromyalgia Impact Questionnaire

REVISED FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQR)

Participant Number _____

Duration of FM symptoms (years): _____

Time since FM was first diagnosed (years): _____

DOMAIN 1: FUNCTION

Directions: For each of the following 9 questions, check the box that best indicates how much your Fibromyalgia made it difficult to perform each of the following activities during the past 7 days. If you did not perform a particular activity in the last 7 days, rate the difficulty for the last time you performed the activity. If you can't perform an activity, check the last box.

BRUSH OR COMB YOUR HAIR

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

WALK CONTINUOUSLY FOR 20 MINUTES

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

PREPARE A HOMEMADE MEAL

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

VACUUM, SCRUB, OR SWEEP FLOORS

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

LIFT AND CARRY A BAG FULL OF GROCERIES

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

CLIMB ONE FLIGHT OF STAIRS

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

CHANGE BEDSHEETS

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

SIT IN A CHAIR FOR 45 MINUTES

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

SHOP FOR GROCERIES

No difficulty 0 1 2 3 4 5 6 7 8 9 10 Very difficult

DOMAIN 1 SUBTOTAL: _____

DOMAIN 2: OVERALL

Directions: For each of the following 2 questions, check the box that best describes the overall impact of your Fibromyalgia over the last 7 days.

FIBROMYALGIA PREVENTED ME FROM ACCOMPLISHING GOALS FOR THE WEEK

Never 0 1 2 3 4 5 6 7 8 9 10 Always

I WAS COMPLETELY OVERWHELMED BY MY FIBROMYALGIA SYMPTOMS

Never 0 1 2 3 4 5 6 7 8 9 10 Always

DOMAIN 2 SUBTOTAL: _____

DOMAIN 3: SYMPTOMS

Directions: For each of the following 10 questions, select the box that best indicates your intensity level of these common Fibromyalgia symptoms over the past 7 days.

PLEASE RATE THE LEVEL OF PAIN

No pain 0 1 2 3 4 5 6 7 8 9 10 Unbearable pain

PLEASE RATE YOUR LEVEL OF ENERGY

Lots of energy 0 1 2 3 4 5 6 7 8 9 10 No energy

PLEASE RATE YOUR LEVEL OF STIFFNESS

No stiffness 0 1 2 3 4 5 6 7 8 9 10 Severe stiffness

PLEASE RATE THE QUALITY OF YOUR SLEEP

Awoke well rested 0 1 2 3 4 5 6 7 8 9 10 Awoke very tired

PLEASE RATE YOUR LEVEL OF DEPRESSION

No depression 0 1 2 3 4 5 6 7 8 9 10 Very depressed

PLEASE RATE YOUR LEVEL OF MEMORY PROBLEMS

Good memory 0 1 2 3 4 5 6 7 8 9 10 Very poor memory

PLEASE RATE YOUR LEVEL OF ANXIETY

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Very anxious

PLEASE RATE YOUR LEVEL OF TENDERNESS TO TOUCH

No tenderness 0 1 2 3 4 5 6 7 8 9 10 Very tender

PLEASE RATE YOUR LEVEL OF BALANCE PROBLEMS

No imbalance 0 1 2 3 4 5 6 7 8 9 10 Severe imbalance

PLEASE RATE YOUR LEVEL OF SENSITIVITY TO LOUD NOISES, BRIGHT LIGHTS, ODORS, AND COLD

No sensitivity 0 1 2 3 4 5 6 7 8 9 10 Extreme sensitivity

10.6. Appendix F: Example recruitment posts

Chapter Three

Participants with IBS

I'm a PhD student at the University of London and I'm conducting research into psychological factors which influence IBS symptoms and coping. It's well known that being upset and worried can give you an upset tummy, so I'm looking at how the expression of these negative emotions relate to the effects of IBS on a person's life.

My study is a series of questionnaires that takes around 15 minutes to complete. They measure your emotions, how you express them and how much your IBS affects your quality of life. I'm hoping to get as many people with IBS to take part as possible to make sure I get a truly representative sample of people who have IBS. If you wouldn't mind taking part, and perhaps sharing this information with any friends who also have IBS, I'd be really grateful.

If you take part you don't have to give your name and you only have to give your email address if you want to be entered into a prize draw to win an Amazon or Topshop/Topman voucher.

The link to the questionnaire is <http://edu.surveymoz.com/s3/1441380/rhul-ibs>

Thanks!

Healthy controls

I'm looking for participants without Irritable Bowel Syndrome to take part in my study. I'm looking at beliefs about emotions and emotional expression in relation to how IBS influences a person's life. We all know that being upset or anxious can affect our bowels, so I'm looking at how these emotions and emotional expression might affect people with Irritable Bowel Syndrome.

Only requirement is that you are over 18 years old.

To do this I need to compare the results of people with IBS to the results of people without IBS. My study is a short series of questionnaires that takes around 15 minutes to complete. You'll be asked questions about irritable bowel symptoms, your beliefs about your emotions, how you express your emotions and then how digestive problems have influenced your life in the past. I'd be really grateful if you could take part and if you do you can enter into a prize draw to win an Amazon or Topshop/Topman voucher.

The survey can be found at: <http://edu.surveymzmo.com/s3/1441380/rhul-ibs>

Thanks!

Chapter Five

Participants with fibromyalgia

Hello,

I'm currently doing a PhD in clinical psychology. I'm conducting a piece of research looking at emotional processing, asking for support and the effects of fibromyalgia on a person's life to see how these variables are related.

Fibromyalgia (as I'm sure you know) can be very difficult to live with, but there is still a lot we don't know about it. This is why more research is needed in this area. I've chosen to look at psychological aspects: As some of you may already be aware, psychological factors can play an important part in determining how much fibromyalgia can affect a person's life.

If you have fibromyalgia and are from the UK, I would be really grateful if you could take part. To find out more and to sign up, click the link below.

I'm also looking to compare these findings to people without fibromyalgia, so please also have a look if you don't have fibromyalgia.

<http://www.surveymzmo.com/s3/1787370/The-relationship-between-emotional-processing-asking-for-help-and-fibromyalgia>

Many thanks!

10.7. Appendix G: BASIE questionnaire as it appears online

Please contact the author for permission to use the BASIE

About your illness

Please move the slider to a position that best describes how you think.

Please note that because people are different, there are no right or wrong answers to these statements.

The way you think about these things might vary depending on who you are talking to, but try focus on how you tend to think in general.

45. If people know that I am struggling in any way (physically or emotionally) with this condition, they will think I am a weak person

Totally disagree  Totally agree

46. If people know that I am struggling in any way (physically or emotionally) with this condition, then I am a weak person

Totally disagree  Totally agree

47. If people know that I am struggling in any way (physically or emotionally) with this condition, then I have failed in some way

Totally disagree  Totally agree

48. If people know that I am struggling in any way (physically or emotionally) with this condition, they will think I have failed in some way

Totally disagree  Totally agree

49. If I ask for help, then I am letting people down

Totally disagree  Totally agree

50. If I have difficulties with this condition, I should not admit it to others

Totally disagree  Totally agree

51. It is shameful to be struggling in any way (physically or emotionally) with this condition

Totally disagree  Totally agree

52. Experiencing symptoms of this condition in front of others is embarrassing

Totally disagree  Totally agree

53. With respect to living with my condition, I should put on a brave face in front of others

Totally disagree  Totally agree

54. If people know about this condition, they will judge me

Totally disagree  Totally agree

55. If people know about this condition, they will treat me like a different person

Totally disagree  Totally agree

56. I should keep this condition a secret from most people I know

Totally disagree  Totally agree

57. People will not want to be friends with me if they know I have difficulties with my condition



58. To be acceptable to others, I should keep my condition mainly to myself



59. Others will expect me to manage this condition without support from them



60. If I tell people about my condition, they will support me



61. If people know about my condition, they will still treat me like 'me'



62. It would be helpful for people to know about my condition as they will understand some of the things I have to do because of my condition.



63. People will not judge me for having this condition



64. If I talk to people about my condition, they will feel pleased that I have shared this with them.



65. Telling friends about my condition would strengthen our friendship



10.8. Appendix H: Inter-item correlations including items with coefficients greater than .8 (Chapter Six)

Table 10.1 Inter-item correlations for BASIE

| | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 |
|----|-------|-------|-------|-------|-------|-------|-------|------|------|------|------|------|----|
| 2 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 3 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 4 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 5 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 6 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 7 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 8 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 9 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 10 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 11 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 12 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 13 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 14 | - | - | - | - | - | - | - | - | - | - | - | - | - |
| 15 | .566 | - | - | - | - | - | - | - | - | - | - | - | - |
| 16 | .582 | .582 | - | - | - | - | - | - | - | - | - | - | - |
| 17 | .531 | .607 | .494 | - | - | - | - | - | - | - | - | - | - |
| 18 | .556 | .549 | .458 | .871 | - | - | - | - | - | - | - | - | - |
| 19 | .594 | .468 | .785 | .562 | .594 | - | - | - | - | - | - | - | - |
| 20 | .543 | .408 | .511 | .495 | .581 | .690 | - | - | - | - | - | - | - |
| 21 | -.354 | -.280 | -.370 | -.381 | -.500 | -.522 | -.554 | - | - | - | - | - | - |
| 22 | -.356 | -.397 | -.336 | -.508 | -.601 | -.479 | -.459 | .700 | - | - | - | - | - |
| 23 | -.127 | -.096 | -.210 | -.061 | -.170 | -.231 | -.132 | .316 | .318 | - | - | - | - |
| 24 | -.328 | -.427 | -.289 | -.541 | -.530 | -.408 | -.430 | .510 | .634 | .259 | - | - | - |
| 25 | -.324 | -.370 | -.420 | -.519 | -.533 | -.576 | -.444 | .616 | .540 | .354 | .695 | - | - |
| 26 | -.368 | -.377 | -.377 | -.445 | -.522 | -.536 | -.397 | .668 | .684 | .334 | .680 | .783 | - |

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |
|----|--------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
| 2 | .748 | - | - | - | - | - | - | - | - | - | - | - | - |
| 3 | .672 | .861 | - | - | - | - | - | - | - | - | - | - | - |
| 4 | .635 | .790 | .795 | - | - | - | - | - | - | - | - | - | - |
| 5 | .758 | .652 | .687 | .744 | - | - | - | - | - | - | - | - | - |
| 6 | .637 | .746 | .870 | .901 | .750 | - | - | - | - | - | - | - | - |
| 7 | .621 | .704 | .781 | .815 | .709 | .844 | - | - | - | - | - | - | - |
| 8 | .629 | .694 | .784 | .777 | .749 | .845 | .909 | - | - | - | - | - | - |
| 9 | .500 | .611 | .660 | .657 | .506 | .723 | .733 | .724 | - | - | - | - | - |
| 10 | .557 | .531 | .586 | .633 | .609 | .667 | .706 | .710 | .619 | - | - | - | - |
| 11 | .326 | .305 | .365 | .545 | .492 | .439 | .516 | .531 | .410 | .576 | - | - | - |
| 12 | .409 | .381 | .426 | .508 | .488 | .492 | .581 | .568 | .489 | .580 | .808 | - | - |
| 13 | .426 | .510 | .569 | .621 | .528 | .629 | .717 | .701 | .609 | .577 | .607 | .637 | - |
| 14 | .477 | .345 | .418 | .379 | .536 | .470 | .469 | .494 | .351 | .483 | .486 | .517 | .452 |
| 15 | .423 | .337 | .457 | .541 | .537 | .524 | .482 | .492 | .510 | .501 | .466 | .438 | .410 |
| 16 | .466 | .477 | .550 | .539 | .524 | .629 | .629 | .615 | .742 | .612 | .430 | .490 | .593 |
| 17 | .493 | .313 | .361 | .447 | .551 | .465 | .458 | .453 | .388 | .421 | .456 | .499 | .355 |
| 18 | .461 | .349 | .327 | .409 | .480 | .428 | .425 | .424 | .382 | .431 | .465 | .539 | .351 |
| 19 | .564 | .525 | .553 | .574 | .603 | .621 | .669 | .654 | .643 | .618 | .516 | .560 | .602 |
| 20 | .443 | .345 | .347 | .333 | .444 | .381 | .382 | .458 | .361 | .436 | .381 | .442 | .488 |
| 21 | -.3266 | -.194 | -.236 | -.222 | -.357 | -.311 | -.292 | -.341 | -.278 | -.311 | -.227 | -.328 | -.248 |
| 22 | -.324 | -.252 | -.240 | -.318 | -.393 | -.343 | -.257 | -.308 | -.253 | -.332 | -.282 | -.303. | -.217 |
| 23 | -.145 | -.153 | -.110 | -.184 | -.201 | -.186 | -.096 | -.073 | -.195 | -.206 | -.001 | -.008 | -.139 |
| 24 | -.270 | -.114 | -.106 | -.227 | -.335 | -.221 | -.147 | -.157 | -.259 | -.246 | -.320 | -.265 | -.196 |
| 25 | -.346 | -.196 | -.203 | -.316 | -.412 | -.354 | -.314 | -.316 | -.343 | -.329 | -.240 | -.291 | -.253 |
| 26 | -.352 | -.239 | -.240 | -.339 | -.437 | -.374 | -.319 | -.314 | -.268 | -.268 | -.230 | -.228 | -.261 |

10.9. Appendix I: Group comparisons between those with FMS and healthy controls for BASIE scores after controlling for affective distress using the entire sample (Chapter Six).

Table 10.2 Estimated marginal means, standard errors and F statistics for BASIE scores after controlling for affective distress

| | FMS | | Healthy controls | | F statistic |
|------------------|---------|-------|------------------|-------|-------------------------|
| | EMM | SE | EMM | SE | |
| BASIE totals | 1080.98 | 34.06 | 669.65 | 64.42 | F(1, 157)=29.71, p<.001 |
| BASIE Factor One | 623.40 | 23.67 | 382.82 | 44.77 | F(1,57)=21.04, p<.001 |
| BASIE Factor Two | 457.58 | 14.53 | 286.83 | 27.47 | F(1,157)=28.15, p<.001 |

**10.10. Appendix J: Participant booklet to accompany the intervention
designed in Chapter Eight**

Please contact the author for permission to use this booklet

Living with IBS: Managing difficult emotions and stress that can accompany living with IBS.



- **Session 1 – Introduction to the Course**

- **Why are we here?**

Everyone attending this course is here because they share the common experience of living with irritable bowel syndrome (IBS). Every individual might differ in terms of what difficulties they have, what can trigger symptoms and how they might deal with these, but all of you have some level of symptoms which can impact on your daily life.

Taking part in this course involves answering questionnaires before, during and after the course. This will allow the researchers to look at trends and how they might change over the course. More information about the research itself can be found in your 'Information Sheet'.

- **About these sessions**

This course will last a total of 5 sessions. In each session we will be learning new information that should help with skills around living with IBS. These sessions will include group discussions which means, if you like, you can all share information with each other about your shared experiences and how you cope with some of your experiences of living with IBS.

We have made some basic assumptions about you while designing this course. This is so it can be designed so you can get the most information from it. These assumptions are:

- Your symptoms and your discomfort are very real. We may not be able to see it or measure it, but we know that you experience discomfort and symptoms on a regular basis.
- Your IBS has a negative impact on your life in some way
- You are ready to learn about IBS and how you think and feel about your symptoms in the hope that you can make some positive changes. This will involve some effort on your part to implement some of the changes we will talk about.

- **More information about the group**

The group will be run by Dr. Abigail Wroe (Clinical Psychologist) and Hannah Bowers (PhD student), whose contact information is provided below

The groups will be held on the following dates at [time]. We will meet at [location, address].

Abigail Wroe

Tel: 01784 276532

Email: Abigail.Wroe@rhul.ac.uk

Hannah Bowers

Tel: 01784 44 3703

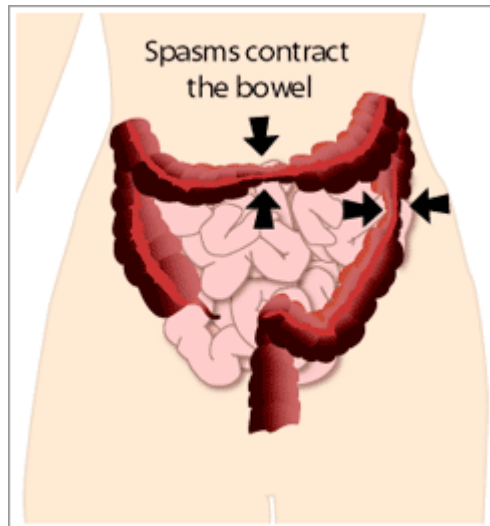
Email:

[Hannah.Bowers.2010@live.rhul.a
c.uk](mailto:Hannah.Bowers.2010@live.rhul.ac.uk)

During this course, we will be talking about symptoms, how we deal with them and how they make us feel. We will also be thinking about how we deal with those emotions. The aims of the course are to teach you new skills to help you cope with any stress and anxiety that can come with IBS. Some people find it difficult to think about, and talk about emotions, and in some case this can affect your symptoms. This might mean you might feel slightly worse before you start to feel better. Remembering this might help relieve any anxiety you might feel at the beginning of the course.

1. What is IBS?

Irritable Bowel Syndrome (or IBS) is a collection of bowel symptoms that might vary from person to person, but can affect a person's daily life and most often includes abdominal (tummy) pain. It has been found to occur in around 10-20% of people in Western countries. These symptoms are not due to a physical disease, but are related to a problem with how your digestive system functions.



These symptoms can really affect a person's life (personal relationships, work, leisure activities) so they should be taken seriously. However, IBS is not a disease. This means there is not any identifiable damage or infection in your body to diagnose the disorder. Instead it is called a syndrome, which means it is diagnosed due to a collection of ongoing symptoms in a particular person. Because there is no noticeable damage or infection, this means IBS is not life threatening, although it should still be taken seriously.

The symptoms of IBS can include:

- Abdominal pain and spasms, often relieved by going to the toilet.
- Diarrhoea, constipation or an erratic bowel habit

- Bloating or swelling of the abdomen.
- Rumbling noises and excessive passage of wind.
- Urgency (An urgent need to visit the toilet).
- Incontinence (If a toilet is not nearby).
- Sharp pain felt low down inside the rectum.
- Sensation of incomplete bowel movement.

What causes IBS symptoms?

The main reason you experience the symptoms of IBS is that there is an abnormality in the movement of the bowel, along with increased sensitivity to the bowel and an altered production of mucus. This means that for whatever reason, your bowel is moving in an irregular pattern which can cause some symptoms. Usually your muscles in your bowel will move in a coordinated and consistent way, but in IBS they may not. This will then affect the consistency of the stool and the number of times you go. It might also result in muscle cramps. Along with this inconsistent bowel muscle movement, over time you will become especially aware of the movement of your bowels which makes you more sensitive to discomfort and pain. You may also find that in response to this, your bowel produces more or less mucus than it normally would.

How do the symptoms start?

For some people the symptoms of IBS begin gradually over a long period of time and only become noticeable when they become more severe. For others the onset might be a bit faster. IBS can be triggered by a particular event. This might be a viral or bacterial infection (like gastroenteritis, also known as stomach flu) or by a stressful event in a person's life.

Stomach Flu and IBS

Research has shown that around 10% of people who have a particular type of bacterial stomach flu go on to receive a diagnosis of IBS 6 months later. It is believed that this is due to some of the toxins present during the infection affecting the nerves that influence the bowel's muscle movements as well as hormone production. It might also be that when someone has stomach flu, their sensitivity to their bowel habits increase which makes them feel pain and discomfort more than people without IBS.

2. Stress and IBS

You may find that during periods of stress, your symptoms get worse. This is quite common in people with IBS. This is because there is a very close relationship between the brain and the gut.



Fight or Flight

The 'fight or flight' response refers to the response in our bodies when we experience stress. Humans are naturally primed to defend themselves when faced with a stressful situation. This means your nervous system becomes more active and there is an increase in stress hormones, such as adrenaline.

Adrenaline has a number of effects on our bodies to help supply us with energy to fight or flee from the situation. It can...

- Increase the heart rate
- Increase breathing rate
- Release more sugar from the liver
- Bowel muscle movements slow down or stop



This system used to be really useful when most stressful events (like attack of a wild animal) could be resolved by fight or flight, but nowadays stress tends to be caused by emotional, social or physical factors.

All of these bodily changes in response to stress can affect the bowel. This might mean that your bowel moves faster or it might move more slowly. So you might find that stress can either result in diarrhoea or constipation, or a bit of both. Some people find stress can also make them feel nauseous. So this might mean that if you're feeling nervous about an exam or a job interview, for example, you might experience these bowel symptoms.

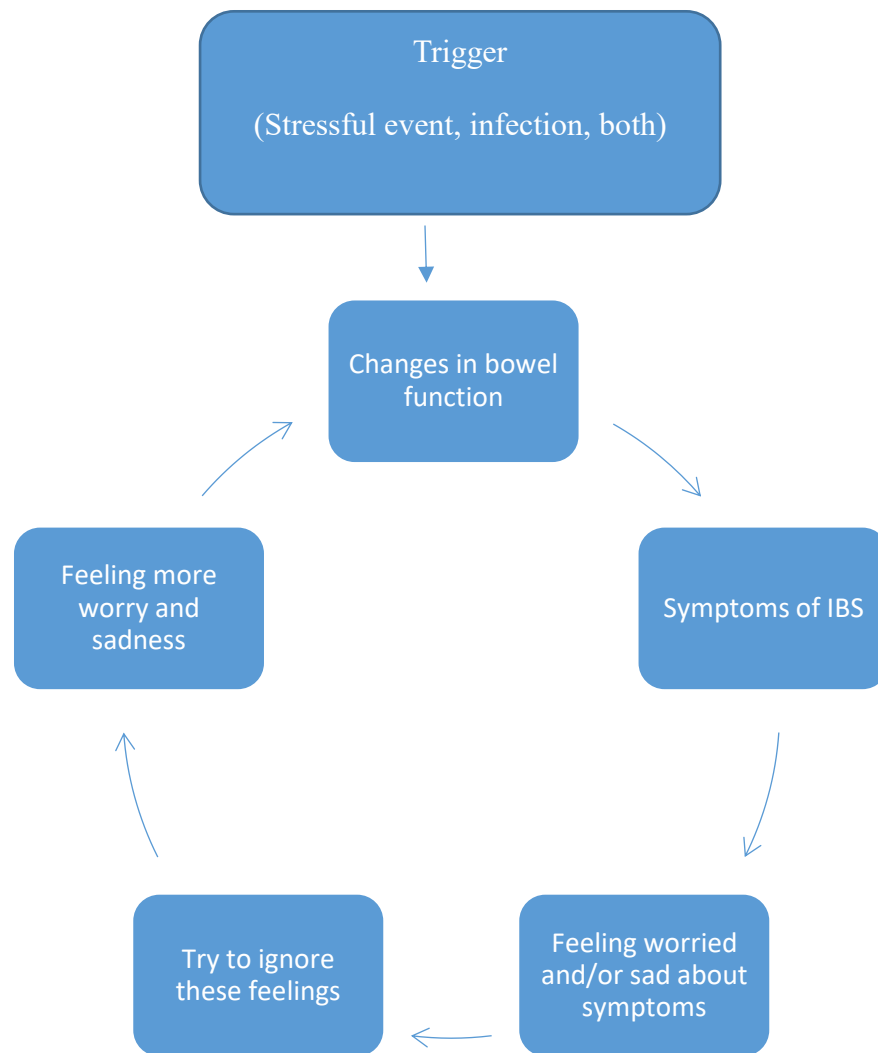
Responding to stress

How we respond to stress is really important. Some people like to tackle problems head on, while others like to power through as if the stress weren't there. Many people can find themselves stuck in a vicious cycle of symptoms, pain and stress due to how they respond to both their symptoms and their stress.

Here's an example of someone who is stuck in a vicious cycle:



Lara started to notice she was going to the toilet more often and that she had stomach cramps and diarrhoea. Lara was very worried by these symptoms, and had been told she had IBS. Lara became increasingly worried about finding herself out somewhere and not being able to find a bathroom quickly enough. In response to this worry, Lara started going out a bit less. This made her upset and anxious. Because of her worries and her upset, the symptoms got worse. Lara didn't feel like she should tell anyone about how she's feeling because she didn't want to seem stupid or weak, so she tried to distract herself from these emotions but found certain thoughts would keep popping up anyway, which just made her worry more.



3. Stress, setbacks and control...

During times of stress or change, your symptoms may flare up.

Making some lifestyle changes can allow you to get your symptoms under control rather than allowing your symptoms to control you. There is no magic cure and this change happens gradually. If you manage to persevere in making some helpful changes, your confidence will grow and minor setbacks will become less traumatic. You will learn how powerful your thoughts are in influencing how you feel and what you can do.

Home task

After each session you will be given a task to complete at home. It is really important that you try to do all home tasks as these will heavily support your learning throughout the course.

For this home task, you are asked to jot down any time you notice a particular symptom that is bothersome to you. Along with this, you should write the thoughts you have in relation to this symptom, how this made you feel emotionally and then what you did with that emotion – did you tell someone about it or did you try to ignore it or distract yourself from it?

There's an example by Lara in the table below to help you fill out the table yourself.

| Symptom | Thought | Feeling/ emotion | How you respond to this feeling |
|---|---|--------------------------------|--|
| <i>Invited out for a curry with friends</i> | <i>I will feel bloated and uncomfortable. People will notice I am on the toilet for</i> | <i>anxious, sad, alone</i> | <i>Keep it to myself and tell friends I have other plans</i> |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Session 2 - Identifying and managing thoughts about emotions

Review of Home Task 1

- Were there any patterns you noticed?
- Did you learn anything new about yourself or your way of thinking?
- Do you think you could have responded differently?

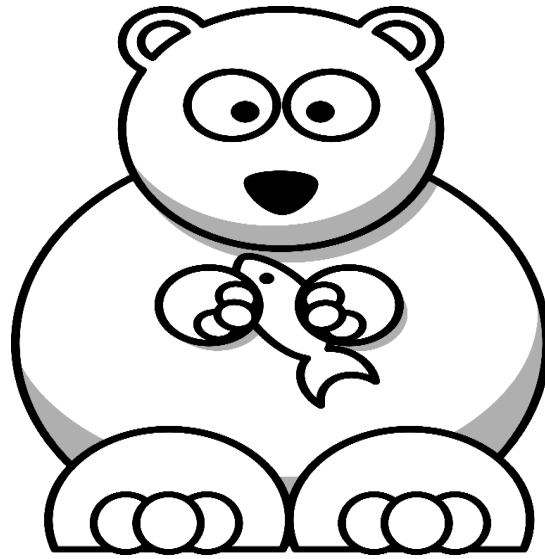
1. How we respond to our emotions

Everyone experiences periods of worry or sadness in their lives, such as worrying about the results of a test. In a lot of these situations, people try to distract themselves or ignore the worry so they can go about their day. This can be effective for short-term problems like awaiting a test result. However if we use this strategy with long-term problems, it can have a negative impact on us mentally and physically.

Some of the worries and struggles that come with IBS can be long-term, such as the daily worry of whether you will experience symptoms while you're out and about. While short-term worries have an end-point, long-term worries don't. This means that for long-term worries, we would need to suppress our negative feelings continually, which would be exhausting.

If we try to control or suppress our thoughts and feelings, they tend to just get bigger and bigger. In this case, avoidance is not the answer. This means that a small to moderate sized worry can become much greater than it really is, just by us trying to avoid it. This can then make us feel even more stressed and anxious because now we're also worried about having a particular thought or feeling.

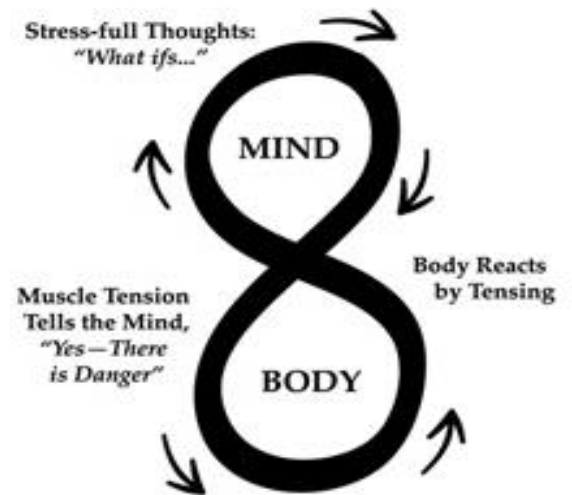
White Bear Challenge



So we know that trying to squash emotions it makes them stronger...

2. What happens in our bodies when we try to control and suppress?

If we're trying really hard to control our thoughts and suppress our emotions, our bodies are going to become very tense, which can make us tired and can cause pain and cramps. If the muscles in our bodies are very tense and rigid, our abdomen will also be tense. If we want to have regular bowel movements, we need our abdomens to be relaxed and free of tension.

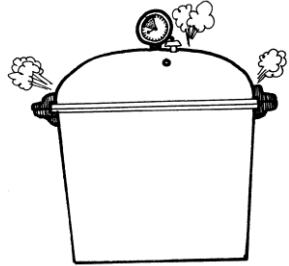




3. How else does trying to control and suppress our feelings affect us?

If we keep our thoughts and feelings to ourselves and put on a brave face, the people around won't know when we're struggling. If we're having a tough time, having the support of the people around can really help. If they don't know we need some comfort or support because we're keeping it all in, they can't help us. If we keep things to ourselves, we can end up feeling alone and isolated from the people around us.



So in summary....

| What happens when we try to push away, hide or ignore our feelings? | |
|---|---|
| 1. It can make them stronger |  |
| 2. It causes muscles to tense e.g. shoulder pain, and muscles in tummy to cramp which can feel painful and lead to bloating and diarrhoea |  |
| 3. We may feel isolated and alone, and miss out of getting helpful practical and emotional support from others |  |

4. What drives us to suppress our emotions?

We all have negative/unhelpful thoughts sometimes. But we may not always be aware of these thoughts because they are automatic. We tend to be able to notice how we feel emotionally, but we don't always notice the thoughts that might underlie these feelings. For example, if you're out with your friends and you need to use the bathroom. You may notice that you feel tense and anxious. However you might not notice the thoughts going on like "I can't let anyone know that I'm worried. I need to keep my cool."

In order to better deal with difficulties, we need to identify the negative thoughts that underlie them. Once you are able to identify these thoughts, you can start to examine and evaluate them. This means you can start to look for helpful, alternative ways of thinking. These alternative won't necessarily be positive, but they will be more realistic ways of looking at a situation.

There is no right or wrong way of thinking, but some thoughts are not as helpful as others. Learning to recognise these patterns of thinking is an important step towards managing your symptoms.

Common unhelpful thoughts:

Here are some common unhelpful thoughts that people with IBS have identified:

1. People will think I'm stupid if I tell them what I'm worried about.
2. I should be able to deal with these worries on my own.
3. I should keep worries and upset to myself otherwise people won't accept me.
4. I shouldn't give in to these feelings. I have to keep fighting.
5. If I think bad thoughts, it means I am weak.
6. People won't like me if I show any signs of weakness.
7. I should control my negative feelings.

Do any of these sound familiar? In the following sections we look at some of the common problems that underlie thoughts such as these.

See if you recognize some of these unhelpful thoughts in your own ways of thinking.

Shoulds

Examples

“I should be able to deal with these worries on my own.”

“I should keep worries and upset to myself otherwise people won't accept

..

Many thoughts include the word 'should'. The word 'should' suggests that there is a standard or rule that must be followed. It can apply to us or to others. We may feel that others 'should' act in a certain way. We also may spend quite a lot of time telling ourselves how we 'should' be acting or what we 'should' be feeling.

This can be unhelpful as it fills us with expectations of others and ourselves that are probably not possible and leave us feeling disappointed or upset. The problem with 'should' thoughts is that they are often not achievable in reality and so they leave us upset when we can't achieve them.

Example

“I should be able to deal with these worries on my own.”

Do you think this is always possible?

Black and white thinking:

Examples

“If I think bad thoughts, it means I am weak.”

“People will think I'm stupid if I tell them what I'm worried about.”

The tendency to think in black and white or in absolutes is another common unhelpful thought. Sometimes these thoughts sound like “if...then...” statements. They tend not to consider other possible outcomes.

How might these thoughts affect us?

Example

“People will think I’m stupid if I tell them what I’m worried about.”

- What might be the impact of thinking like this?
- If you believe this, how would you feel if you ask for help?
- What are some of the other possible outcomes of this situation?

Lara believes some of these unhelpful thoughts. Believing these thoughts means she feels a need to suppress her thoughts and feelings. Because of this suppression, Lara is feeling very tense which is giving her a tummy ache. She also feels quite worried and lonely. As we’ve already learned, keeping our thoughts and feelings to ourselves can have negative effects on us emotionally and physically, so this isn’t the best way to handle our emotions

In addition to this, because Lara believes other people will reject her, or feel she is stupid if she shares her thoughts and feelings, she won’t tell people how she feels or that she needs support. If we are struggling emotionally or with physical symptoms, having support from the people around us can be really useful. If they don’t know you need help, they can’t help you. So because of this, Lara doesn’t have the support she needs from her friends and family, which makes things harder.

Lara is so worried about showing other people how she’s feeling that she’s been avoiding seeing her friends and family. Because of this Lara has begun to feel lonely and isolated.

Home Task

1. This home task is very similar to Home Task 1. Once again you’ll be identifying thoughts and feelings that are bothersome to you and noticing how you respond to that thought/feeling. In addition, this time, you’re invited to write down alternative ways of responding.

The aim is to notice when you experience emotions and what we do with them. If you can, try out new ways of responding to your emotions.

2. Look over next week’s workbook (Session 3) and write down some goals in section “4 – Goals.” E.g. to notice when I experience an emotion. To notice what I do in

response to emotions, to think about people who I could be more open about my emotions, to practice expressing emotions e.g. to self, to others.

| Symptom | Thought | Feeling/e motion | How you respond to this feeling | Alternative response to that feeling | What is the impact of this response? |
|---|--|------------------|--|---|--------------------------------------|
| <i>Invited out for a curry with friends</i> | <i>I will feel bloated and uncomfortable. People will notice</i> | <i>Anxious</i> | <i>Keep it to myself and tell friends I have other plans</i> | <i>Tell a friend I am feeling worried and suggest going somewhere else, or say that you will just eat plain rice and a little curry</i> | |
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Session 3 - Thinking about change

Review of Home Task 2

- Did you notice any of the same patterns as before?
- In what ways could you have responded differently?
- How might this different response have changed the situation?

Responding to our Feelings

We know from previous sessions that stress and tension can affect us emotionally and physically. This can then affect our symptoms of IBS. As much as we may like to, we cannot stop ourselves having feelings.

What we can change is how we respond to and deal with any feelings that might be unpleasant.

In the box below, write down as many different possible ways of responding to this feeling:

“I’m upset because my bowel is really bothering me today”

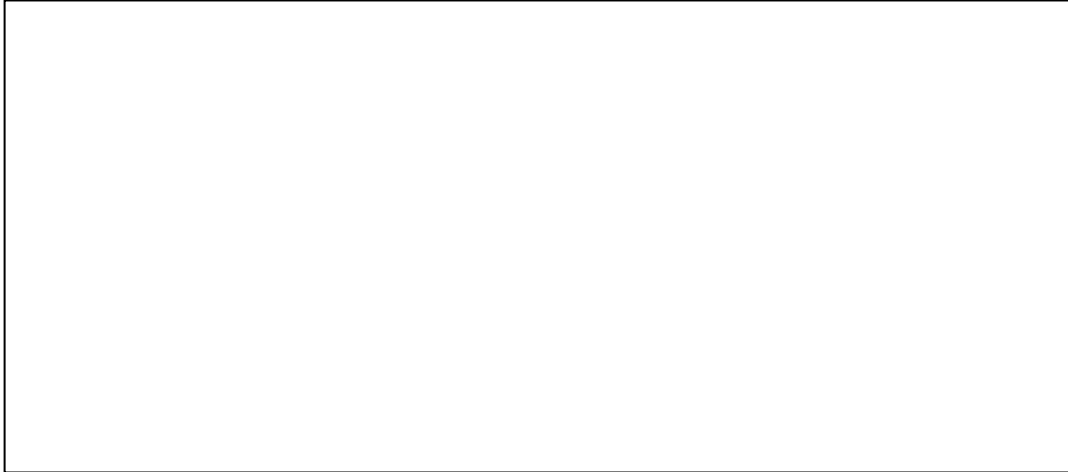
Lara:

I should cancel my plans with my friends and stay at home alone. I can tell them something important came up.

Talking to Others

Sharing your worries and upset with others can be really helpful for many reasons. Firstly, you avoid the tension and added stress that comes with trying to control or suppress your thoughts and feelings, which means your body (and bowel) is more relaxed. Secondly it means others can offer you support and help which can alleviate some of your worries. They might be able to offer a new perspective that can help you feel better, they might have a solution to a pragmatic problem or they might just be able to offer you some comfort and emotional support.

In the box below, list the people you think you could talk to about either emotional or physical struggles you might be experiencing. It might be a friend, family, partner or colleague. Alternatively it might be a more formal form of emotional support like a counsellor, support group or online forum.



1. Problem solving

Are there different ways we could express emotions? E.g. to others (identify certain people), to the group, to ourselves, in a journal?

2. Thought challenging

Once you have identified your patterns of negative thinking, the next step is to evaluate your thoughts and to look for more helpful alternatives.

Thoughts are not Facts

Sometimes if we have a set way of thinking about things, we assume it's always true. Actually, our thoughts are just thoughts, they are not facts. Sometimes it can be difficult to tease apart our thoughts from facts.

Let's think about 'is the thought helpful?' If not, then we can think of a few tools to manage the thought:

One way to help with this is to try to notice your thoughts and rephrase them so that they begin with "I am having the thought that..."

For example, if you were running late meeting a friend because you were felt unwell because you were worried about leaving the house, you might start thinking "they're going to think I'm stupid for being worried about leaving the house". Instead rephrase that as "I am having the thought that they're going to think I'm stupid for being worried about leaving the house."

Does this change how this particular thought might make you feel now you've rephrased it? Often rephrasing it as a thought, and not a fact can make it much less daunting and seem more manageable. Once you can realise it is not a fact, you can start to challenge these unhelpful thoughts.





Weighing things up

It may be helpful to consider how balanced the thought is. Imagine you are in court trying to weigh up how accurate the thought is.

What is the evidence for this thought?

What is the evidence against it?

Is there a more helpful, more balanced thought? What would I tell someone else in this situation?

You may also wish to ask yourself:

- Am I seeing the situation in black and white?
- I am expecting the worst or catastrophising?
- Am I trying to read other people's minds?
- Am I jumping to conclusions?

The goal of this for you to consider how helpful the thought is, and if it is not helpful, then to think about what you can do about it. Sometimes you can develop a more helpful, and more balanced thought.

Lara's example

| | |
|--|---|
| Thought: People will think I'm weak if I tell them I am upset about my IBS symptoms | |
| Evidence for | Evidence against |
| Some people think being ill is a sign of weakness | When I did tell a friend, she helped me |
| | Lots of people have symptoms of IBS |

| | |
|---|------------------------------------|
| | Its ok to struggle if I am in pain |
| | |
| | |
| | |
| <p>New, more balanced thought: It's ok to feel upset about my symptoms. Although I don't want to tell everyone, there are a few friends I can trust and they will take me for who I am. They may be able to support me. (what would I tell someone else in this situation)</p> | |

3. Pros and Cons of Sharing with Others

There are many reasons why we might choose to talk to others or to keep things to ourselves.

Lara thinks about telling her close friend that she is struggling with symptoms and this upsets her and has filled out some pros and cons of telling her friend. Use the space below to list any positives and negatives you can think of about trying to share with others more.

| Pro | Con |
|--|--------------------------------------|
| She will understand why I sometimes say no to going out | She may feel burdened by my problems |
| She will stop wondering what is going on for me | She may not understand |
| She may be able to support me | She may treat me differently |
| She can help encourage my friends to go to places that are easy for me e.g. not go for a curry | |
| It will make me feel better that someone knows | |
| She will feel good that I have shared my feelings with her | |
| We will be become closer friends | |
| | |

Sharing with Each Other

One of the added benefits of these sessions is that you are with other people who understand your experience with IBS. This means they can offer insight, understanding and compassion towards any struggles you might be experiencing. If you feel comfortable, you may want to share some of the thoughts or feelings that particularly bother you. For example, one of the situations written on your Home Task sheet from sessions one and two.

Did you notice any unhelpful thoughts or worries about sharing with each other in that task?

4. Goals

Let's set some clear goals.

- Goals can help to give us focus and work towards particular things that are important to us.
- Goal setting can also be a helpful process in helping to face our fears, BUT if we want them to be effective; we need to make them SMART!



Short term goals (to focus on in the next 2 weeks)

Lara's short term goals:

- To notice when I experience an emotion
- To notice what I do in response to emotions
- To think about people who I could be more open with about my emotions
- To practice expressing emotions e.g. to self and in this group

Your short term goals:

-
-
-
-

Medium term goals (by the end of the course)

Lara's medium term goals:

- To be skilled at noticing my emotions
- To talk to friends about my emotions
- To go out for dinner with friends and tell them when I need the toilet
- To tell friends why I might say no to going out

Your medium term goals:

-
-
-
-

Long term goals (for the future)

Lara's short term goals:

- To be able to express my emotions when helpful
- To notice unhelpful thoughts about emotions and look for alternate ways of thinking

Your long term goals:

-
-
-

Home Task

This week you're going to be starting to write down your feelings. This involved jotting down how you're feeling and what you're thinking regularly. You should aim to do this at least once a day. We will contact you via phone, text or email to remind you and link you to your online writing portal. What you write down is only for you and the people running the group to read. What you write will not be shared with other participants of the group unless you choose to bring it up in person.



In addition to your journals, you should try to identify any unhelpful thoughts about how you're feeling and weigh up the evidence for and against. Use Lara's example above to help you. Try to do this as often as you notice any of these thoughts.

| Thought: | |
|------------------------------------|-------------------------|
| Evidence for | Evidence against |
| | |
| | |
| | |
| | |
| | |
| New, more balanced thought: | |
| | |

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|------------------------------------|-------------------------|
| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |
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| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |
| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |
| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |
| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |

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| Thought: | |
| Evidence for | Evidence against |
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| New, more balanced thought: | |

Session 4: Anxiety and Stress

Review of Home Task 3

How did you find it? Were there any challenges? Any unhelpful thoughts about completing the task?

1. What is anxiety?

Anxiety is a completely normal and natural response to situations that we perceive as threatening. Everyone experiences anxiety, although the level of anxiety and the situations in which it presents itself can differ from person to person. For example, some people are terrified of speaking in front of a large audience, whereas other people are able to do this and remain calm.

Fight or Flight

We already talked a little bit about Fight or Flight in session one, but let's take a closer look at how being anxious can influence us.

Anxiety serves a very important function – to protect us from danger. When we are faced with a threat our bodies produce a surge of adrenaline that equips us to deal with that threat. This is commonly referred to as 'fight or flight'.

Imagine this scene: A caveman is out hunting for his dinner, when he is faced by a hungry tiger.



What does he need to do in order to survive?

He needs to either fight the tiger off or run away!

In order to fight or flee, the body must prepare itself in a number of ways:

- The brain sends messages to the body to pump adrenalin into the bloodstream and large skeletal muscles of the arms and legs
- As a result the heart pumps faster and needs more oxygen
- The body needs to cool down so it sweats, causing clamminess or capillaries to come to the surface of the skin resulting in blushing
- To be as light as possible there may be a need for the bowels to empty or frequent urination to occur

In modern life it is very unlikely that we will be faced with hungry tigers – but we are still exposed to real or imagined threats or stressors in daily life and our bodies respond to these with the same response. If the situation is not physically threatening (e.g. giving a presentation) then this response is not helpful for coping with the situation and can actually be quite frightening.

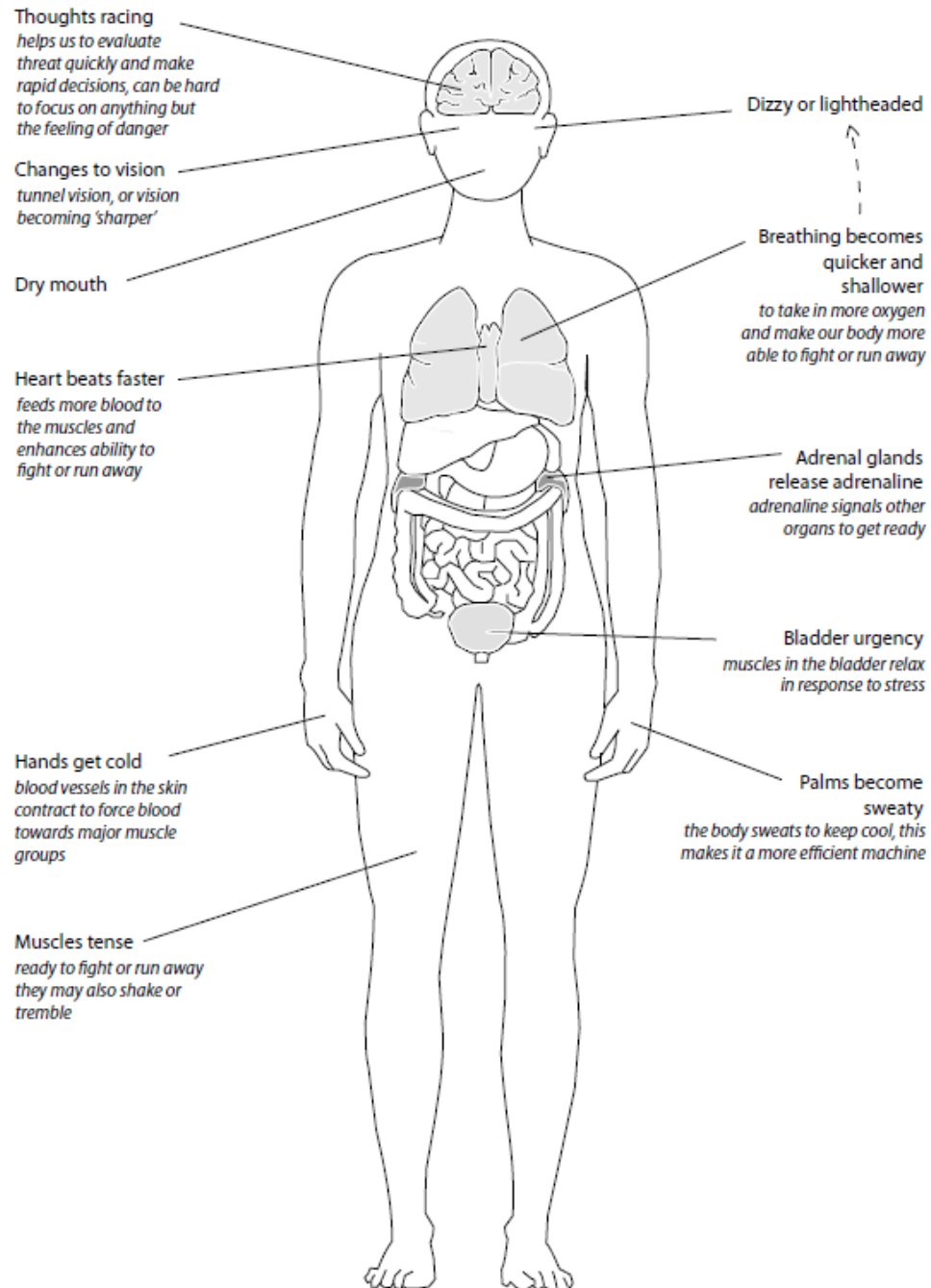
Anxiety: What do you experience?

- | | |
|---|--|
| <input type="checkbox"/> Palpitations/ rapid heart | <input type="checkbox"/> Clammy hands |
| <input type="checkbox"/> Faintness/ dizziness | <input type="checkbox"/> Tiredness |
| <input type="checkbox"/> Numbness | <input type="checkbox"/> Sweating |
| <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> Headaches |
| <input type="checkbox"/> Choking feeling | <input type="checkbox"/> Chest pain/tightness |
| <input type="checkbox"/> Butterflies | <input type="checkbox"/> Stomach pains |
| <input type="checkbox"/> Appetite | <input type="checkbox"/> Muscle ache/pain |
| <input type="checkbox"/> Flushes/chills | <input type="checkbox"/> Problems swallowing |
| <input type="checkbox"/> Feel sick | <input type="checkbox"/> Shaky / trembling |
| <input type="checkbox"/> Visual changes | <input type="checkbox"/> Pains in head |
| <input type="checkbox"/> Pins and needles | <input type="checkbox"/> Voice tremor |
| <input type="checkbox"/> Dry mouth | <input type="checkbox"/> Jelly legs |
| | <input type="checkbox"/> Bladder/bowels |

What happens in our body when we're anxious?

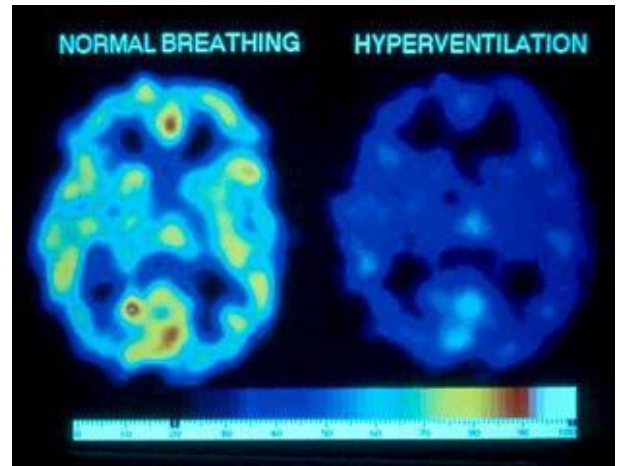
Threat System (Fight or Flight)

The 'fight or flight' response gets the body ready to fight or run away. Once a threat is detected your body responds automatically. All of the changes happen for good reasons, but may be experienced as uncomfortable when they happen in 'safe' situations.



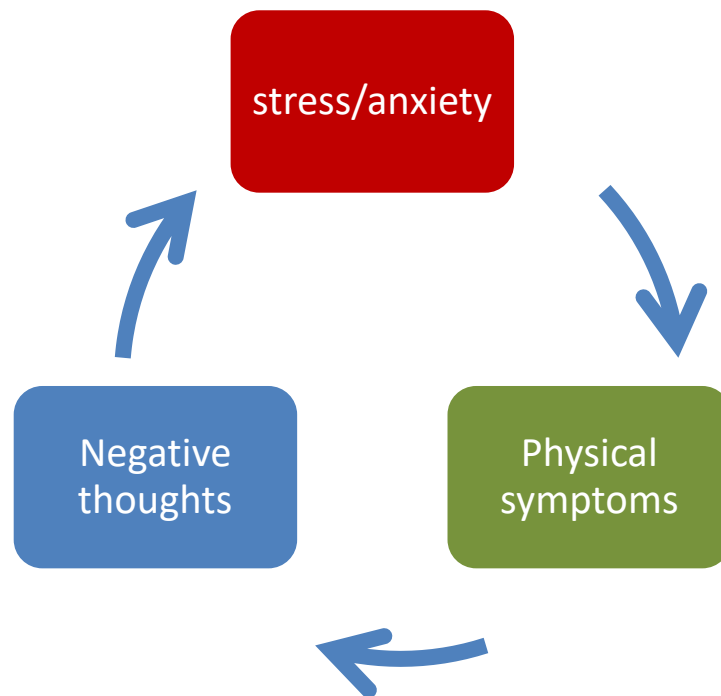
Breathing & Anxiety

- Worries lead to changes in breathing patterns – short & shallow
- Changes levels of oxygen & carbon dioxide – push out more CO₂
- Leads to other physical symptoms



Vicious Cycle

Anxiety symptoms can impact on your health.



Use the space below to jot down some worries, physical symptoms and negative thoughts that you think might be in your vicious cycle.

Stress/anxiety/worry:

E.g. I might need to go to the toilet.

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.....

Physical symptoms:

E.g. Butterflies in tummy.

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.....

Negative thoughts:

E.g. I'm going to have a toilet accident and it will be humiliating. People will notice. I cant tell people I am worried as they will judge me

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.....

2. What Keeps Anxiety Going?

Avoidance

Lara has found that when she is feeling unwell with her IBS that going out places with friends is quite stressful. To avoid this stress, Lara will often make an excuse to cancel plans with friends and instead stay at home alone when she is feeling unwell.

Common sense says that if doing something makes you more tense, you should avoid it.

COMMON SENSE IS WRONG.

Avoiding may help in the short term, but in the long run, you just build up more trouble for yourself. You have to face up to the problems in your life. Facing up to stress will be hard in the short term but, in the long run, will greatly help you control your stress.

Examples of avoidance include:

- Not telling people what is going on for me
- Reduced activity – seeing friends, interests
- Ignoring things
- Withdrawing
- Not making decisions or taking responsibility
- Taking the easy option

Write some of your examples of avoidance here:

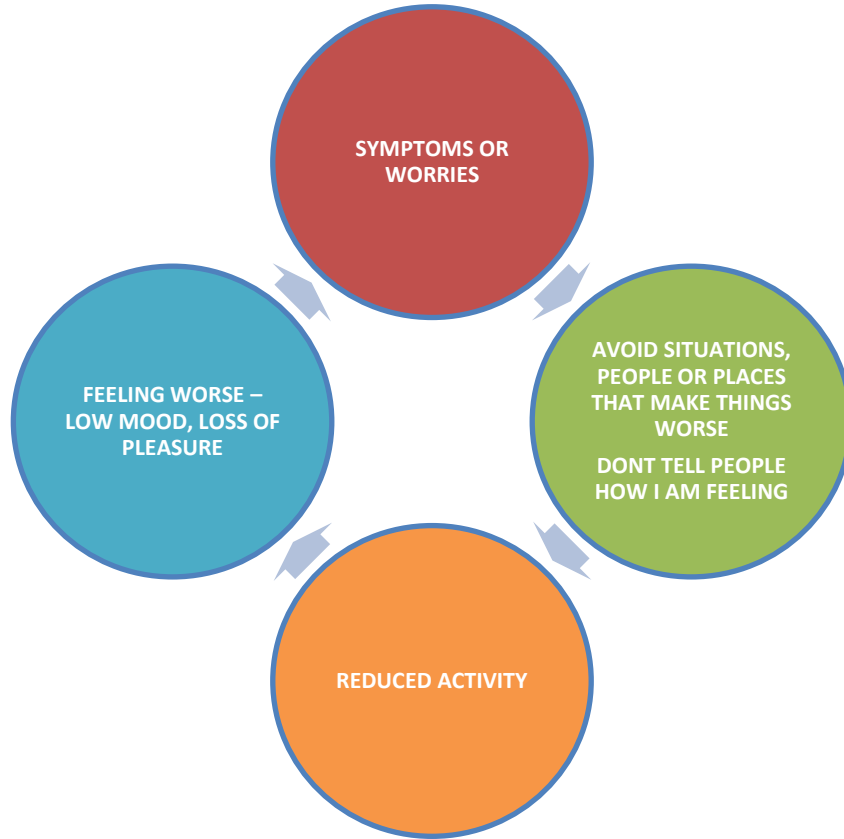
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Avoidance Cycle



What do you notice about this avoidance cycle?

.....

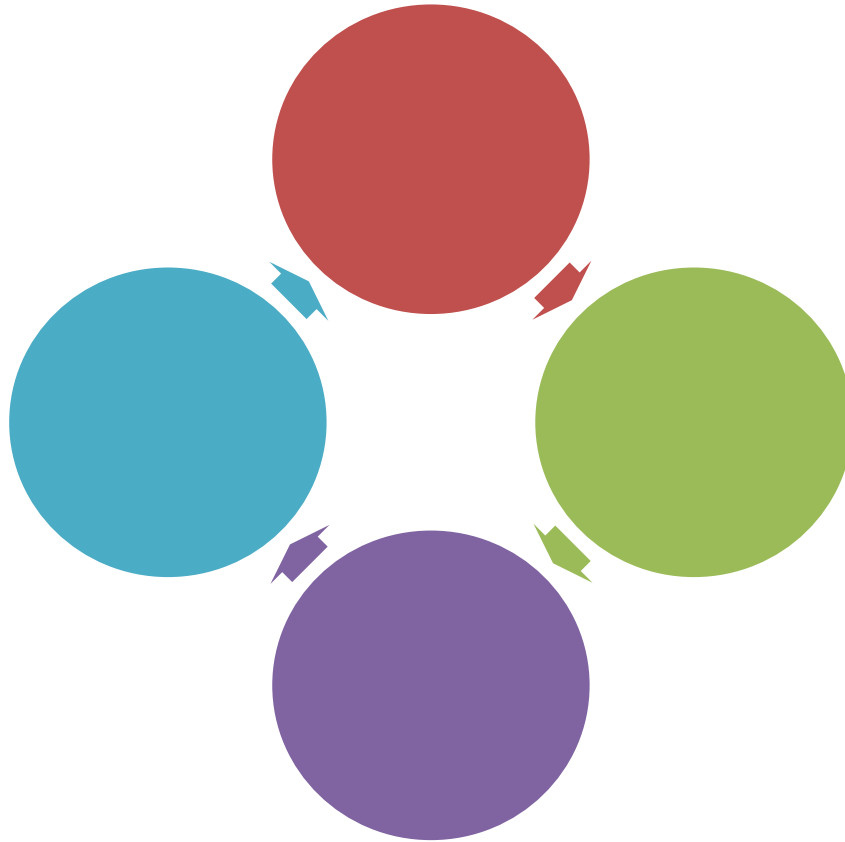
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Complete your own avoidance cycle below:



What do you notice about your own avoidance cycle?

.....

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Effects of Avoidance

- Feeling like we can't cope
- Loss of pleasure/interest from life
- Restricted lifestyle
- Reduced confidence and self-esteem
- We don't find out that people may support us if we spoke to them



Write some of the effects avoidance has for you here:

.....

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.....

Start by noticing your avoidance strategies!

NOTICE



Facing our fears

What fears do you need to face?



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Acceptance

In the space below write down the first thing that comes to mind when you think of the word 'acceptance'. Think of this in terms of 'accepting your emotions' or 'accepting your symptoms'.

You can define acceptance as a way of addressing a situation or experience that cannot be changed. Acceptance isn't the same as defeat, helplessness, quitting or giving in to a life of unhappiness. When we talk about acceptance of emotions, we are talking about allowing yourself to experience and express the emotions you're feeling as opposed to trying to ignore them in the hopes that they go away.

We already learnt in Session 2 that if we ignore, distract from or suppress our thoughts and feelings, it can often end up making us feel worse. This could be through the

'white bear effect', increased body tension or people who care about us being less able to show help and support. It's one thing to express our thoughts and feelings to those around us, but it is a separate skill to be able to accept our emotions ourselves.

Acceptance is an ongoing process. You might consider it a journey. On this journey you can learn to live your life more fully without trying to change, alter or control some of the thoughts and feelings you experience.

The Unwelcome Party Guest

Below is an example of how acceptance can be beneficial, while ignoring or fighting a problem can be futile and often leave you feeling tired and more stressed.

Watch the video here: <https://www.youtube.com/watch?v=VYht-guymF4>



Willingness

“Accept” comes from the Latin root "capere" meaning “take.” Acceptance is the act of receiving or “taking what is offered.” Sometimes, in English, “accept” means “to tolerate or resign yourself” (as in, “I guess I have to accept that”), and that is precisely not what is meant here. By “accept,” we mean something more like “taking completely, in the moment, without defense.”

Rob Grellman, in Stephen Hayes “Get out of your Mind and into your Life”

The aim of willingness is to open yourself up to the vitality of the moment and to move more effectively towards the things you value. The goal is to feel all of the feelings that arise more completely, even the bad feelings.



Willingness is...

- Holding your unpleasant emotions as you would hold a delicate flower in your hand
- Embracing your emotions as you would embrace a crying child
- Sitting with your emotions the way you would sit with a person who has a serious illness
- Looking at your emotions the way you would look at an incredible painting
- Walking with your emotions the way you would walk while carrying a sobbing infant
- Honouring your emotions the way you would honour a friend by listening
- Inhaling your emotions the way you would take a deep breath
- Abandoning the war with your emotions like a soldier who puts down his weapons to walk home
- Getting with your emotions like drinking a glass of pure water
- Carrying your emotions the way you would carry a picture in your wallet

Willingness is not...

- Resisting your emotions
- Ignoring your emotions
- Forgetting your emotions
- Burying your emotions

Home Task

For this home task, you are asked to keep writing in your online journals. We will continue to send helpful reminders via text, phone or email.

You should try to reflect on how you think it went, anything you noticed in your body and any thoughts (helpful or unhelpful) that came up for you.

In line with keeping up with some of what we've been talking about, this week, you should start trying to share your feelings with others. The key to this task is to try to express a little more than you were before and see how it feels. You can decide how much you want to share and who you want to share it with. In the space provided, write down how you think this went.

Starting thinking about your short and medium term goals from session three. Think about whether you are on track to reaching those goals and what you can do to keep working towards these.

Testing out Sharing Emotions at Home

| What you shared | Who you shared with | How it went |
|-----------------|---------------------|-------------|
| | | |
| | | |
| | | |
| | | |

Session 5 -Maintaining Change

Review of Home Task 4

How did you find sharing your emotions with others? Were there any unhelpful thoughts you noticed?

1. Coping with Setbacks

Experiencing setbacks can be a normal and routine part of living with IBS. Experiencing difficult days is part of everyday life, and it happens for everyone regardless of their difficulties. If you have a setback, it can often feel like you are sliding backwards, and returning to old unhelpful patterns; such as avoiding seeing friends or talking to loved ones about what you're going through.

It is important to remember that setbacks are a part of managing any difficulties, and whilst they may not always be avoidable, it may be possible to manage them. It may be helpful to learn how to recognise a setback if it occurs, so that you can take some positive steps to help manage it.

Common Triggers of setbacks

Setbacks can sometimes occur for no clear reason, but there are also times where setbacks are more likely to happen. Setbacks may occur as a result of situations that increase the levels of fatigue you experience, and reduce your opportunities to maintain your regular activity.

These types of situations may include:

- An illness or infection
- Major life events (e.g. moving house, bereavement, ending a relationship, a new job, etc)

- Stressful conditions (e.g. difficulties at work, family illness, children being off school)
- Depressed mood
- No longer using your helpful coping strategies

What are the events or situations that make me more *vulnerable* to my difficulties and a setback?

Planning ahead for stressful events

Sometimes you may not be able to predict or anticipate stressful life events; but often you can. For example, you might know when your car MOT is due for renewal, or when a family wedding is due to take place, and we definitely know when Christmas is each year. It can be tempting to pretend these things aren't happening until the last minute and put off doing anything about it, but this isn't usually a helpful strategy, because a normally stressful event can become even more stressful if you have not prepared for it. Planning ahead for such events or life-changes can greatly reduce any short term stress.

Identifying when symptoms are returning

If you experience a setback, sometimes symptoms do worsen or return and you may start finding things difficult again. Don't panic if you notice these symptoms - it does not necessarily mean that you are getting worse!

The first step is to be aware of your own warning signs. Often, when you experience a setback, you can be the last person to notice. Be aware of the signs and symptoms that you experience, such as avoiding things, aching more and lacking motivation. It can

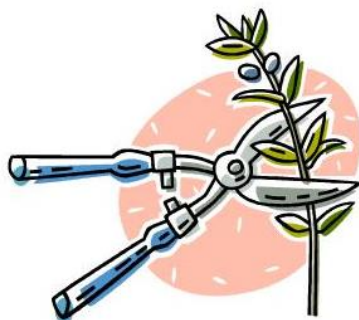
also help to get someone you trust to watch out for these symptoms too, so that if they happen, they can talk to you about it.

My warning signs are....

2. How to manage setbacks...a few tips!

The importance of practice

If you have tried some of the techniques in this booklet, you may have found that some are more helpful for you than others. We would recommend practicing the techniques that are most helpful for you.



Nip it in the bud!

Try to tackle your difficulties as soon as you notice you aren't managing as well as you have been, or that your symptoms are returning, as it will take you less time to get back on track again.

Prioritise

If you aren't able to do all of your planned activities, or don't have the time, don't give up on them, but modify your plan so that you can get back on track again.



Balance

Try to make sure your days have a balance (and variety) of activities and relaxation.

Manage your expectations

When things are difficult, you may not be able to do as much as you have previously been doing. It is important to lower your expectations of what you can manage, and remind yourself of what you have achieved – and give yourself praise for this!

3. Planning for the Future

We hope that this workbook has supported you to think of different strategies you can use to manage your symptoms, and given you more confidence to be able to do this. In order to continue your progress, and maintain the improvements you have already made, it can be helpful to reflect on what you have learnt from this course:

What factors may contribute to my difficulties continuing?

(thoughts, behaviours, physical sensations and emotions that keep my problems going)

What techniques seem to help me?

What are my warning signs to a setback?

What should I do if I notice these warning signs?

4. Continuing your progress

Setting Goals

You may wish to add to your long terms goals- what will you continue to do when the group has finished?

Lara's goals:

Goal 1: I will let my friends know how I am feeling

| Week | Target |
|-------------|---|
| 1 | <i>I will mention to someone if I'm feeling stressed/overwhelmed</i> |
| 2 | <i>I will explain what's been giving me stress/making me worried to someone I'm close to</i> |
| 3 | <i>I will be open with that person about when I'm struggling emotionally</i> |
| 4 | <i>I will be open with that person about when I'm struggling emotionally, or with my symptoms</i> |

(In this example, the goal is to practice speaking to others about emotions until they become a habit. This means once you have mastered how to open up to others, you can do so easily and only use it when needed)

Goal 1: _____

| Week | Target |
|-------------|---------------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |

Goal 2: _____

| Week | Target |
|------|--------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |

Goal 3: _____

| Week | Target |
|------|--------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |

Goal 4: _____

| Week | Target |
|------|--------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |

Goal 5: _____

| Week | Target |
|------|--------|
| 1 | |
| 2 | |
| 3 | |
| 4 | |

Goodbyes...

Over the past 5 sessions we have covered a whole range of different factors that relate to living with IBS. We have talked about how stress and anxiety can affect our bodies, how our response to our emotions can be unhelpful, how certain thoughts about our emotions can be unhelpful and how to think differently and try to reduce anxiety and stress.

As we discussed in the previous session, acceptance is a journey, an ongoing process. This means that even though the course is over, you should still try to learn and grow from everything you've learnt in these sessions.

Resource List

Books

| Author | Title | Topics |
|-------------------------------|--|-------------------|
| Leonora Brosan & Gillian Todd | Overcoming Stress | Managing stress |
| Stephen Hayes | The Happiness Trap | Managing emotions |
| Rosemary Nicol | The Irritable Bowel Stress Book (Overcoming common problems) | IBS |

Websites

IBS Network: <http://www.theibsnetwork.org/>

10.11. Appendix K: Ideographic measures for each Case

Case A

IBS-QoL

I feel fat because of my bowel problems

I have to avoid stressful situations because of my bowel problems

I have to watch what kind of food I eat because of my bowel problems

HADS

I get a sort of frightened feeling as if something awful is about to happen

Worrying thoughts go through my mind

I feel as if I am slowed down

I feel restless as if I had to be on the move

CECS

When I feel angry I keep quiet

When I feel unhappy I put on a bold face

When I feel afraid I let others see how I feel

When I feel afraid I keep quiet

When I feel afraid I tell others about it

When I feel afraid I say what I feel

BES

I should be able to control my emotions

I should be able to cope with difficulties on my own without turning to others for support

It would be a sign of weakness to show my emotions in public

Case B

IBS-QoL

I feel fat because of my bowel problems

I feel like I'm losing control of my life because of my bowel problems

I feel uncomfortable when I talk about my bowel problems

I worry that my bowel problems will get worse

I have to watch what kind of food I eat because of my bowel problems

I feel sluggish because of my bowel problems

I fear that I won't be able to have a bowel movement

HADS

I can sit at ease and feel relaxed

I feel restless as if I had to be on the move

CECS

When I feel angry I say what I feel

When I feel unhappy I put on a bold face

When I feel unhappy I let others see how I feel

When I feel unhappy I smother my feelings

When I feel afraid I let others see how I feel

When I feel afraid I tell others all about it

When I feel afraid I say what I feel

BES

If I have difficulties I should not admit them to others

I should be able to control my emotions

If I am having difficulties it is important to put on a brave face

I should not let myself give in to negative feelings

I should be able to cope with difficulties on my own without turning to others for support

Others expect me to always be in control of my emotions

Case C

IBS-QoL

I feel like my life is less enjoyable because of my bowel problems

I have to watch the amount of food I eat because of my bowel problems

I have to watch what kind of food I eat because of my bowel problems

HADS

I get a sort of frightened feeling as if something awful is about to happen

When I feel angry I say what I feel

When I feel angry I avoid making a scene

When I feel angry I hide my annoyance

When I feel unhappy I refuse to say anything about it

When I feel unhappy I keep quiet

When I feel unhappy I bottle it up

When I feel afraid I keep quiet

When I feel afraid I tell others all about it

When I feel afraid I say what I feel

When I feel afraid I bottle it up

BES

It is a sign of weakness if I have miserable thoughts

I should be able to control my emotions

If I am having difficulties it is important to put on a brave face

I should not let myself give in to negative feelings

It would be a sign of weakness to show my emotions in public

Case D

IBS-QoL

I feel embarrassed by the smell caused by my bowel problems

I feel isolated from others because of my bowel problems

Long trips are difficult for me because of my bowel problems

It is important to be near a toilet because of my bowel problems

HADS

I feel tense or wound up

I get a sort of frightened feeling as if something awful is about to happen

I feel restless as if I had to be on the move

CECS

When I feel angry I keep quiet

When I feel angry I say what I feel

When I feel angry I avoid making a scene

When I feel afraid I let others see how I feel

When I feel afraid I tell others about it

When I feel afraid I say what I feel

BES

If I lost control of my emotions in front of others, they will think less of me

I should be able to control my emotions

I should not let myself give in to negative feelings

It would be a sign of weakness to show my emotions in public

1 **10.12. Appendix L: Transcript from participant interview following**
2 **intervention in Chapter Eight**

3 [Start of interview]

4 Interviewer: So the first thing I wanted to ask was what aspects of the
5 group sessions and the meetings did you like or find helpful?

6 D: I think knowing, feeling.., knowing that .., not so isolated knowing
7 other people you know have similar you know problems. It was just
8 really nice to be among people who were experiencing similar things.
9 Definitely.

10 C: Yeah I'd agree with that as well that's definitely the best thing.
11 Because it isn't one of those things that you're happy to talk about like
12 you might talk about a broken ankle or something to somebody you're
13 not going to sort of raise it in normal day to day conversation.

14 B: And it was nice to hear their reactions and the way they deal with it
15 the same as you, so you don't feel that you're a complete lunatic
16 sometimes. Is this... My solution to this problem would be doing this
17 which is quite normal in my world but you would never dream of
18 telling anyone else, and then you find out that "yeah that's my solution
19 to that problem as well". It's reassuring and enlightening really.

20 D: Yeah

21 Interviewer: So you mentioned it was nice to be able to talk about
22 these things because you wouldn't normally talk about them outside
23 of, kind of, that context. In what way did you find that, you said that
24 it's reassuring to hear other people say it and enlightening to hear
25 other people do it... In terms of just talking with other people were
26 there any other benefits to that?

27 B: We were given challenges. It made you rethink your whole situation
28 but we weren't given challenges to deal with other people or change
29 our our normal routine of just saying no we don't want to go to dinner,
30 we don't want to do this, or I'm not going to tell anyone about it. It
31 actually challenged me and the others too to do something new. And
32 for me talking about it to my partner and a close friend is like, it was
33 like a pressure released that you didn't even realise was there because
34 you live with it. You didn't realise what a relief it was to discuss it and
35 get it out in the open.

36 D: Kind of liberating

37 B: Yeah

38 Interviewer: So is that something you two have also found, or did you
39 find something a bit different?

40 D: I guess a bit different because I have.., well I have talked about to
41 other people but obviously nobody really understood. So it was nice to
42 be in a room full of people who understand um.., And again just kind of
43 feeling.., although I... because I'd already shared things with family and
44 work and things so I didn't need to change that. But it did make me
45 feel less awful about it. Less like I was some kind of problem or... Does
46 that make any sense? Definitely yeah although I didn't actually do
47 anything differently, the fact that I knew other people were going
48 through the same things changed how I thought about it. For sure.

49 Interviewer: That's really interesting thank you. Is that something you
50 also found?

51 C: I think it was something. I refused to sort of...either not dealing with
52 it not trying to think about it ignore it until it sort of sort of physical
53 nature of it sort of totally impinged um so that I think this was helpful
54 in getting me to sort of think about it instead of ignoring it and think
55 about how I can live my life and make choices, better choices than
56 perhaps I have been doing.

57 D: I think the bits about um it kind of taught me it's kind of a self—
58 perpetuating thing as well. You had the stress and the symptoms I
59 suppose and the symptoms create even more and more stress so
60 learning that.., you know that you can make it worse helped to kind of
61 divide those extra feelings of — and try and relax a bit more about it
62 when it happens I suppose. And it's definitely made me accept that it
63 happens to other people therefore it's nothing to be you know. It's just
64 one of those things. Not a very nice thing, but one of those.

65 Interviewer: So that's different from how you've thought about it
66 before?

67 D: Well yeah because when it happens when you have a bad bought
68 it's so easy to get more and more and more stressed about what's
69 happening once it once it kicks off once you feel the first like.., mm..,
70 and then to just worry about it and it gets worse and worse and then it
71 gets worse and worse and worse and it's a bit sort of self—

72 perpetuating to think— to try and sort of relax about it if you can
73 which isn't that easy but to sort of draw a line where the pain starts I
74 suppose and then..., yeah and accept that it's just happening and it just
75 is you know a thing that happens.

76 C: And it will pass.

77 D: Yeah it will go.

78 C: Quite often you sort of get this feeling it is never going to end. And
79 what are you going to do, how are you going to manage.

80 D: yeah..., yeah...

81 C: And then you have to keep reminding myself it will pass and I'll be
82 ok again but just not at the moment.

83 D: And you can forget that you have been alright and you feel like it's
84 gone on forever and you have to keep reminding yourself that no this
85 has happened before and it has gone and it will go again and this is not
86 you know... yeah...yeah

87 Interviewer: That all sounds really good. Is there anything else anyone
88 wants to add to that in terms of what they've found helpful.

89 B: We did learn some techniques to relax which I do find useful
90 especially when it is bad or it does — I said it's frustrating it's annoying
91 it gets you down. When you start to think actually like you said it will
92 be temporary I can deal with this I can use these techniques and they
93 do help to relax which we learnt which I had no idea these techniques
94 even existed but they were really useful to just sit down on your own
95 and go you know what just breathe think about something else, think
96 of it and try and see the positive side of this it was really useful.

97 Interviewer: That's really good. So when you said see the positive side,
98 of the kind of the relaxation bit?

99 B: Yeah and it has a knock on effect of making you just feel better
100 whether it's because you feel you're better able to cope whether you
101 feel.., um, there's light at the end of the tunnel, that it's temporary or
102 you just know there's other people going through the same thing it
103 makes you feel a lot more positive, which has a knock on effect for the
104 symptoms as well I think

105 D: You feel more relaxed about it when it happens which has got to
106 help., I think., sort of

107 B: It's not like here we go again...

108 D: Yeah stress stress stress.

109 B: Oh god stress stress stress.

110 Interviewer: So you think some of these things have had a knock on
111 effect on you physically?

112 B: Yeah.

113 D: Yeah I think so.

114 Interviewer: So the second thing I wanted to ask was was there
115 anything in here you would like to see improved. Was there anything
116 you found that we did that wasn't helpful? Or anything that we didn't
117 do that you might have found helpful and you would have liked to have
118 seen?

119 (Laughter)

120 B: I don't know. It's hard. I've never done anything like this before.

121 D: Me neither.

122 B: I've never had any counselling any...

123 D: Oh I've had counselling.

124 B: Just apart from seeing a GP that's it so..., I don't know what I'm
125 missing almost.

126 C: Yeah I don't think probably may not have been appropriate for this
127 group, but when I first came I was hoping that I'd get some sort of help
128 I didn't actually get from the GP I might some useful advice on how to
129 actually treat it with diet or or or whatever., but you know as time
130 went on I sort of like I sort of got to understand what the purpose of
131 the group was and saw the benefit of it but yeah initially I was still sort
132 of annoyed about the lack of support from the GP and was hoping
133 there would be some kind of you know practical advice I could take
134 away from it or what to do.

135 Interviewer: So is there anything else like that maybe expectations you
136 had that you would kind of get and we didn't do?

137 D: I don't know I kind of knew that it was going to be about.., not —
138 well I kind of had a vague idea that it was going to be about.., not
139 about finding solutions which you always hope somebody's going to
140 hand you the miracle cure or diet or whatever that's going to solve the
141 whole problem I kind of knew it wasn't going to be yeah... I mean it
142 would have been great [laughter] I don't know what I expected really I
143 didn't know what to expect.., I think.., I think I was hoping for some
144 kind of psychological cure, which obviously couldn't happen anyway
145 but I guess that's where my unreal expectations were really that I'm
146 going to sit and talk through this and.., you know.., I'll be cured, I'll be
147 fine, so yeah... Yeah. It's kind of interesting because I think we've all
148 come into it from different – although we've all got this thing, we've all
149 come into it with different kind of from different angles different
150 expectations and different.., different lives and different you know
151 reasons for it all sorts of different — so it's kind of yeah I don't know I
152 don't know. It's not very helpful, is it?

153 [To 2] Interviewer: So is there anything you kind of went in expecting
154 that we would do that we didn't

155 B: I had no expectations at all. I thought about doing it. And thought
156 “mmmm”.., you know I didn't expect it to help in anyway at all but you
157 just think I've had this problem for years, it said have I been diagnosed
158 with this, yes I have, had it for years, lived with it, what harm could it
159 do just to tell people so I had no expectations that I would benefit. I
160 just thought I was giving out my experiences that's what I thought I'd
161 be doing. This is how it affects my life. I did not expect it to help me at
162 all, and it did, so...

163 Interviewer: That's really interesting

164 D: I know I also thought when I saw it on the college intranet I sort of
165 thought 'thank god somebody's doing something that looks at this'
166 because nobody— it's like we said in the sessions, like nobody really
167 seems to sort of — it's quite marginalised. I thought “somebody's
168 actually looking at it!” You know it's like you say the GPs don't just tell
169 you you've got it and don't really.., that's it. I think yeah. Thank
170 goodness somebody's actually taken this and is yeah looking into it I
171 suppose is what I thought.

172 C: I'm just remembering before I came to the first one I can remember
173 thinking about what it was going to be like and for a start I thought

174 there was going to be a lot of people because I knew it's a it is a
175 common problem even though it's not addressed but so I did think it
176 was going to be a room full of people but also I remember thinking it
177 would be a bit like sort of what I imagine what going to an AA meeting
178 is like [laughter]

179 D: Yes! Yeah yeah yeah...

180 (Inaudible)

181 C: Feeling a bit ashamed, a bit ashamed...

182 (Laughter)

183 C: It just shows you what my mind-set was, that it was something
184 shameful.

185 D: Yeah yeah yeah. I did think there was going to be a circle full of
186 people and like we're going to have to share the most intimate details
187 of everything and I was yeah yeah I didn't know quite what to expect
188 on that score.., At least it wasn't that!

189 (Laughter)

190 Interviewer: So was there anything maybe that we did that not
191 necessarily something you would improve or maybe wasn't particularly
192 relevant for you? Anything we sort of discussed or talked about that
193 you thought this is interesting but this isn't something for me?

194 D: I definitely found it interesting that... because I've sort talked about
195 it, but I've got a history of kind of having therapy and all sorts of stuff
196 — but how other people -although there's certain aspects I keep quiet
197 about it- but how other people kept it so close into themselves without
198 letting anybody know I thought that was really you know.., kind of how
199 successfully people hide it from other people because.., it's quite a big
200 thing, and the rigmarole that you go through. You know, and don't hide
201 it from family and close friends they don't really get it. Um. Yeah.

202 Interviewer: So is there anything that we talked about for you two that
203 you thought maybe wasn't as relevant for you that we covered?

204 B: Well at the time I might not have thought it was relevant certain
205 things like some of the relaxation techniques and other stuff you think
206 'This isn't really me'. But then I found out you know, give it a go what
207 harm can it do and it did help but at the time when she first started

208 telling us “why do I need to relax? That’s not going to help me” that’s
209 how I saw it. But yeah ok I’ll try that and then well let’s give it a go and
210 it did actually work, so.., I just didn’t think it would help. It was relevant
211 to me – “relaxing? Why do I need to relax?”, but it helped.

212 C: I found that the sort of analogies like the playing tennis and the bus
213 one. I didn’t find they worked of me.

214 D: Oh I did find them— that people on the bus one, although I was
215 thinking oh I kind of know this, but I really found that stayed in my
216 head. The bus people shouting everywhere

217 C: Interesting. It didn’t really do anything for me, but it’s still
218 interesting to see about it and see other people taking it.

219 Interviewer: So was it any of the particular analogies or just the
220 analogies as a whole?

221 C: Just as a whole really. Yeah.

222 Interviewer: Okay that’s interesting. Um, so if you were going to kind of
223 give us any advice if we were going to do this again. What kind of
224 advice would you give to tweak anything or change anything?

225 C: I suppose in the initial advert maybe just say a little bit more about it
226 because.., yeah I mean the IBS thing obviously leapt out at us, but I
227 don’t recall there being much else that might attract people.

228 Interviewer: I think part of the reason we didn’t do that is because we
229 wanted to collect questionnaires from people before they’d had any
230 influence of kind of what we were trying to do so we thought if we
231 don’t give too much information away there then we know that when
232 they do the questionnaires that they’re not thinking ‘oh this is going to
233 be relevant’ too much. So that’s why we didn’t do it. But that’s really
234 good to know, hearing all of your different expectations or that you
235 didn’t have any expectations is really useful. If we were to do it again
236 it’s definitely something to take on board that could be clearer. Any
237 other points on that?

238 D: I think I just generally have a problem with questionnaires and
239 getting the questions wrong. Because I know from talking to Abigail,
240 one of the things we had that I kind of felt like ‘oh I’d never taken that
241 question like that’ so but that might just be me and my strange brain I

242 don't know. But it's kind of you know I thought 'I hadn't read it as that I
243 hadn't' so yeah...

244 Interviewer: That's really good to know because I think these
245 questionnaire often are somewhat subjective

246 D: Yeah very subjective yeah.

247 Interviewer: So I think that's ok to take a different meaning as long as
248 you're the one taking that meaning fairly consistently then.

249 (Inaudible)

250 Interviewer: And that's how you interpreted it. That's really interesting
251 thank you. So is there anything else about the groups in particular
252 before we start talking about the questionnaires?...So was 5 sessions
253 enough? Too much?

254 B: It wasn't too much.

255 D: No, it wasn't too much. In fact I really missed them actually.

256 B: Yeah.

257 Interviewer: Do you feel like 5 meetings was enough., I mean to get
258 what you got out of it?

259 C: Probably enough but it would be nice to sort of carry on.

260 D: Yeah.

261 Interviewer: So it would be nice to keep going, but 5 probably was
262 enough?

263 C: Yeah

264 Interviewer: I mean there's nothing stopping you guys, you know,
265 going and meeting in _____ or whatever for a catch up

266 B: Well we did say at the last meeting that we would like to keep in
267 touch especially as we're all around college it would be good to that

268 Interviewer: That might be a really nice way to sort of carry it on.,
269 Okay so back to the questionnaires, I know you said you had some
270 trouble or at least different ways of interpreting the questions. Did
271 anyone else have any issues with the questions themselves and
272 anything like that?

273 C: Well just., some of the questions asked about your emotions in the
274 last few days and I was thinking., sort of feeling angry was one of
275 them. And I found it hard to answer because if I didn't recall feeling
276 angry in the last week then it's — you feel like you're sort of making it
277 up in a way.

278 D: Yeah if you had an uneventful, I mean — I don't think I was very good
279 at the questionnaires really but I kind of — it was hard not to see
280 certain parts of your life as constant so therefore my answers weren't
281 very varied because I was seeing certain things as constant, so I found
282 it really hard to just think of the past few days

283 C: Yeah

284 D: And I was looking back overall at you know, I don't know, you know
285 my life I suppose and the sort of person I see myself as and I found it
286 really hard to separate my picture of me, how I am with what had
287 happened weekly, if you see what I mean.

288 Interviewer: [to 2] How did you find it in terms of reflecting on the last
289 few days?

290 B: Like I said mine was pretty constant because like you said this is me
291 this is my life oh oh oh but it's only the last — I think I tried to answer
292 sort of quickly because you go by your— rather than brew over it. Just
293 actually how has it been over the last few days but I think for some of
294 the more recent ones my answers changed a bit because specifically
295 how you're feeling do you, you know, is this going to be something you
296 can deal with you know that's just slightly a problem yeah slightly a
297 problem, you know it's —

298 D: Yeah I did a little bit in the end.

299 B: Rather than very much very much very much so it did ease that
300 much and I thought hold on. Normally it's just yeah yeah totally agree
301 and then it did alter as we went along so they did change slightly but
302 generally it was staying the same because as you said, that's the
303 person I am. That's how I've been dealing with stuff.

304 Interviewer: That's interesting. Is there anything else about the
305 questionnaires I mean how did you find it in general having to do
306 them?

307 D: They were ok. They were all quite short. Weren't they? Quite quick
308 to do.

309 C: It was useful to have the reminders though.

310 D: Yeah definitely.

311 (Laughter)

312 C: Yeah it's the sort of thing you can easily forget if you don't get the
313 reminder.

314 D: I found myself thinking 'I hope nobody walks behind me' while I'm
315 doing this on my computer in the office like yeah.

316 Interviewer: Um, do you think that the questions that we asked kind of
317 captured what we talked about in the sessions? Or did they capture
318 things that you felt might be changing over that period of time?

319 (Silence)

320 Interviewer: I know you said there was a bit of a shift in some of those
321 things.

322 B: There was for me yeah the earlier set about how you actually felt.
323 And how you were coping and can you sit at ease and things like that.
324 They did change. So yeah for me it was all -obviously the questions
325 were adjusted- but you know they were relevant about the emotions
326 and how you deal with and do you tell other people and that yeah

327 Interviewer: How about you two? Do you feel that they kind of
328 captured the stuff that we'd talked about that things that were helpful
329 and things that might have changed?

330 C: Yeah I think so I found it — I just found it difficult if I hadn't
331 experienced some of the things I was being asked to say how I felt
332 about them. Um...

333 D: I don't know, but I think because I'd talked — I'd not kept things —
334 They did highlight something weird to me actually. Because I had sort
335 of talked about it to people, I thought I was being quite open um. Yet
336 still going through hoops trying to live with it in a warped weird way. I
337 think the questions in the more emotional part... and I kept I.., I kept
338 thinking well I'm almost sort of in the middle or slightly agree or...
339 because I my ideas of myself were different probably to what maybe I
340 really am if that makes any sense.

341 Interviewer: So you kind of found it hard to decide?

342 D: Well I kind of knew what I like I say my answers didn't change that
343 much especially in that emotional bit about bits about feeling anger
344 and stuff., and I'd always thought I was a fairly open sort of person.
345 But — and I did answer all the questions truthfully that I slightly — but
346 I it did make me wonder about how really how open I was about it all
347 and... do you see what I mean? and yeah.

348 Interviewer: So I guess there's different ways to be open about it?

349 D: Yeah so although I probably did mostly the same thing over and over
350 again it did make me think actually

351 Interviewer: So even though the answers may not have changed, the
352 way you kind of thought about those questions did change?

353 D: Yeah

354 Interviewer: Um, did you find answering the questionnaires alongside
355 doing kind of going to the meetings and stuff, did you find the
356 questionnaires helped at all? Or did you find them just sort of
357 something you did alongside?

358 C: Yeah just found them something outside

359 D: Yeah

360 C: Didn't really sort of connect the two to be honest

361 Interviewer: [To 4 and 2] Okay. Is that something you two kind of
362 found?

363 D: Yeah I think I felt like... yeah I didn't connect between the...

364 Interviewer: [To 2] What about you was it the same or a bit different?

365 B: Like I said they didn't really connect with what we'd actually
366 discussed in the meetings but they did separately make me think as I
367 was answering them going "good grief I'm just giving the same answers
368 here. Is this me?"

369 D: I know! I kept thinking oh no how disappointing

370 B: You know they're going to get the same form the same unknown

371 D: I really thought it was just me

372 B: Am I really? I don't do this and I don't do that. Keep it to myself and
373 you just think. And it made me think about me because of the answers
374 I kept giving.

375 Interviewer: So there was some reflection there even if it wasn't
376 connected to the actual

377 B: Oh yeah! —to the actual discussion

378 Interviewer: Um, so if you had to kind of summarise what you've got
379 out of this group how you sort of summarise the key things you've
380 taken away from this?

381 B: Relief!

382 (Laughter)

383 D: Yeah definitely that you're not on your own you know that,
384 yeah...and to actually talk about it with people properly, like people
385 who know what it is like it's such a new thing it's kind of.., support I
386 suppose

387 Interviewer: [to 3] Did you have anything you wanted to add to that?

388 C: No. I'd agree with that as well.

389 [End of interview]

390

10.13. Appendix M: Published papers arising from work presented in this thesis

The following paper includes material presented in Chapter Three:

Bowers H, & Wroe A (2016). Beliefs about emotions mediate the relationship between emotional suppression and quality of life in irritable bowel syndrome. *Journal of Mental Health*, 25, 154–158.

The following paper includes material presented in Chapter Four:

Bowers, H. M., Wroe, A. L. & Pincus, T. (2016). The relationship between beliefs about emotions and quality of life in irritable bowel syndrome. Manuscript under revision.

The following paper includes material presented in Chapter Five:

Bowers, H. M., Wroe, A. L. & Pincus, T. (2016). Isn't it ironic? Beliefs about the unacceptability of emotions and emotional suppression relate to worse outcomes in fibromyalgia. Manuscript under revision.

The following paper includes material presented in Chapter Eight:

Bowers, H. M. & Wroe, A. L. (2017). An emotional intervention for IBS: A single case experimental design. Manuscript submitted for publication.