

**Complementary and alternative medicine use in Irritable  
Bowel Syndrome: an examination of the influence of  
illness and treatment representations**

**Lee John Usher**

**A thesis submitted in partial fulfilment of the requirements of the  
University of West London for the degree of Doctor of Philosophy**

**September 2011**

## **Abstract**

Irritable Bowel Syndrome (IBS) is a chronic functional disorder of the gastrointestinal system with prevalence in adults of 10-20%. IBS is characterised by a number of troublesome symptoms including abdominal bloating, pain and excess gas, and has substantial impact on quality of life in addition to wider economic implications. Conventional medical treatment can be problematic however, due to the lack of established aetiology and the number of symptoms reported. Concurrently, use of complementary and alternative medicine (CAM) to relieve IBS symptoms is reported to be as high as 50%, although the benefits and impact of such treatments are not fully substantiated by primary research data. However, evidence has shown that people affected may benefit from psychological intervention in terms of reduced use of health care services and reported symptoms.

This thesis has examined psychological factors that influence use of CAM and quality of life in individuals affected by IBS. These factors were explored within the theoretical framework of an extended common-sense model of illness representations (CSM), which incorporated treatment beliefs. The main aim of the thesis was twofold: to examine the illness perceptions and treatment beliefs that influenced CAM use and to explore pathways from illness and treatment representation to quality of life in CAM-users and those not using CAM (non-users).

A web-based cross-sectional study and minimum six month time-period follow-up study were conducted. Participants were primarily recruited from an IBS self-help network in the UK and other online message boards. The cross-sectional study (n=653) considered illness perceptions and treatment beliefs associated with CAM use and how these factors differed in influencing coping strategies and quality of life in CAM-users and non-users. The follow-up study (n=197) focused on

exploration of the influence of illness perceptions and treatment beliefs at study time one, on coping strategies and quality of life at study time two.

The findings demonstrated that components of illness perceptions influenced CAM use, coping strategies and quality of life. Treatment beliefs were more strongly implicated in influencing the use of CAM. At the cross-sectional stage, stronger perceptions of illness consequences and emotional representations were major influences on reduced reported quality of life measures and poorer emotional outcomes in both survey groups, where similar strength effects were observed. There were many observed instances of partial mediation of maladaptive and dysfunctional coping strategies such as self blame and behavioural disengagement. In addition, follow up data demonstrated a reduction of the influence of illness perceptions (time one) on quality of life (time two) compared to the cross-sectional data. Moreover, evidence of mediation effects was only detected in CAM-users in the follow-up study.

These results highlight the importance of psychological factors, in particular illness perceptions, and to an extent, treatment beliefs in influencing coping strategies, quality of life and emotional outcome in those affected by IBS. Practical and theoretical implications of the findings are considered and future applications discussed. This thesis concludes with the proposal of a novel conceptual model to utilise a multiconvergent approach to enhance the quality of life and emotional outcomes in those affected by IBS.

## **Acknowledgements**

I firstly owe huge thanks and great acknowledgement to both my supervisors, Professor Kathryn Mitchell and Dr. Pauline Fox. They have both offered untold encouragement, inspiration, guidance and support over the past few years and were the people that gave me this opportunity to embark on this intellectual journey. I have learned so much along the way.

I am also incredibly grateful to all the people that took the time to participate in this research. Some of the emails and comments from individuals were incredibly touching and really brought the impact of this illness into perspective. Also thanks go to the numerous people (the IBS network and various message board administrators) who helped with or allowed me permission to advertise my research.

I have to acknowledge the 'informal' chats with colleagues and fellow PhD students on the 'third floor' that have led to intellectual inspiration, entertainment and sometimes much needed off-topic discussion.

I also wish to thank Professor Nicky Robinson for several reads of the systematic review and to Pam Kaur for being super efficient and for the tiresome task of printing several chapter drafts.

Extra special thanks go to my partner, Sophie, who has been unwavering in her support and has been an absolute rock for me whilst I have embarked on this journey and for always managing to say the right things at the right time.

Finally, my thanks go to my parents Gill and John, and my brother Adrian for always asking 'how things are going' and for always being interested in my work. And to the several friends, who have been both curious and supportive regarding my Ph.D. And to anyone else I have forgotten to mention directly. Thank you.

## Table of Contents

Abstract.....	2
Table of Contents.....	5
List of Tables.....	14
List of Figures.....	17
Overview of thesis.....	19
<b>Chapter 1 .....</b>	<b>23</b>
<b>Irritable Bowel Syndrome, illness perceptions and the use of complementary and alternative medicine: an introduction to the research .....</b>	<b>23</b>
PART 1:.....	23
1.1 The importance of psychological factors in Irritable Bowel Syndrome .....	23
1.1.1 <i>Definition of IBS</i> .....	23
1.1.2 <i>Diagnosis and prevalence of IBS</i> .....	24
1.1.3 <i>Aetiology</i> .....	29
1.1.3.1 <i>The influence of personality, stress, mood and abuse on             IBS symptoms</i> .....	31
1.1.4 <i>Treatment and management strategies</i> .....	33
1.1.4.1 <i>Impact of IBS</i> .....	33
1.1.4.2 <i>Management of IBS symptoms</i> .....	35
1.1.5 <i>Illness perceptions</i> .....	39
1.1.6 <i>Explaining CAM use in IBS</i> .....	43
PART 2:.....	49
1.6 Factors associated with complementary and alternative medicine use in Irritable Bowel Syndrome: a systematic review.....	49
1.6.1 Method.....	49
1.6.1.1 <i>Search Strategy</i> .....	49
1.6.1.2 <i>Selection process</i> .....	49
1.6.1.3 <i>Data analysis</i> .....	50
1.6.2 Results.....	50
1.6.2.1 <i>Methodological comparison</i> .....	50
1.6.2.2 <i>Extent of CAM use</i> .....	54

1.6.2.3 <i>Reasons for CAM use</i> .....	55
1.6.3 Discussion.....	58
1.6.3.1 <i>Summary of main findings</i> .....	58
1.6.3.2 <i>Limitations of review</i> .....	60
1.6.3.3. <i>Implications for the thesis</i> .....	61
1.6.3.4 <i>Conclusions</i> .....	62
1.7 Chapter summary and aim of thesis .....	63
<b>Chapter 2 .....</b>	<b>66</b>
<b>Theoretical framework.....</b>	<b>66</b>
2.1 Theory-based research in health psychology .....	66
2.2 The common sense model of illness representation.....	67
2.2.1 <i>Illness representations</i> .....	68
2.2.1.1 <i>Evidence for the role of illness representations in IBS and CAM use</i> .....	72
2.2.1.2 <i>Measurement of illness representations</i> .....	73
2.2.1.3 <i>Application of the CSM to IBS</i> .....	75
2.2.1.4 <i>Application of the CSM to CAM use</i> .....	76
2.2.2. <i>Influence of illness representations on coping strategies</i> .....	77
2.2.2.1 <i>Coping strategies and measurement of coping</i> .....	77
2.2.2.2 <i>Relationships between illness representations and coping</i> .....	79
2.2.3 <i>Appraisal of coping procedures</i> .....	82
2.2.3.1 <i>Relationship of illness representations with illness outcomes</i> .....	83
2.3 Extending the common-sense model .....	87
2.4 Comparison of CSM with social cognition models .....	90
2.5 Application of CSM research findings.....	93
2.6 Chapter summary and research objectives .....	95
<b>Chapter 3 .....</b>	<b>97</b>
<b>Methodological framework.....</b>	<b>97</b>
3.1 Design .....	97
3.1.1 <i>Philosophical framework</i> .....	98
3.1.1.1 <i>Deductive and inductive approaches to research</i> .....	98

3.1.1.2 Advantages of harmonising deductive and inductive approaches.....	99
3.1.2 Data collection .....	101
3.1.2.1 The internet: access, health information and e-interventions.....	101
3.1.2.2 Web-based surveys.....	102
3.1.2.3 Benefits of web-based surveys.....	103
3.1.2.3.1 Access to specialist samples and increased disclosure .....	103
3.1.2.3.2 Economic and participant response benefits of online research.....	104
3.1.2.3.3 Practical benefits to the researcher.....	105
3.1.2.3 Participant recruitment in web-based surveys .....	106
3.1.2.4 Potential issues with web-based surveys .....	106
3.1.2.5 Summary of issues related to conducting web-based surveys.....	108
3.1.3 Identification of variables for measurement.....	109
3.1.4 Presentation of survey and response format.....	109
3.1.5 Study design .....	111
3.2 Sample size.....	112
3.2.1 Determination of sample size.....	113
3.2.2 Obtained sample size.....	114
3.3 Measures/materials .....	114
3.3.1 Background questions.....	114
3.3.2 Predictive/explanatory measures.....	114
3.3.2.1 Illness perceptions.....	115
3.3.2.2 Beliefs about conventional medication .....	117
3.3.2.3 Beliefs about CAM.....	118
3.3.2.4 Brief-COPE.....	120
3.3.3 Outcome measures.....	121
3.3.3.1 CAM use.....	121
3.3.3.2 Quality of life.....	122
3.3.4 Demographics.....	124
3.4 Procedure .....	125
3.4.1 Pilot procedure.....	125
3.4.2 Advertisement of study.....	125
3.4.3 Participant information and ethical information .....	126

3.4.4 Survey completion.....	127
3.5 Ethical approval .....	128
3.6 Statistical methods .....	128
3.6.1 <i>Missing data</i> .....	128
3.6.3 <i>Statistical tests</i> .....	130
3.6.3.1 <i>Differences between CAM-users and non-users</i> .....	130
3.6.3.2 <i>Predicting CAM use</i> .....	130
3.6.3.3 <i>Diagnostic tests for logistic regression model</i> .....	131
3.6.3.4 <i>Testing for Mediation</i> .....	131
3.7 Overview and Summary .....	134
<b>Chapter 4 .....</b>	<b>136</b>
<b>Applying the common-sense model of illness representations to the exploration of CAM use in IBS .....</b>	<b>136</b>
4.1 Introduction.....	136
4.2 Method.....	138
4.2.1 <i>Design</i> .....	138
4.2.2 <i>Participants</i> .....	138
4.2.3 <i>Measures</i> .....	139
4.2.4 <i>Procedure</i> .....	139
4.2.5 <i>Statistical methods</i> .....	140
4.2.5.1 <i>Computing instrument scales</i> .....	140
4.2.5.2 <i>Data screening</i> .....	140
4.2.5.3 <i>Principal Components Analysis of IPQ-R causal items</i> .	141
4.2.5.4 <i>Statistical tests</i> .....	145
4.3 Results.....	147
4.3.1 <i>Participant demographics</i> .....	148
4.3.2 <i>Extent of CAM use in IBS</i> .....	150
4.3.4 <i>Age, IPQ-R, BMQ and CAMBI scale associations with number of CAM treatments used</i> .....	150
4.3.5. <i>Group differences in age, IPQ-R, BMQ and CAMBI scales</i> 154	
4.3.5.1 <i>Age and IPQ-R sub-scales</i> .....	155
4.3.5.2 <i>BMQ and CAMBI sub-scales</i> .....	156
4.3.6 <i>Predicting CAM use from demographic factors and scales of the IPQ-R, BMQ and CAMBI</i> .....	160



4.3.6.1	<i>Relative contribution of demographic and CSM variables</i>	161
4.3.6.2	<i>Contribution of demographic variables</i>	161
4.3.6.3	<i>Contribution of illness and treatment representations</i>	162
4.3.7	<i>Accuracy of logistic regression model</i>	163
4.4	<b>Discussion</b>	165
4.4.1	<i>Prevalence of CAM use in IBS</i>	166
4.4.1.1	<i>IPQ-R, BMQ and CAMBI scale correlations with number of CAM treatments used</i>	166
4.4.1.2	<i>Differences between CAM-users and non-users with IBS on scale variables</i>	168
4.4.1.3	<i>Predicting CAM use in IBS from the CSM and demographic items</i>	170
4.4.2	<i>Theoretical considerations</i>	174
4.4.3	<i>Limitations of the study</i>	175
4.4.4	<i>Conclusions</i>	179
<b>Chapter 5</b>		<b>181</b>
	<b>An examination of components of the Common-Sense Model of illness between CAM-users and non-CAM users with IBS</b>	<b>181</b>
5.1	<i>Introduction</i>	181
5.2	<i>Method</i>	184
5.2.1	<i>Design</i>	184
5.2.2	<i>Participants</i>	184
5.2.3	<i>Measures</i>	184
5.2.4	<i>Procedure</i>	185
5.2.5	<i>Statistical methods</i>	186
5.2.5.1	<i>Computing scales</i>	186
5.2.5.2	<i>Data screening</i>	186
5.2.5.3	<i>Statistical tests</i>	187
5.2.5.3.1	<i>Process to determine mediation</i>	188
5.3	<i>Results</i>	191
5.3.1	<i>Differences between CAM-users and non-users: IBS-QOL scores</i>	192
5.3.2	<i>Differences between CAM-users and non-users: Brief-COPE scores</i>	193
5.3.3	<i>Relationships between illness perceptions and treatment beliefs</i>	201

5.3.3.1 Non-users.....	201
5.3.3.2 CAM-users .....	203
5.3.4 Testing the theorised mediating role of coping.....	206
5.3.4.1 Step one: Predictor–outcome relationship.....	209
5.3.4.2 Step two: predictor–mediator relationship .....	210
5.3.4.2.1 Non-users .....	210
5.3.4.2.2 CAM-users.....	212
5.3.4.3 Step three: mediator–outcome relationship, controlling for predictor variable.....	213
5.3.4.3.1 Step three of mediation testing: IPQ-R symptom based scales (identity, timeline chronic and consequences) and IBS-QOL scores.....	214
5.3.4.3.2 Step three of mediation testing: for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) and IBS-QOL scores.....	221
5.3.4.3.3 Step three of mediation testing: for IPQ-R emotional representations and causal scales (and IBS-QOL scores) ....	225
5.3.4.3.4 Step three of mediation testing: for BMQ and CAMBI scales (and IBS-QOL scores) .....	230
5.3.4.3.5 Step three of mediation testing: for IPQ-R emotional representation scale and emotional outcome .....	232
5.4 Discussion .....	235
5.4.1 CAM-user and non-user differences on IBS-QOL and Brief-COPE scales.....	235
5.4.2 Relationships between illness representations and treatment beliefs .....	236
5.4.3 Illness and treatment perceptions, coping and quality of life	239
5.4.4 Limitations of the study .....	246
5.4.5 Conclusions and implications.....	249
<b>Chapter 6 .....</b>	<b>253</b>
<b>A prospective examination of pathways in the Common-Sense Model of illness representations between CAM-users and non-users with IBS.....</b>	<b>253</b>
6.1 Introduction.....	253
6.2 Method.....	255
6.2.1 Design.....	255
6.2.2 Participants .....	256
6.2.3 Measures .....	256

6.2.4 Procedure .....	257
6.2.5 Statistical analyses.....	258
6.2.5.1 Computing scales.....	259
6.2.5.2 Data screening .....	259
6.2.5.3 Statistical tests.....	261
6.3 Results.....	262
6.3.1 Participant demographics.....	262
6.3.2 Differences between responders and non-responders on CSM scale variables and age .....	266
6.3.3 Differences in CSM variable scores at time one and time two .....	273
6.3.3.1 Illness and treatment perceptions.....	274
6.3.3.2 Brief-COPE scales.....	277
6.3.3.3 IBS-QOL scales.....	280
6.3.4 Mediation tests of illness and treatment perceptions at time one, and Brief-COPE and IBS-QOL scores at time two .....	286
6.3.4.1 Step one: Predictor (time one) and outcome (time two) relationship.....	286
6.3.4.2 Step two: predictor (time one) and mediator (time two) relationships .....	289
6.3.4.2.1 Non-users .....	289
6.3.4.2.2 CAM-users.....	290
6.3.4.3 Step three: mediator–outcome relationship, controlling for predictor variable.....	291
6.3.4.3.1 Step three of mediation testing: IPQ-R scales (time one) and IBS-QOL scores (time two).....	293
6.3.4.3.2 Step three of mediation testing: for IPQ-R emotional representation (time one) and emotional outcome (time two).....	295
6.4 Discussion .....	297
6.4.1. Differences between responders and non-responders on CSM variables.....	298
6.4.2 Differences in CSM variable scores over time .....	299
6.4.3 Illness perceptions, treatment beliefs, coping and outcome.....	302
6.4.4 Limitations of the study .....	305
6.4.5 Conclusions and implications.....	307
<b>Chapter 7 .....</b>	<b>310</b>
<b>General discussion and conclusions.....</b>	<b>310</b>

7.1 Introduction.....	310
7.2 Discussion of research findings.....	311
7.2.1 <i>Use of complementary and alternative medicine in IBS</i> .....	311
7.2.2 <i>Illness perceptions and treatment beliefs</i> .....	313
7.2.2.1 <i>Influence of illness perceptions and treatment beliefs on CAM use</i> .....	313
7.2.2.2 <i>Illness perceptions, treatment beliefs, coping and quality of life</i> .....	315
7.3 Implications for theory and practice.....	320
7.3.1 <i>Practical implications</i> .....	321
7.3.2 <i>Theoretical implications</i> .....	324
7.4 Limitations of thesis.....	326
7.5 Future directions.....	331
7.6 Conclusion.....	340
<b>References.....</b>	<b>342</b>
<b>Appendix I: advertisement posted on the IBS Network website....</b>	<b>369</b>
<b>Appendix II: Study information.....</b>	<b>370</b>
<b>Appendix IV: The illness perceptions questionnaire revised version.....</b>	<b>372</b>
<b>Appendix V: The Brief-COPE.....</b>	<b>376</b>
<b>Appendix VI: The IBS-QOL.....</b>	<b>378</b>
<b>Appendix VII: Questions about healthcare.....</b>	<b>379</b>
<b>Appendix VIII: The beliefs about medicines questionnaire (general version).....</b>	<b>380</b>
<b>Appendix IX: The complementary and alternative medicine beliefs inventory.....</b>	<b>381</b>
<b>Appendix X: Questions about complementary and alternative medicine use.....</b>	<b>382</b>
<b>Appendix XI: Demographic information and thank you message.....</b>	<b>384</b>
<b>Appendix XII: First email sent to participants regarding the follow-up study.....</b>	<b>387</b>
<b>Appendix XIII: First email reminder sent to participants regarding the follow-up study.....</b>	<b>388</b>

<b>Appendix XIV: Second email reminder sent to participants regarding the follow-up study.....</b>	<b>389</b>
<b>Appendix XV: Write-up for thematic analysis of participants' open text responses.....</b>	<b>390</b>
<b>Appendix XVI: Participant text from open survey question .....</b>	<b>418</b>

## List of Tables

Table 1.1 Key IBS symptoms reported and pattern of diagnosis in adults .....	27
Table 1.2 Comparison of Manning, Rome I and Rome II symptom-based criteria for IBS. ....	28
Table 1.3 Summary of treatment guidelines for adults with IBS; adapted from the NICE guidelines .....	38
Table 1.4 Summary of studies included in the systematic review .....	52
Table 4.1 Pattern coefficients resulting from Principal Components Analysis on IPQ-R causal items .....	146
Table 4.2 Participant mean ages, split by gender and CAM use.....	148
Table 4.3 Key participant demographic data by category and extent of CAM use .....	152
Table 4.4 Scales of the IPQ-R, BMQ and CAMBI scales and Pearson's correlations with number of CAM treatments used.....	154
Table 4.5 Descriptive statistics and <i>t</i> -tests for differences on scale variables between CAM-users and non-users with IBS .....	157
Table 4.6 Summary of logistic regression analysis of IPQ-R, BMQ, CAMBI scales and demographic factors in predicting CAM use in IBS	164
Table 5.1 Descriptive statistics illustrating differences between CAM- users and non-users on IBS-QOL scale and subscales.....	194
Table 5.2 Descriptive statistics and <i>t</i> -values for differences between CAM-users and non-users on brief-COPE scales .....	200
Table 5.3 Relationships between IPQ-R, BMQ and CAMBI scales (non- users): Pearson's <i>r</i> .....	207
Table 5.4 Relationships between IPQ-R, BMQ and CAMBI scales (CAM- users): Pearson's <i>r</i> .....	208
Table 5.5 Relationships between IPQ-R, BMQ, CAMBI scales, IBS-QOL total score: Pearson's <i>r</i> .....	211
Table 5.6 Relationships (Pearson's <i>r</i> ) between IPQ-R 'emotional representations' scale and IBS-QOL 'dysphoria' subscale (emotional outcome) .....	212
Table 5.7 Relationships between IPQ-R, BMQ and CAMBI scales and Coping strategies (non-users): Pearson's <i>r</i> .....	216
Table 5.8 Relationships between IPQ-R, BMQ and CAMBI scales and Coping strategies (CAM-users): Pearson's <i>r</i> .....	217
Table 5.9 Mediation tests for IPQ-R symptom based scales (identity, timeline chronic and consequences) for non-users .....	219
Table 5.10 Mediation tests for IPQ-R symptom based scales (identity, timeline chronic and consequences) for CAM-users .....	220

Table 5.11 Mediation tests for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) for the non-users .....	225
Table 5.12 Mediation tests for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) for CAM-users .....	226
Table 5.13 Mediation tests for IPQ-R emotional representations and causal scales for non-users .....	229
Table 5.14 Mediation tests for IPQ-R emotional representations and causal scales for CAM-users.....	230
Table 5.15 Mediation tests for BMQ overuse scale for CAM-users.....	231
Table 5.16 Mediation tests for BMQ overuse and CAMBI natural treatments scales for non-users.....	232
Table 5.17 Mediation tests for IPQ-R emotional representation scale and emotional outcome for CAM-users.....	234
Table 5.18 Mediation tests for IPQ-R emotional representation scale and emotional outcome for the non-users.....	234
Table 6.1 Key participant demographic (time one) data by frequency and frequency of CAM use in responders .....	265
Table 6.2 Descriptive statistics and unrelated t-tests for responder /non-responder differences on illness and treatment perception scales (and age) between CAM-users and non-users with IBS.....	268
Table 6.3 Descriptive statistics and unrelated t-tests for responder /non-responder differences on brief-COPE scales between CAM-users and non-users with IBS .....	270
Table 6.4 Descriptive statistics and unrelated t-tests for responder /non-responder differences on IBS-QOL scale and subscales between CAM-users and non-users with IBS .....	272
Table 6.5 Illness and treatment perception differences over the two study time-points in CAM-users and non-users .....	274
Table 6.6 Brief-COPE scale differences over the two study time points in CAM-users and non-users .....	277
Table 6.7 IBS-QOL scale and subscale differences over the two study time points in CAM-users and non-users .....	281
Table 6.8 Pearson's <i>r</i> correlations between IPQ-R, BMQ, CAMBI scales (time one) and IBS-QOL total score (time two) for CAM-users and non-users .....	286
Table 6.9 Relationships (Pearson's <i>r</i> ) between IPQ-R 'emotional representations' scale and IBS-QOL 'dysphoria' subscale (emotional outcome) .....	287
Table 6.10 Pearson's <i>r</i> correlations between IPQ-R (time one) and brief-COPE (time two) scales in non-users .....	288

Table 6.11 Pearson's *r* correlations between IPQ-R (time one) and brief-  
COPE (time two) scales in CAM-users .....292

Table 6.12 Mediation tests for IPQ-R scales at time one and outcome  
(time two IBS-QOL scores) at time two for CAM-users .....296



## List of Figures

Figure 1.1 A biopsychosocial conceptualisation of IBS illustrating the relationship between early life, physiology, psychological factors, symptom experience, illness related behaviour and outcome. ....	33
Figure 1.2 Flow chart showing the process of identifying relevant studies .....	51
Figure 2.1 Flow diagram of an extended version of Leventhal et al's. (1992; 1998) Common-Sense Model of Illness Representations .....	71
Figure 3.1 Flow chart of participant route through the study web pages .....	129
Figure 3.2 Illustration of 'simple' Mediation .....	133
Figure 4.1 Scree plot derived from Principal Components Analysis of causal items from IPQ-R .....	144
Figure 4.2 Pie chart illustrating geographical location of participants (percentage of the whole sample) .....	149
Figure 4.3 Bar graph illustrating reported use of most popular CAM treatments in CAM-users with IBS .....	153
Figure 4.4 Bar graphs illustrating significant differences between CAM-users and non-users on IPQ-R scales .....	158
Figure 4.5 Bar graphs illustrating significant differences between CAM-users and non-users on BMQ and CAMBI scales .....	159
Figure 5.1 Bar graphs illustrating significant differences between CAM-users and non-users on IBS-QOL subscales (total score, dysphoria, interference with activity, body image, health worry and food avoidance) .....	196
Figure 5.2 Bar graphs illustrating significant differences between CAM-users and non-users on IBS-QOL subscales (Social reaction, sexual and relationships subscales) .....	197
Figure 5.3 Bar graphs illustrating significant differences between CAM-users and non-users on brief-COPE scales (self-distraction, active coping, denial, emotional support, instrumental support and venting emotions) .....	198
Figure 5.4 Bar graphs illustrating significant differences between CAM-users and non-users on brief-COPE scales (Positive reframing, planning, humour, acceptance, religion and self blame) .....	199
Figure 6.1 Pie chart illustrating geographical location of participants for follow-up study (percentage of the whole sample) .....	263
Figure 6.2 Bar graphs to illustrate significant differences between responders and non-responders on IPQ-R, BMQ and CAMBI scales for both CAM-users and non-users .....	270

Figure 6.3 Bar graphs to illustrate significant differences between responders and non-responders on brief-COPE scales and IBS-QOL subscales in CAM-users .....	272
Figure 6.4 Bar graphs to illustrate significant differences between time one and time two responses on IPQ-R scales for CAM-users and non-users .....	276
Figure 6.5 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on brief-COPE scales at time one and time two .....	279
Figure 6.6 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL scale and subscales at time one and time two.....	283
Figure 6.7 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL subscales at time one and time two.....	284
Figure 6.8 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL subscales at time one and time two.....	285
Figure 7.1 Provisional study protocol for CSM based pilot intervention for IBS .....	339

## **Overview of thesis**

Irritable Bowel Syndrome (IBS) is a functional, chronic disorder affecting the bowel and is characterised by a number of symptoms including bouts of abdominal pain and bloating. Prevalence in the population is indicated to be between 10-20% of the population (Jones & Lydeard, 1992; Wilson, Roberts, Roalfe, Bridge, & Singh, 2004) with a well documented female predominance in terms of health care seekers (Hungin, Chang, Locke, Dennis, & Barghout, 2005). The impact of IBS on everyday life is substantial (Amouretti et al., 2006; Lea & Whorwell, 2001). In wider economic terms, it has been documented those affected with IBS are frequent users of health care services (Talley, 2008) and contribute to a significant proportion of lost working hours (Hungin et al., 2005).

Treatment can often be problematic and reported to be unsatisfactory for many with IBS (Hayee & Forgacs, 2007). Such insufficient scope of conventional treatment is seemingly mirrored by estimates that as many as 50% of those with IBS will use CAM for their symptoms (Kong et al., 2005). Concerns exist with CAM treatments for IBS as many lack demonstrated efficacy (Wersch, Forshaw & Cartwright, 2009), there may be potential for conventional and CAM treatment interactions (e.g. Shane-McWhorter & Geil, 2002) in addition to significant financial impact to the individual. Improved management of IBS is therefore a desirable objective from many angles.

As IBS is a functional illness with no organic manifestation of disease, aetiological focus has repeatedly fallen on the examination of psychological factors. Evidence from both IBS and other chronic illness populations has suggested that perceptions related to illness influence quality of life and outcomes, more so than the illness itself (Drossman et al., 1999; Hayee & Forgacs, 2007). Exploration of CAM use has also indicated stronger perceptions of illness may be indicative of a worse

illness experience in those that opt to use CAM (Hilsden, Scott, & Verhoef, 1998). Individuals may also have concerns with their treatment that leads them to try what they perceive as more natural treatments (e.g. Bishop, Lewith, & Yardley, 2006).

Identification of psychological factors that are influential on health related quality of life may enhance understanding of the role of psychology in IBS and offer future opportunities for focus on improving management (Rutter & Rutter, 2002; 2007). Furthermore, by exploring reasons for CAM use and how CAM-users' beliefs and perceptions differ from those not using CAM. It may also be determined those using CAM perceive a more intense illness experience that may influence CAM use and if use of CAM affects quality of life judgements. This thesis reports research which systematically addresses illness perceptions in those affected with IBS and the relationship of such perceptions with CAM use and reported quality of life. To date, no published research has amalgamated these factors in the context of a systematic and theoretical framework.

The aim of the research presented in this thesis is to examine the illness perceptions and treatment beliefs of individuals affected by Irritable Bowel Syndrome (IBS), using the common-sense model (CSM) of illness representations (Leventhal, Leventhal, & Contrada, 1998). Two specific areas of investigation are presented. Firstly, an exploration of which illness perceptions and treatment beliefs are associated with use of complementary and alternative medicine (CAM) in IBS is presented. Secondly, the influence of illness perceptions and treatment beliefs on coping and quality of life is considered in both those using CAM and those opting not to use CAM to relieve IBS symptoms. The research presented has implications both for greater understanding of illness perceptions and treatment beliefs in IBS. There is also potential for findings to potentially assist in developing future self-management strategies and patient centred medical consultations for those people presenting with IBS.

The following chapter introduces these two branches of research and is split into two parts. The first part of the chapter (section 1.1) presents research that has highlighted the importance of psychological factors in IBS, with particular focus on illness perceptions and their influence on health related quality of life and CAM use. In the second part of the chapter (section 1.6), a systematic review is presented that considers factors associated with CAM use in IBS. Further evidence also suggests a role for treatment beliefs in influencing CAM use in that individuals may be concerned by effects of conventional medication while also having more positive beliefs about CAM.

Chapter two outlines the theoretical approach of the research, proposing an extended version of the common-sense model of illness representations (e.g. Leventhal, Diefenbach, & Leventhal, 1992) as the most appropriate theoretical framework for the research. This model allows for a structured and systematic approach to examining which illness perceptions and treatment beliefs are influential in CAM use. The model also allows examination of pathways from perceptions and beliefs to outcome and if these can be explained through coping strategies, a process referred to statistically as mediation. Also considered are the benefits of a prospective study, to examine changes in CSM components over time.

Chapter three outlines the methodology employed in the research. It considers a suitable approach to incorporating a qualitative component into a survey based design. The protocol for conducting both a cross-sectional and a follow-up study are outlined. As the research was conducted via the internet, issues relevant to web-based research are also considered. This chapter also outlines the statistical methods that were employed in chapters four, five and six.

Chapter four presents the first part of the research analysis from the cross-sectional study. This chapter examines the role of illness perceptions and treatment beliefs in influencing CAM use in those

affected by IBS. Illness perceptions and treatment beliefs between CAM-users and non-users (those not using CAM for IBS) are considered and how these factors influence use of more than one type of CAM (in CAM-users) and which factors predict CAM use.

Chapter five provides an examination of the pathways within the CSM and this is examined for CAM-users and non-users. Relationships between components of illness perceptions and treatment beliefs are considered in addition to consideration of differences in quality of life between the two groups. The CSM pathways are tested for evidence of mediation in each group. Illness perceptions and treatment beliefs are firstly correlated with outcome and then coping. Significant relationships are then tested for a relationship between coping and outcome whilst controlling for perceptions and beliefs.

Findings from the follow-up study are outlined in chapter six. Changes in components of the CSM are examined across the two study time points. Similar to the analysis conducted in chapter five, mediation was tested by assessing the influence of perceptions and beliefs (at study time one) on outcome (time two) and on coping (time two). Significant relationships are then assessed for an influence of coping on outcome (time two) when controlling for illness perceptions and beliefs at time one.

Chapter seven offers reflection and discussion of the research findings, conclusions, implications and areas for future direction. This chapter considers all the findings presented in the thesis and considers the strengths, limitations and the practical and theoretical implications of the research conducted. This chapter argues that the research presented in the thesis makes a new and substantial contribution to the understanding of CAM use in those affected by IBS and how the pathways in the CSM may differ over time depending on whether or not individuals use CAM to relieve the symptoms of IBS. Future directions for the research are also considered.

## Chapter 1

### **Irritable Bowel Syndrome, illness perceptions and the use of complementary and alternative medicine: an introduction to the research**

*This chapter reviews the role of psychological factors and illness perceptions in Irritable Bowel Syndrome (IBS) and thus outlines the broad psychological context within which the research is set. Specifically, the chapter addresses the relationship between IBS symptoms and depression, anxiety and stress, and the role of illness perceptions in quality of life and healthcare seeking including CAM use. A systematic review of the use of CAM in IBS is presented and informs the rationale for the research presented in this thesis.*

#### **PART 1:**

### **1.1 The importance of psychological factors in Irritable Bowel Syndrome**

This section introduces a definition, prevalence figures and process of diagnosis for IBS. Aetiology of IBS is also briefly considered in addition to highlighting the importance of psychological factors in IBS and in influencing CAM use and quality of life.

#### **1.1.1 Definition of IBS**

IBS is a chronic functional disorder of the bowel characterised by a varying number of recurrent symptoms. It is one of the most commonly reported disorders of the group of Functional Gastrointestinal Disorders (FGID) (Drossman et al., 1999). Functional illnesses are classified as such when no aetiological factor or biological marker is present. The National Institute for Health and Clinical Excellence guidelines (NICE) refer to IBS as:

*“a chronic, relapsing and often life-long disorder. It is characterised by the presence of abdominal pain or discomfort, which may be associated with defecation and/or accompanied by a change in bowel habit. Symptoms may include disordered defecation (constipation or diarrhoea or both) and abdominal distension, usually referred to as bloating. Symptoms sometimes overlap with other gastrointestinal disorders such as non-ulcer dyspepsia or celiac disease. People with IBS present to primary care with a wide range of symptoms, some of which they may be reluctant to disclose without sensitive questioning.”* (NICE, 2008, p.4).

The NICE definition recognises the possibility for co-morbidity with other organic and functional conditions, a factor suggestive that IBS can be influenced by somatic sensations from other conditions. The key symptoms in IBS are abdominal pain or discomfort accompanied by constipation, diarrhoea and abdominal bloating. The presence of numerous symptoms, indicate the motivation behind the classification of IBS as a syndrome.

### **1.1.2 Diagnosis and prevalence of IBS**

Prevalence of IBS is estimated to range from 10% to 20% in western populations (Jones & Lydeard, 1992; Thompson, Heaton, Smyth, & Smyth, 2000; Wilson et al., 2004). Corresponding rates have been reported in non-western populations from China (Drossman, 1999) although reported rates from a Thai population were lower than those from British and American participants (Danivat, Tankeyoon & Sriratanaban, 1988). Moreover, more recent data from a large scale web-based study in the US showed slightly lower prevalence of 7% (Andrews et al., 2005). However, current prevalence estimates may under estimate actual prevalence as many that fit IBS diagnostic criteria have been found to not seek medical care (Jones & Lydeard, 1992; Saito, Schoenfeld, & Locke, 2002; Thompson et al., 2000).

From both postal and web-based studies, IBS seems most prevalent in those in middle adulthood, approximately ages 30 to 50 (Hungin et al., 2005; Wilson et al, 2004) and declines with age (Corazziari, 2004).



Those with IBS have also been shown to be more likely to have a lower income, lower levels of education and feel as though they have lived with symptoms over a number of years (Andrews et al., 2005). Prognosis estimates indicate an average duration of 10 years or greater and many report no improvement in symptoms over time (Hungin et al., 2005).

Evidence has suggested female predominance in healthcare seeking for IBS (Andrews et al., 2005; Hungin et al., 2005; Thompson et al., 2000; Wilson et al., 2004). However, as many with IBS do not seek healthcare (Saito et al., 2002), the prospect that a proportion of non-seekers of healthcare are male is possible. It is currently unclear whether the gender disparity in IBS care seeking represents biological or environmental distinctions related to gender or differences in reasons for healthcare seeking (Corazziari, 2004).

Diagnosis of IBS in adults, until recently, involved elimination of possible organic causes often resulting in both unnecessary investigations and lengthy referrals to specialists (Foxy-Orenstein, 2006; NICE, 2008). It is in this way that 'functional' illnesses are sometimes considered to be diagnoses of exclusion. Increased understanding of IBS however, has resulted in a shift towards validated symptom-based diagnostic criteria (table 1.2) which has helped 'legitimise' IBS as a recognised medical complaint (Drossman, 1999; Lea & Whorwell, 2003). This move has seen an emphasis on firstly the Manning criteria (Manning, Thompson, Heaton & Morris, 1978) and more recently successive versions of the Rome criteria (e.g. Drossman, 1999; Drossman & Dumitrascu, 2006). As well as IBS, the Rome criteria list over 30 FGID complaints including functional heartburn and functional abdominal pain syndrome (Drossman, 1999). Diagnosis of IBS relies on close examination of an individual's symptoms. The basis of the Rome II criteria for IBS is the presence of continuous symptoms for a minimum of 12 weeks during the preceding 12 months. Within such diagnostic criteria, the early elimination of possible 'red flag' signals such as unexplained weight loss or rectal bleeding is vital as this may indicate possible serious organic

conditions needing immediate medical attention (NICE, 2008). NICE guidelines currently recommend that abdominal pain or discomfort, bloating or a change in bowel habit (tables 1.1 & 1.2) that has been present for the previous six months is indicative of IBS (NICE, 2008).

Symptom led criteria have been useful in determining IBS in research studies and in influencing how IBS is diagnosed in general practice (table 1.2). The recent move to the Rome III criteria has seen a relaxation on the idea that symptoms should be present during the previous 12 months. The Rome III criteria, proposes symptoms should be evident during the previous six months (Drossman & Dumitrascu, 2006) and consequently, prevalence has been shown to increase with this relaxation of symptom duration (Sperber, Shvartzman, Friger, & Fich, 2007). The influence of the Rome III criteria on current NICE guidelines is evident in terms of both the type and duration of problematic symptoms (table 1.1) and suggests greater applicability of the Rome criteria into clinical practice. Although clearly beneficial, symptom led criteria have been criticised on the grounds that the lack of a 'gold standard' of IBS classification and constant revision of criteria (as well as the use of different criteria) results in problems with diagnosis and therefore estimates of prevalence become less reliable (Boyce, Koloski, & Talley, 2000; Corazziari, 2004).

The Rome criteria also recognise sub-types of IBS, which have been used largely for research purposes. There may be a diagnosis of either diarrhoea predominant IBS (IBS-D) if there are no constipation related symptoms present or constipation predominant IBS (IBS-C) with no indicators of diarrhoea. If no one type of IBS can be identified then the person may be classed as 'alternating' (IBS-A) in that there is sufficient variation in symptoms that no overwhelming sub-type is recognized. In addition to the subtypes of IBS, there also exists a classification of 'refractory IBS' for particularly severe cases (NICE, 2008).

**Table 1.1 Key IBS symptoms reported and pattern of diagnosis in adults (adapted from Agrawal & Whorwell, 2006; NICE, 2008)**

---

***Abdominal pain or discomfort present for at least 6 months that is:***

---

- relieved by defecation

Or:

- associated with altered bowel habit or stool appearance

And at least **two** of the following symptoms:

- Abdominal bloating, distension, hardness or tension
- Altered stool evacuation (straining, urgency or feelings of incomplete evacuation – may form diagnosis of either diarrhoea or constipation predominant IBS, IBS-D and IBS-C respectively)
- Symptoms are made worse by eating
- Passage of mucus

**The following symptoms may also be used to support diagnosis:**

- Low backache
- Nausea
- Lethargy
- Leg pain
- Urinary symptoms (increased frequency, urgency or urge incontinence)

**Possible 'red flag' symptoms to refer for further investigation:**

- Unexplained or unintentional loss of weight
  - Rectal bleeding
  - A family history of ovarian or bowel cancer
  - Looser and more frequent stool over 6 weeks in people over 60
  - Anaemia
  - Abdominal or rectal masses (e.g. lumps or obstructions)
  - Inflammatory markers indicative of inflammatory bowel disease
- 

Several studies have shown that diagnosing IBS for research purposes using the Manning criteria results in higher prevalence than when compared with Rome I or II (Corazziari, 2004; Hillilä & Färkkilä, 2004; Koloski, Talley, & Boyce, 2001; Yale et al., 2008). Similarly, comparison

of the Rome I and II criteria suggests that rates of IBS decrease further when using the Rome II criteria (Boyce, Talley, Burke, & Koloski, 2006; Corazziari, 2004), however other studies have shown moderate agreement between Rome I and II criteria (Yale et al., 2008). These inconsistencies in diagnostic criteria may cast some doubt on the reliability of prevalence statistics and also highlight the need for a gold standard of diagnostic criteria for IBS (Hillilä & Färkkilä, 2004). The move towards symptom led diagnosis has however removed the need for time consuming, costly and invasive GI investigations.

**Table 1.2 Comparison of Manning, Rome I and Rome II symptom-based criteria for IBS (adapted from Corazziari, 2004).**

<i>Manning criteria</i>	<i>Rome I criteria</i>	<i>Rome II criteria</i>
Abdominal pain relieved by bowel movement	Continuous/recurrent symptoms of: Abdominal pain relieved by bowel movement or associated with change in frequency or consistency of stool.	Continuous/recurrent symptoms for at least 12 weeks in preceding 12 months: Abdominal pain or discomfort accompanied by two out of three features:
Pain associated with looser stools	In addition to two or more of the following (at least a quarter of the time):	Relief with defecation Associated with a change in onset frequency Or, change in consistency of stool
Pain associated with more frequent bowel movements	Altered stool frequency Altered stool form (hard or loose)	Symptoms that cumulatively support IBS diagnosis: Over 3 bowel movements a day Less than 3 bowel movements a week
Sensation of incomplete evacuation	Altered stool passage (straining or urgency, feeling of incomplete evacuation)	Altered stool frequency (solid/lumpy or watery/loose)
Passage of mucus	Passage of mucus	Altered stool passage – straining, urgency or feeling of incomplete evacuation
Distension of abdomen	Bloating or feeling of abdominal distension	Passage of mucus; bloating or feeling of abdominal distension

Individuals with IBS may present with other functional GI symptoms such as functional dyspepsia (FD) and gastro-oesophageal reflux disease (GORD) (Quigley, 2006; Corazziari, 2004) and non-GI complaints such

as chronic fatigue syndrome/myalgic encephalomyelitis, joint pain and pelvic complaints (Whitehead, Palsson, & Jones, 2002). The fact that many with IBS also report non-GI symptoms has led to some speculation that there may be a degree of hyper-vigilance in regard of being aware of symptoms (Talley, 2008). There may also be 'secondary' complaints of tiredness, lethargy and urinary problems (table 1.2). Recommendations now include these factors (e.g. NICE, 2008) although there is no directive to treat factors such as fatigue or urinary problems per se. The implicit assumption appears to rest on these problems decreasing following successful treatment of the most troublesome symptoms (Quigley, 2006).

### **1.1.3 Aetiology**

As IBS is a functional gastrointestinal (GI) illness, with an as yet unidentified aetiology, a number of hypotheses regarding the aetiology of IBS have been proposed. Visceral hypersensitivity (Quigley, 2006), altered gut motility (Jones et al., 2000; Quigley, 2006) and environmental factors (Hayee & Forgacs, 2007) have all been suggested as aetiological factors. Some cases develop as post-infectious IBS, although these are thought to reflect a minority of individuals (Foxy-Orenstein, 2006). Genetic influences on IBS have been suggested however parental response to the illness has been shown to have a greater influence on children of those parents with IBS than genetic influences (Levy et al., 2001). Localised actions in the intestine, such as disrupted handling of gas, have also been proposed as causal factors (Caldarella, Jordi Serra, Fernando Azpiroz, & Malagelada, 2002; Serra, Azpiroz, & Malagelada, 2001). Full consideration of these factors however, is beyond the aims of the research presented in this thesis.

In the absence of established aetiological factors, IBS has been conceptualised as a biopsychosocial disorder where several factors may influence the onset and maintenance of IBS symptoms (Drossman, et al., 1999; Hayee & Forgacs, 2007). In this context, IBS is considered a result of disruption in the brain-gut neural axis, where a complex

interaction between biological and psychosocial factors occurs resulting in symptoms (Drossman, et al., 1999).

Current aetiological explanations for IBS have focused on the brain-gut axis (Drossman et al., 1999; Hayee & Forgacs, 2007). In the complicated array of neurotransmitters, nerves and muscles between brain and gut, disruption of the pathways results in the manifestation of IBS symptoms such as abdominal pain and excess gas in the bowel (Guthrie & Thompson, 2002). The biopsychosocial framework allows for consideration of the contribution of psychological and environmental factors on symptoms and behaviour (Drossman, 1998; Engel, 1977). In some cases, it is thought a genetic predisposition to IBS may be evident that may be triggered by social, psychological or environmental stimuli (Drossman, 1998). Early life events, attitudes to illness and possible traumatic events may all influence the development of an individual in psychosocial terms. In turn this may affect a disposition for stress, emotional state, coping skills or learning illness behaviour from a family member (Drossman et al., 1999). Moreover, there is evidence to suggest the onset and maintenance of IBS symptoms may be related to psychological factors such as stress, anxiety or depression (figure 1.1; Drossman et al., 1999; Lea & Whorwell, 2003).

Current understanding of the interaction between brain and gut implicates a bi-directional process of emotional or perceptive states affecting GI sensation, motility and other IBS symptoms (Mulak & Bonaz, 2004; Posserud, Ersryd, & Simrén, 2006). Conversely, visceral sensation may affect perception of (abdominal) pain and emotional states resulting in escalation of symptoms (Drossman, 1999). IBS symptoms are said to occur when communication between the GI muscle structure, the central nervous system (CNS), the autonomic nervous system (ANS) and neurons in the enteric nervous system (ENS) is disrupted (Foxy-Orenstein, 2006).

### ***1.1.3.1 The influence of personality, stress, mood and abuse on IBS symptoms***

Some people diagnosed with FGIDs (including IBS) report a history of sexual or physical abuse in their past (Drossman et al., 1999). This may be categorised as unwanted touching or being exposed to unpleasant images (Talley, Boyce, & Jones, 1997). One problem with many studies reporting abuse is their reliance on retrospective self-report data which may over or under-estimate this association (Koloski et al., 2001). Certain psychological correlates appear to have particular significance in relation to IBS. Drossman et al. (1999) found that between 42 and 61% of patients seen in gastroenterology clinics for FGIDs fall into the categories of anxiety disorders, mood disorders (including depression) or somatoform disorders (including hypochondria and somatisation disorders, where individuals express psychological distress through bodily symptoms). However, population based studies by Talley, Boyce, and Jones (1998) and Talley et al. (1997) conducted in Australia, suggest no relationship between care seeking in IBS and anxiety, mood or somatoform disorders.

Despite there being no personality 'profile' distinct to IBS (Drossman et al., 1999) those with IBS have shown higher levels of both trait anxiety and neuroticism (Drossman, Whitehead, & Camillieri, 1997). Neuroticism in particular seems to give rise to an exaggerated response to physiological sensation or symptoms (Koloski et al., 2001). Drossman et al. (1988) found that IBS patients scored higher on personality traits such as hypochondria, hysteria and depression than non-consulters whilst symptom severity was controlled. The findings from this study suggest that such personality factors may be independent of IBS itself and attributable to the individual. The small number of studies in this area suggests further research needs to be conducted before ruling out the role of personality traits as an aetiological factor (Koloski et al., 2001).

The link between increased stress and IBS is long established (Wilhelmsen, 2000). Stress has been found to be a predictor of

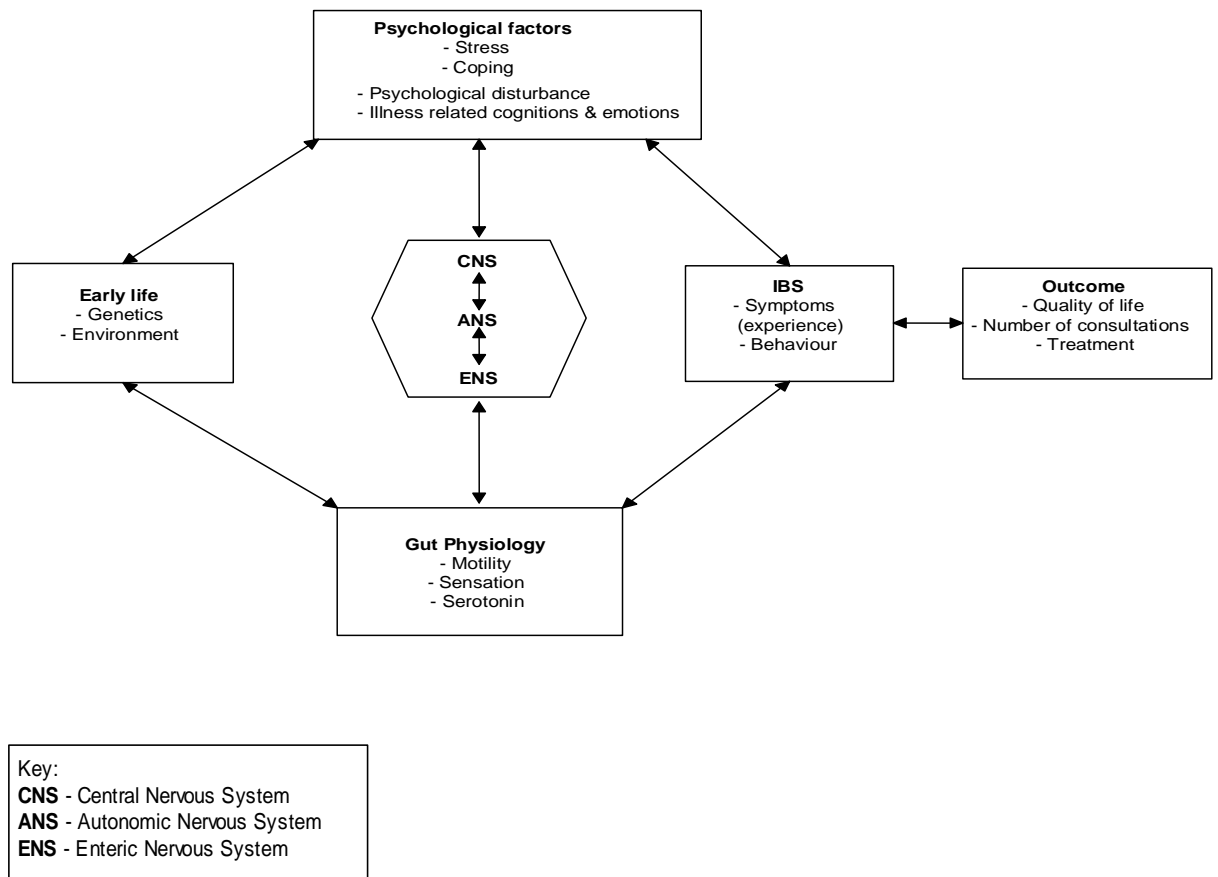
exacerbating symptoms and prompting healthcare seeking (Drossman et al., 1999). Stress has also been strongly linked with severity of symptoms. Over the course of 16 months in a sample of 117 outpatients with IBS, chronic life stress predicted 97% of the variance in symptom intensity (Bennett, Tennant, Piesse, Badcock, & Kellow, 1998). Participants who showed improvement were not subject to chronic stress in their everyday life. A further study by the same authors with 188 outpatients fulfilling various FGIDs found that chronic stress provoked intestinal symptoms to a greater degree in the IBS sub-group of participants (Bennett et al., 1998).

Stress has also been investigated using exclusively female samples. Levy, Jarret, Cain, & Heltkemper (1997) found a positive correlation between stress and IBS symptoms over one menstrual cycle. When controlling for the menstrual cycle, stress was still linked to GI symptoms but not attributed to increases in stress during certain phases during a menstrual cycle (Levy et al., 1997). However, the sample in this study was small (n=26) and only 38% of women reported a relationship between stress and IBS symptoms. In larger samples, the relationship between stress and IBS symptoms appears to be small over time. Over the course of a year, 383 women were found to demonstrate a weak correlation between stress and IBS symptoms (Whitehead, Crowell, Robinson, Heller, & Schuster, 1992). It is clear however, that stress is a contributory factor in the experience of IBS and may influence differences in individuals' responses to symptoms.

It is plausible in this context, that psychological factors can precipitate and maintain symptoms of IBS. Initial mood or emotional disturbances may affect GI symptoms as well as GI sensations affecting mood and emotions. The variation in psychological influence on bowel function may also explain the variation in quality of life reported in IBS, which may result from such factors as poor coping strategies (Drossman et al., 1999).



**Figure 1.1 A biopsychosocial conceptualisation of IBS illustrating the relationship between early life, physiology, psychological factors, symptom experience, illness related behaviour and outcome (adapted from Mulak & Bonaz, 2004 and Drossman et al., 1999).**



### **1.1.4 Treatment and management strategies**

The impact of IBS on the individual and in wider economic terms is often substantial. Conventional medical treatment has a number of options that attempt to reduce this impact (summarised in table 1.3) albeit the emphasis is on management of symptoms rather than cure.

#### **1.1.4.1 Impact of IBS**

The preceding sections have highlighted those with IBS have the potential for an extensive symptom experience meaning there is often

considerable impact of IBS. Effective treatment is therefore desirable from both an individual and wider economic perspective. Those affected with IBS tend to use healthcare services more often (Talley, 2008) and may be referred for costly secondary consultations (Wilson et al., 2004). In wider economic terms, IBS also contributes to a significant proportion of lost working hours and productivity (Dean et al., 2005; Hungin et al., 2005; Wilson et al., 2004). Moreover, several studies have demonstrated that IBS has a detrimental effect on multiple facets of daily life such as sleep, diet, sexual function, travelling and absence from work (Amouretti et al., 2006; Chang, 2004; Dancey & Backhouse, 1993; Dancey, Hutton-Young, Moye, & Devins, 2002; Faresjo, Grodzinsky, Foldevi, Johansson, & Wallander 2006; Halder et al., 2004; Lea & Whorwell, 2001; Luscombe, 2000; Spiegel et al., 2004).

Dancey and Backhouse (1993) examined the impact of IBS with data gathered from 148 users of a self-help network in the UK. Open questionnaire responses showed many participants reported feelings of anxiety and depression, felt unable to talk to others about their IBS and believed others could often be unsympathetic. Participants felt IBS affected their working life. Personal and intimate relationships also suffered as intimacy or even meeting someone could be problematic due to pain. Over two thirds of participants stated that travel and leisure were affected. Many participants in addition, felt stressed and had tried to alter their lifestyle, work and diet in an effort to make their IBS more manageable. GPs were perceived to show a lack of sympathy as well as not explaining symptoms or stating there was nothing wrong. Similarly, Amouretti et al. (2006) in examining 253 participants diagnosed with IBS found having IBS had a significant impact on reported quality of life. Longer symptom duration and perceived severity were predictive of more impaired quality of life. In comparing people with IBS to healthy controls, IBS negatively impacted on elements of daily living, leisure activities, work, travel and social relationships and for some individuals was perceived to have become more severe since the onset of their symptoms. There has been further suggestion that reported quality of

life may differ in different sub-groups of participants. A US study performed a comparison of 147 patients recruited from a GI clinic and 84 patients with IBS via the internet. Those recruited online reported significantly poorer quality of life scores when compared to the GI clinic group suggesting the online participants may represent a distinct group of people affected by IBS (Jones, Bratten, & Keefer, 2007). Further study however, is needed to substantiate these findings.

#### **1.1.4.2 Management of IBS symptoms**

It is recommended (NICE, 2008) that GPs adopt a patient centred approach incorporating dietary advice, suggested fibre supplementation and prescription of anti-spasmodic or anti-diarrhoeal medication as first line treatments. If symptoms persist anti-depressants may be recommended or, in some cases, psychological treatments may be suggested if symptoms continue for over 12 months (NICE, 2008). Some GPs may also recommend complementary and/or alternative medicine (CAM) to relieve symptoms, although some CAM treatments have been shown to offer no benefit to those affected with IBS (table 1.3).

One randomised controlled trial conducted on 116 patients with IBS examined the effect of standard Chinese herbal medicine, personalised Chinese herbal medicine and placebo, found a significant improvement in symptoms rated by both patients and gastroenterologists. The personalised treatment group still showed benefits up to 14 weeks later (Bensoussan et al., 1998). Similarly, Yadav, Jain, Tripathi, and Gupta (1989) found herbal preparations to be useful over 6 weeks of treatment in 169 patients with IBS when compared with placebo, although standard treatment was more effective. Both treatments were no better than placebo at six month follow up.

As both conventional medical care and CAM treatments have debatable application in IBS, psychological treatments may be of benefit. A number of psychological treatments may be recommended for IBS including

Cognitive Behavioural Therapy (CBT), Biofeedback, relaxation training and hypnosis (NICE, 2008). Despite some claims that psychological treatments fare better than standard conventional care (Hayee & Forgacs, 2007), evidence for psychological treatments appears to be mixed. Snelling (2006) argues that trials are often with small samples or lack necessary control in terms of blinding or control groups. One study that compared CBT, relaxation and standard care found no difference between the three treatments (Boyce, Talley, Balaam, Koloski, & Truman, 2003). Although other studies have reported benefits, the studies often fall short of requirements for controlled trials (Snelling, 2006).

Gonsalkorale, Miller, Afzal, and Whorwell (2003) suggest that hypnosis may work well in reducing symptoms for up to five years as well as reducing consultation rates and conventional medication use following hypnosis. In reviewing studies that used hypnotherapy to control IBS symptoms, hypnosis was found to be effective in over half of trials included in the review (10 out of 18 studies) (Wilson, Maddison, Roberts, Greenfield, & Singh, 2006). Although the results for hypnosis appear promising, it is argued this should take place as part of a specialist care programme and is not suitable for everyone affected by IBS (Hayee & Forgacs, 2007; Whorwell, 2006). Promising results also come from CBT studies. However as with hypnotherapy, this approach is also not suited to every individual (Hayee & Forgacs, 2007). CBT attempts to adjust the impact of cognitions and behaviour that may result in increased stress and GI symptoms (Lackner et al., 2007). A meta-analysis of controlled trials has shown success rates for psychological treatments to be promising (Lackner, Mesmer, Morley, Dowzer, & Hamilton, 2004). Despite this success, local availability of such treatments may be limited for many (Lea & Whorwell, 2004). The success of psychological treatments does however provide further support for a psychological approach to managing IBS symptoms.

Other psychological techniques have also been incorporated into self-management interventions for IBS. These approaches have focused on attempting to control symptoms by facilitating a greater understanding of IBS. Ringström, Störsrud, Lundqvist, Westman and Simrén (2009) reported a promising pilot study based on an intervention educating individuals about aspects of IBS, known as 'IBS school.' Although no control group was used with this small sample (n=12), participants reported satisfaction with the information provision and knowledge about IBS increased. Quality of life also improved and GI symptoms were reduced. Ringström et al. (2010) compared 71 IBS patients who received the 'IBS school' intervention to 72 patients who received written information about IBS. The structured education sessions had significant benefits in reducing symptoms, illness related anxiety, and facets of quality of life improved when compared with the information only group (Ringström et al., 2010).

Similarly, Robinson et al. (2006) used a self help guidebook for IBS, with a participant group of 420. The guidebook contained information to help participants cope with their IBS including information about treatments, diet and lifestyle. Participants received either the book alone, the book with attendance at a one-off self-help group (which provided the guidebook and a group session) or were assigned to a control group with no intervention (i.e. usual care for IBS). The guidebook group over the course of a year reported a 60% reduction in healthcare consultations for their IBS and a reduction in symptoms compared to the control group. The self-help group seemed to offer no additional benefit and symptom scores (as oppose to perceived symptoms) did not change significantly in any group. The fact that perception of IBS changed and the number of healthcare consultations declined, suggest that the provision of self-help information about IBS at the time of consultation was beneficial. Similarly, Jarrett et al. (2009) assigned 188 participants with IBS to either a 'usual care' group, a self management session (including information about diet, education, relaxation and cognitive-behavioural strategies) delivered in person, or a third group that had a mixture of in-person

contact and self-help sessions over the telephone. Over the course of 12 months, the self-help groups reported fewer GI symptoms and improved quality of life compared with the 'usual care' group.

**Table 1.3 Summary of treatment guidelines for adults with IBS; adapted from the NICE guidelines (NICE, 2008).**

<i>Treatments for IBS</i>	<i>Treatment details</i>
Dietary and lifestyle advice	Self help information (exercise, time for relaxation and medication). Dietary advice on eating regularly with enough liquids and fibre and cutting down on unhealthy food and drink (and specific ingredients found in some foods). The use of pro-biotic cultures may be recommended for a period of 4 weeks.
Pharmacologic treatments	Antispasmodic medication, Loperamide (anti-diarrhoeal treatment) or laxatives are first line pharmacologic treatments. Anti-depressants are second line treatments if first line medication has limited success. Doses at all stages should be reviewed according to clinical effect and potential side effects.
Psychological treatments	Treatments such as Cognitive Behavioural Therapy, Biofeedback or Hypnosis should be considered if pharmacologic treatment is unsuccessful after 12 months.
Complementary and alternative medicines	There is limited evidence for relief of symptoms from some herbal compounds although more research is needed. There is no current evidence that Acupuncture or Reflexology will give symptom relief (NICE, 2008).

The preceding studies offer interesting and valuable findings suggesting symptoms may be reduced by enhancing feelings of control and understanding of IBS. The benefits of a 'positive' diagnosis of IBS (NICE, 2008) on presentation with symptoms has positive therapeutic benefits (Hayee & Forgacs, 2007). In treating IBS, GP consultations are important aspects of the treatment process where certain therapeutic qualities of the consultation may be enhanced by addressing patient concerns about their symptoms (Ilnyckyj, Graff, Blanchard, & Bernstein, 2003).

### **1.1.5 Illness perceptions**

The promise shown by psychological treatments, self-management and education based interventions for IBS may be seen as support for a supposition that psychological factors play a role in the onset and maintenance of IBS. As has been suggested those affected by IBS may be prone to problems with depression, stress and anxiety (Lea & Whorwell, 2003). These factors are implicated in the cause and maintenance of symptoms via bi-directional pathways in the brain-gut axis (figure 1.1). It is rare for a patient presenting to their GP with IBS symptoms to be screened for such disorders unless they report such problems exist. However, a further important psychological factor in IBS is individuals' beliefs and perceptions about the illness.

Symptom perception is a subjective experience (especially so in the case of IBS) so experience of the same symptoms will not necessarily result in all individuals seeking healthcare (van Dulmen, Fennis & Bliejenberg, 1998). This subjective variation in sensation of pain, discomfort or perception of seriousness of the symptoms may help to explain the discrepancy between consulters and non-consulters in IBS. Despite the subjectivity involved in symptom perception in IBS, there is evidence that shows cognitions and emotions related to the illness are important in the prognosis and experience of IBS.

In IBS there may be somatoform disorders present (section 1.1.4.1) and exploration of these factors has determined there may be tendency for individuals to exhibit more body awareness of visceral symptoms. Such body awareness may result in 'catastrophising' (Drossman et al., 1999; Lackner, Quigley, & Blanchard, 2004), an emotional reaction that symptoms represent a more serious condition (such as cancer). Gomborone, Dewsnap, Libby, and Farthing (1995) found that when comparing IBS patients with depressed patients, organic GI patients and healthy controls, the IBS group reported significantly more bodily preoccupation, disease phobia and greater hypochondriacal beliefs. This study suggests that these factors exist independently of psychological

morbidity (depression was measured in this study) and presents the possibility that such emotional factors may influence symptom experience and quality of life in those with IBS.

A number of studies have shown the value of intervening in illness related cognitions of referred IBS patients. Patients were screened for somatic abnormalities that may have explained their IBS symptoms. These studies found that if Doctor-Patient agreement was high in relation to IBS related cognitions and anxiety, future use of primary healthcare services was reduced. If agreement was low, in that patients may continue to attribute their symptoms somatically, then use of primary care remained high. It also appears that GPs may reinforce somatic beliefs in referring patients for secondary care (van Dulmen, Fennis, Mookink, & Bleijenberg, 1996; van Dulmen, Fennis, Mookink, van der Velden, & Bleijenberg, 1994). Illness related cognitions and emotions have also been associated with healthcare seeking (van Dulmen et al., 1998), so providing effective reassurance during medical consultations may help to reduce healthcare seeking. Addressing patient cognitions using portable data units over a four week period in 37 individuals with IBS (with 38 in a control group), resulted in improvement in quality of life, and reduced catastrophising thoughts and pain (Oerlemans, van Cranenburgh, Herremans, Spreeuwenberg, & van Dulmen, 2010). Only reporting fewer catastrophising thoughts however, remained stable at three months after the intervention (Oerlemans et al., 2010).

There is suggestion that perceptions related to IBS may have greater influence on quality of life judgements than actual symptoms. One study of patients attending a referral clinic suggested that health related quality of life was more influenced by psychological factors than severity of symptoms (Hahn, Kirchdoerfer, Fullerton, & Mayer, 1997) while other studies have suggested both symptoms and perception of symptoms influence quality of life (Naliboff, Balice, & Mayer, 1998; Spiegel et al., 2004; Whitehead, Burnett, Cook, & Taub, 1996).



Specific illness related cognitions have been shown to be related to self-reported quality of life in people with IBS. Rutter and Rutter (2002) found weaker beliefs about the consequences of IBS and greater control over symptoms were related to better quality of life ratings. Beliefs in more serious consequences were also consistently related to poorer reported quality of life over a 12 month period (Rutter & Rutter, 2007).

The evidence presented suggests illness related perceptions are important influences on illness experience, quality of life (Chang, 2004; Luscombe, 2000) and healthcare seeking (van Dulmen et al., 1994; 1996; van Dulmen, Fennis, Mookink, van der Velden, & Bleijenbergh, 1997). The supposition that illness perceptions influence quality of life and healthcare seeking also fits into the biopsychosocial explanation of IBS (e.g. Drossman et al., 1999; Lea & Whorwell, 2004). As previously considered, quality of life is significantly impaired in IBS (e.g. Lea & Whorwell, 2001). The lack of biological/organic markers in IBS means that many studies utilise self-report measures of quality of life (Lea & Whorwell, 2001; Patrick, Drossman, Frederick, DiCesare, & Puder, 1998; Rodríguez & Fernández, 2003) as a study outcome or barometer of symptom experience. In IBS, reported quality of life has been shown to be poor, even when compared with more serious potentially life threatening conditions (Drossman et al., 1999) and when compared with healthy controls (Lea & Whorwell, 2001). This may be indicative of why large numbers of those affected with IBS use CAM. However, despite using CAM, reported quality of life in CAM-users has been shown to be poorer than that of non-users (i.e. those not using CAM) with IBS (van Tilburg et al., 2008). There is also little known about the processes through which illness perceptions may influence reported quality of life in IBS.

Evidence also demonstrates that those affected with IBS will have causal beliefs, many of which imply psychological factors are instrumental in onset and maintenance of symptoms. From 261 participants diagnosed from the Rome criteria, high numbers cited anxiety, diet and depression

as causes of their symptoms. Few (less than 30%) knew that abdominal pain was one of the key symptoms in diagnosis (Lacy et al., 2007). Stress has also been cited as either one of the main causal factors (Hungin et al., 2005) or triggers in IBS (Casiday, Hungin, Cornford, de Wit, & Blell, 2009). Rutter and Rutter (2002) found that beliefs in a psychological cause resulted in higher levels of anxiety being reported. Individuals with IBS seem to acknowledge that IBS may have a variety of causes (Dancey et al., 2009) but successful treatment of IBS is more important to those affected than causal explanations (Casiday et al., 2009; Dancey et al., 2009). There may also be differences in causal beliefs according to gender or type of care being received. Males with IBS in primary care reported similar abdominal complaints, causal attributions, related health complaints and had similar demographics to IBS outpatients. Conversely, female outpatients were shown to attribute their IBS to somatic causes whereas patients in primary care more readily attributed their IBS to stress (van der Horst et al., 1997).

Some affected with IBS will adopt what are considered avoidant, maladaptive or dysfunctional coping strategies. Some demonstrate avoidant behaviour of certain activities, or feel so constrained by their symptoms that they effectively stop taking part in activities previously enjoyed (e.g. Dancey & Backhouse, 1993). This avoidant behaviour may be influenced by perceptions of whether symptoms would cause a particular problem, resulting in a response of avoiding the task or action. Dancey and Backhouse (1993) also found evidence of self blame in those affected by IBS, where individuals appeared to blame themselves for their IBS through causal explanations of lifestyle, stress and dietary habits. Self blame has been classified as a maladaptive form of coping (e.g. Carver, 1997) and as considered previously such coping styles have been associated with poorer outcomes in functional bowel disorders (Drossman et al., 1999; Drossman, Leserman, et al., 2000).

In contrast, evidence suggests those affected go to great lengths to cope with their IBS by using numerous coping strategies such as relaxation

techniques, utilising the support of others and making dietary modifications (Casiday et al., 2009; Fletcher, Schneider, Van Ravenswaay, & Leon, 2008). It has also been suggested that individuals with IBS perceived they could cope more effectively if they had been given more information and had better understanding of IBS (Dancey & Backhouse, 1993). Rutter and Rutter (2002) found different coping strategies to be related to illness perceptions in individuals affected by IBS further suggesting an important and influential role for illness perceptions.

To determine the significance and influence of illness perceptions in IBS, it would be logical to examine their influence on quality of life and coping strategies. Evidence from a number of chronic illnesses (e.g. head and neck cancer and rheumatoid arthritis) illness related perceptions or cognitions have been shown to influence coping strategies (Carlisle, John, Fife-Schaw, & Lloyd, 2005; Llewellyn, McGurk, & Weinman, 2007).

#### ***1.1.6 Explaining CAM use in IBS***

Symptoms may respond well to a combination of medication and diet modification or supplementation of fibre (Hammerle & Surawicz, 2008). Reviews of controlled trials however, suggest the efficacy of pharmacologic treatment and dietary supplementation is questionable (Ford et al., 2008; Lesbros-Pantoflickova, Michetti, Fried, Beglinger, & Blum, 2004). Responses to conventional medical treatments have also been shown to be variable and can lack lasting success (Hayee & Forgacs, 2007) leading to feelings of frustration (Casiday et al., 2009). Pharmacologic treatments have also been associated with negative GI side effects thus limiting any benefit (Hussain & Quigley, 2006). Anti-depressant medication may be introduced as a second line of treatment if first line treatments (table 1.3) are unsuccessful, and have shown promising findings (Hayee & Forgacs, 2007).

It is therefore perhaps not surprising that CAM use in IBS is reported to be high. In a sample of 281 participants with IBS, one study found over

50% had used some form of CAM (Kong et al., 2005). Similarly, van Tilburg et al. (2008) found CAM use of approximately 35% in a sample of 1012 individuals with functional bowel disorders (FBD), rising to 38.4% when IBS (n=419) was considered independently. As previously considered, there are a small number of studies that suggest some forms of CAM may be useful in treating IBS (e.g. Bensoussan et al., 1998; Yadav et al., 1989). Many CAM treatments however, still lack demonstration of efficacy based on randomised controlled trials although this very premise of demonstrating efficacy of CAM through randomised controlled trial is sometimes regarded as an affront to particular CAM philosophies (Wersch et al., 2009).

Although defining CAM can be problematic, it is generally accepted that CAM modalities include treatments, practices or therapies that tend to operate differently to the biomedical model of most conventional medical treatment. Treatment is usually self-funded by the individual as most treatments are not covered by state funded healthcare. Demarcation has previously existed between 'complementary' treatments typically used in conjunction with conventional medication and 'alternative' treatments, used in place of conventional medicine (Wersch et al., 2009). Within the domain of CAM there is often categorisation of treatments into mind-body therapies, biologically based treatment, manipulative treatment, holistic practices and energy based healing (Hilsden, Verhoef, Rasmussen, Porcino, & DeBruyn, 2011). Problems in defining CAM are further compounded by the extensive variation within different CAM treatments where different treatments have differing philosophical orientations (Aakster, 1986; Zollman & Vickers, 1999). Furthermore, there are issues with grouping treatments that are purchased over the counter with therapies that require contact with a practitioner (Wersch et al., 2009). There is also evidence that users of different CAM modalities possess different characteristics (Kelner & Wellman, 1997). This research is not an attempt to disseminate such differences but to consider CAM-users as a group of individuals who seek treatment for IBS outside of conventional medicine.

Definitional issues aside, in general populations CAM use appears to be extensive. One large scale survey conducted in the US suggests that CAM use in the population grew from 33% in 1990 to 42% in 1997 (Eisenberg et al., 1998). In the UK, 10% of people indicated they had used CAM in the preceding 12 months, with 90% using CAM at some point in their lives (Thomas, Nicholl, & Coleman, 2001). This is contrasted with 41% of those in the US using two or more CAM treatments in the preceding year (Tindle, Davis, Phillips, & Eisenberg, 2005). In this context, the use of CAM may be seen as one form of adaptive coping behaviour (Suarez & Reese, 2000), as it represents a move towards attempting to control symptoms.

Despite the extensive use of CAM, there remain concerns with such aspects as efficacy and regulation of treatments. In the UK, government legislation (Department of Health, 2001) has sought to prevent unjustified health claims by practitioners and those in the conventional medical domain have the power to advise if a treatment works or not (Wersch et al., 2009). If CAM treatments are found to show significant effects, regulation and further testing are essential as there may be potential for harm in an active component of treatment (Wersch et al., 2009). Even without claims of efficacy, there may be potential for harmful interactions between pharmacologic treatment and some forms of CAM (Leung, Shalansky, Lo, & Jadusingh, 2009; Shane-McWhorter & Geil, 2002; Vincent & Furnham, 1997). Furthermore, current NICE guidelines recommend against using reflexology and acupuncture for IBS as current findings suggest there is no beneficial effect for either of these treatments (NICE, 2008).

One further criticism of CAM treatments is that they may subject to an increased placebo (i.e. a perceived or actual) effect, especially in the case of a consultation with a CAM practitioner (Kaptchuk, 2002). Dorn, Kaptchuk, Park, Nguyen and Canenguez (2007) compared placebo responses in a number of CAM and conventional medication trials. Nineteen trials were reviewed with a pooled estimation of placebo rate of

42%, and this was found to increase the longer the treatment period (Dorn et al., 2007). This rate may be underestimated as the difference in CAM and conventional consultations is well documented to differ on such factors as time spent with a client and perceived increased levels of empathy in CAM consultations which may 'enhance' any placebo effect (Kaptchuk, 2002). Such factors may even 'pull' people towards using CAM, as an extended consultation may be regarded as a desirable or positive aspect of treatment (Vincent & Furnham, 1997). At this point it is worth clarifying that this thesis is not intended to be either a critique or endorsement of CAM, but an exploration of the perceptions and beliefs of those that use CAM.

CAM availability has increased in the last three decades with several GPs now offering CAM treatments directly or referring patients to CAM practitioners (Thomas, Nicholl, & Coleman, 2003). These factors do not solely account for the increase CAM use. Work with non-illness specific populations has established being female, having higher disposable income and higher educational attainment are all socio-economic factors shown to predict CAM use (Astin, 1998; Bishop & Lewith, 2010). Those with chronic health conditions have been shown to be more likely to utilise CAM treatments (Astin, 1998; Bishop & Lewith, 2010; Vincent, Furnham, & Willsmore, 1995).

Existing research exploring CAM-user beliefs and attitudes has suggested having a positive attitude towards CAM, feeling conventional treatment has failed to cure or relieve illness, having concerns in relation to harmful effects of medication and some unease with communication with doctors influence CAM use (Vincent & Furnham, 1996). Other studies have also cited beliefs about the potential harmful effects of conventional medication as influences on CAM use (Bishop et al., 2006; Horne, Weinman, & Hankins, 1999). CAM users have also been shown to have a holistic (i.e. a whole body) approach to health rather than just treating the health problem (Astin, 1998; Testerman, Morton, Mason, & Ronan, 2004) as well as seeking greater control in the treatment (Bishop,

Yardley, & Lewith, 2007) and being less likely to smoke or drink alcohol (Nahin et al., 2007). Furthermore, positive beliefs regarding CAM appear not to be related to outcomes following CAM treatment (Lewith, Hyland, & Shaw, 2002).

Illness perceptions have also been shown to be related to CAM use (Bishop et al., 2006; Bishop et al., 2007; Searle & Murphy, 2000). Beliefs in a psychological cause influenced whether participants adhered to a homeopathic treatment regimen (Searle & Murphy, 2000). However, this study only had a small sample (n=30), making it difficult to generalise findings. Bishop et al. (2006) studied a much larger general population sample recruited from the internet. Stronger beliefs in an emotional cause, greater understanding of illness and poorer consequences all predicted CAM use (Bishop et al., 2006) in a logistic regression model that accounted for a moderate 36% of the variance in CAM use. A further study (Bishop, Yardley, & Lewith, 2008) showed much weaker associations between illness representations and adherence to CAM suggesting illness representations may be more important predictors of CAM initiation than repeated use (Bishop et al., 2008).

In chronic fatigue syndrome/myalgic encephalomyelitis and other fatigue related illnesses, CAM use has been found to be as high as 77% in a sample of 444 participants (Jones, Maloney, Boneva, Jones, & Reeves, 2007). This high use was attributed to symptoms and having other medical or psychiatric complaints (Jones, Maloney et al., 2007). In organic bowel conditions, such as Inflammatory Bowel Disease (IBD) patients have been shown to be more likely to use CAM if they perceive their symptoms to be poorer than those of others with IBD and if symptoms hindered their everyday life. Longer illness duration and a history of hospitalisation are also factors that have been shown to influence CAM use (Hilsden, Scott & Verhoef, 1998; Scott, Verhoef & Hilsden, 2003). One study of 239 UK GI outpatients with IBD found 26% were currently using CAM for IBD, with 53% stating it had helped with symptoms (Langmead, Chitnis, & Rampton, 2002). CAM prevalence

surveyed from a number of western populations appears to fall within 21%-60% for IBD, for both present and past CAM use (Hilsden et al., 2011).

Furthermore, concerns about harmful effects of medication and the feeling that conventional medicine was 'failing' also predict CAM use in IBD (Hilsden et al., 1998) as do concerns about doctor-patient communication (Scott et al., 2003). Other studies with IBD patients suggest a poorer reported quality of life increases the likelihood of using CAM for symptom relief (Langmead et al., 2002). Emotional and social anxieties are also associated with patients turning to CAM. Additionally, patients with gastrointestinal (GI) disorders have been shown to associate perceived profits with CAM use, that is rewards, such as decreased stress, anxiety and pain, which outweigh perceived costs such as pain, nausea and financial outlay (Giese, 2000).

Conventional healthcare seeking behaviour seems to be prompted by discomfort or prolonged symptoms (Talley et al., 1997) and there is evidence that conventional healthcare seekers have a more 'severe' illness experience. Similarly, Bishop and Lewith (2010) reported CAM-users as perceiving inferior health status than non-users. Wilson et al. (2004) found consulters of healthcare had poorer quality of life than non-consulters with IBS. It is therefore plausible to suggest that those using CAM for their IBS will have a more intense illness experience than those not using CAM, which is also reflected in the lower quality of life reported in CAM-users with IBS (van Tilburg et al., 2008). To date, no published research has examined this possibility.

Examining existing studies that have considered CAM use in those affected by IBS may illustrate where the shortcomings in research exist and where future research may direct attention. Therefore as part of this research, a systematic review was conducted to examine the prevalence of, and factors associated with, CAM use in those affected by IBS.



## **PART 2:**

### **1.6 Factors associated with complementary and alternative medicine use in Irritable Bowel Syndrome: a systematic review**

The aim of the systematic review was to examine and quantify the extent of CAM use and reasons for CAM uptake in those affected by IBS.

#### **1.6.1 Method**

##### ***1.6.1.1 Search Strategy***

Searches were conducted for articles published from 1978 onwards, when the first symptom based criteria, the Manning criteria, for diagnosing IBS was published (Manning et al., 1978). The AMED, EMBASE, Cinahl, PubMed, PsychINFO and the Cochrane database for systematic reviews were searched to identify all studies that considered the prevalence of and factors that influence CAM use in those with IBS. This electronic search was carried out using the terms 'irritable bowel syndrome', 'complementary' and 'alternative'. Further searches were carried out using the terms 'functional gastrointestinal' and 'functional bowel' in conjunction with the terms previously listed. There were no further restrictions on date of publications.

##### ***1.6.1.2 Selection process***

Duplicates were removed from the search and all abstracts (n=1264) subsequently read. Selected studies were included if 1) there was measurement of the extent of CAM use in the sample and 2) they had examined which factors may have a role in those with IBS using CAM treatments. There were no restrictions placed on the type of analysis or design the studies used. Only published, English language studies were included. Where it was unclear if the study would fit the review criteria, the paper was obtained in full. The reference lists of all papers were checked for additional studies that met the review's inclusion criteria. The search process is outlined in figure 1.2.

### **1.6.1.3 Data analysis**

Due to the variation in sample size and the differences in measures used in the selected studies, meta-analysis was thought to be inappropriate and results are presented using a tabular and narrative summary.

### **1.6.2 Results**

Five published studies met the review inclusion criteria. The resulting studies were conducted in the UK (Smart, Mayberry, & Atkinson, 1986), Holland (Donker, Foets, & Spreeuwenberg, 1999), Canada (Verhoef, Sutherland, & Brkich, 1990), Australia (Koloski, Talley, Huskic, & Boyce, 2003) and the US (van Tilburg et al., 2008). Four studies used a survey/questionnaire design and one (Donker et al., 1990) used quantifiable structured interviews. A summary of the findings of each of the studies can be found in Table 1.4.

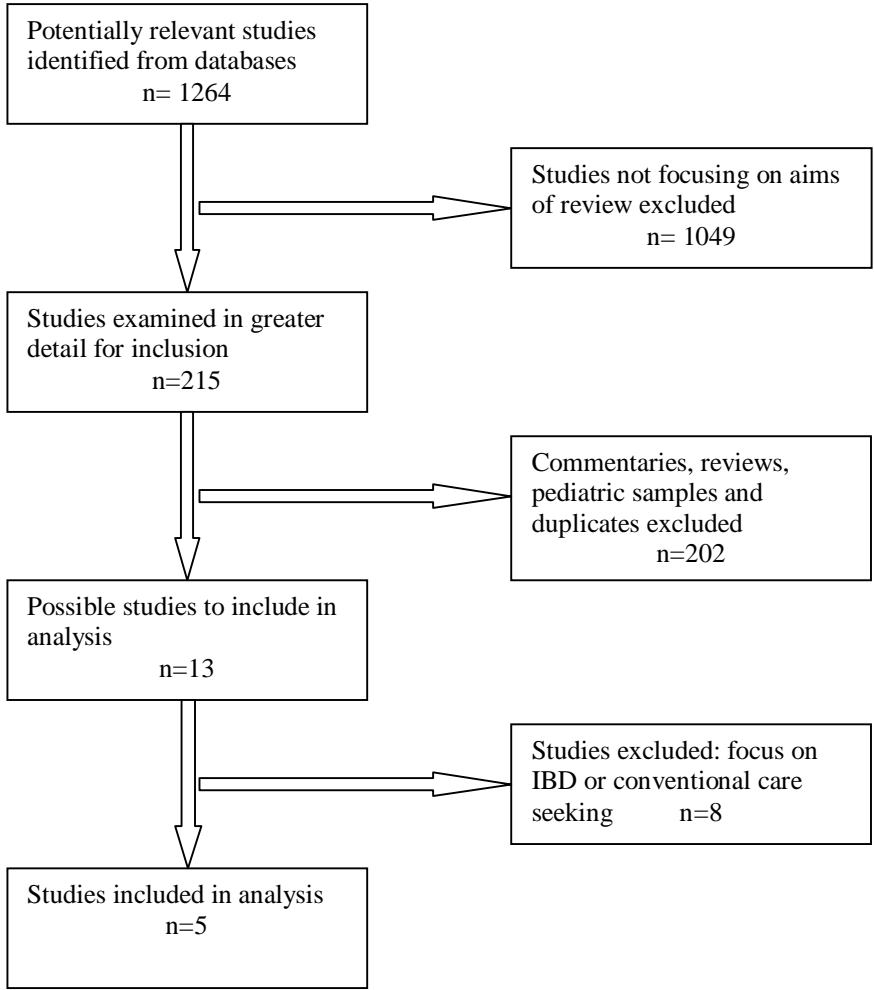
All of the studies examined responses (to questionnaires/interviews) of a group of participants with a functional bowel disorder (FBD) or focused specifically on IBS. Recruitment varied from postal questionnaires (Smart et al., 1986), to general practitioner clinic (Donker et al., 1999) and outpatient clinic (Smart et al., 1986; Verhoef et al., 1990). Two studies used data collected from a previous healthcare survey for those with FBD (van Tilburg et al., 2008) and previous population surveys (Koloski et al., 2003). All reviewed studies reported a larger number of female participants ranging from approximately 60-75% of sample sizes.

#### **1.6.2.1 Methodological comparison**

All studies used group comparisons as a focal point of analysis. Two studies (van Tilburg et al., 2008; Verhoef et al., 1990) used one group of IBS/FBD outpatients, analysed in terms of those who had used CAM and those that had not, drawing participants from an outpatient clinic. Smart et al. (1986) compared 96 IBS patients, 143 patients with other unspecified organic upper GI disorders (both from an outpatient clinic) with 222 Crohn's disease patients contacted by post. The remaining

studies (Donker et al., 1999; Koloski et al., 2003) used an IBS group compared to a control group of healthy participants.

**Figure 1.2 Flow chart showing the process of identifying relevant studies**



**Table 1.4 Summary of studies included in the systematic review**

<i>Study</i>	<i>Participants</i>	<i>Diagnosis of IBS</i>	<i>Design</i>	<i>Extent of CAM use</i>	<i>Reasons for CAM use</i>
Smart et al. (1986) (UK)	n=96 IBS patients (n=67 female); n=143 organic GI (n=84 female); n=222 Crohn's disease (n=137 female).	IBS - Manning et al. (1978).	Questionnaire – practices and practitioners. No. of treatments, treatment options.	CAM use: IBS (11%); GI (4%); Crohn's (6%). Consulted CAM practitioner: IBS (16%); GI (2%); Crohn's (6%).	CAM use significantly more likely if conventional treatment 'had failed' those with IBS.
Verhoef et al. (1990) (Canada)	n=395 GI adult outpatients (n= 237 female) (n=63 Functional diagnosis)	Gastroenterologist consensus scale 1(functional) – 5 (organic).	Questionnaire CAM use and scepticism towards conventional medicine.	50% of CAM users had functional diagnoses (13% of non users). 41% of CAM use not for bowel disorder but other health issue.	CAM users significantly less satisfied with conventional treatment (54% v 85% non users); had more stressful life events in previous year (70% v 47%); more sceptical of conventional medicine (49% v 13%) and less satisfied with conventional practitioner answers (77% v 91%).
Donker et al. (1999) (Holland)	Population: n=10787 GP registered (age 15+, 51% female) n=53 (n=37 female) IBS patients via General practice.	Diagnosed prior to study.	Questionnaire – experienced health; GHQ (30); no of complaints (14 days prior); BIOPRO scale (N=53 interviews).	32% of those with IBS consulted CAM practitioner (15% non-IBS).	IBS patients had significantly poorer health (and 'other' complaints); higher GHQ & BIOPRO scores compared to population group.
Koloski et al. (2003) (Australia)	n=207 IBS/FD patients (n= 143 female); n=100 controls (no symptoms – not included in all analyses).	Abdominal pain > 1 month; Rome I criteria. IBS or functional dyspepsia.	Healthcare seeking SSI; symptom status; Psychological morbidity.	86.5% functional GI group sought conventional healthcare. 20.8% had sought alternative healthcare. 9% had used CAM in previous 12 months.	Females significantly more likely to use CAM in contrast to greater pain and perception of symptoms predicting conventional care seeking.
van Tilburg et al. (2008) (US)	n=1012 patients with IBS or other functional diagnosis (n=248 male). CAM users and non-CAM users compared.	Patient index cards screened to determine IBS or other functional diagnosis.	Questionnaires completed including; symptom severity (IBS-SS); Quality of life (IBS-QOL); Psychological distress (Brief symptom inventory – BSI); Ratings of perceived effectiveness of treatment.	CAM use was 35% over past three months in FBD, 38% in IBS; ginger, massage and yoga were the most popular CAM treatments.	Factors that predicted CAM use were being female, higher education level and higher anxiety (BSI). Dissatisfaction with conventional care and perception of lack of effectiveness of prescription medication were not associated with CAM use.

<p><b>Key:</b>  <b>GHQ – General Health Questionnaire</b>  <b>IBS-SS – IBS symptom severity scale</b>  <b>IBS-QOL – Irritable Bowel Syndrome Quality of Life</b></p>	<p><b>SSI – Semi-structured interview</b>  <b>BIOPRO – Biographical list of problems</b>  <b>BSI – Brief Symptom Inventory</b></p>
--	--

Smart et al. (1986) assessed the frequency of CAM use in patients with a diagnosis of IBS according to the Manning criteria (Manning, Thompson, Heaton, & Morris, 1978) and for whom a full clinical examination revealed no bowel abnormalities. Patients with organic GI disorders were recruited from the same outpatient clinic and the Crohn's patients were contacted via post. All participants completed a questionnaire based on alternative medicine consultations.

Verhoef et al. (1990) examined patients who sought alternative treatment for the problem which had required a consultation with a GI specialist in the past two years. Differences in demographic and health status between those that used CAM and those that did not were compared. Of the 395 GI patients recruited, 55 were classed as having a functional GI disorder. Diagnosis was carried out by four GI specialists who had a high agreement rate (89%) for the study. This study excluded patients who used CAM for health problems other than their diagnosed GI disorders. Participants completed a questionnaire based on scepticism towards conventional medicine and were asked if they had used alternative medicines during the last two years.

Donker et al. (1999) focused on the health status of 53 patients with IBS recruited from general practices participating the Dutch National Survey of Morbidity and Intervention in General Practice and compared their use of healthcare services including CAM to the population sample of 10,787. Participants were asked about their healthcare use and completed the General Health Questionnaire (GHQ) a screening tool for psychiatric illness (Goldberg, 1972) and the biographic problem list (BIOPRO) which measures social problems (Hosman, 1983). In addition, they were asked about any health problems in the two weeks prior to being questioned. Additional measures included health related behaviour (e.g. smoking, exercise) and the amount of healthcare sought. This ranged from seeing the GP (in the previous three months), a physical therapist (in the previous 12 months), a specialist in the last two years and an alternative therapist in the previous five years.

Using semi-structured interviews and questionnaires, Koloski et al. (2003) considered rates of use of both conventional and alternative healthcare in 207 patients with functional GI diagnoses (IBS or functional dyspepsia). Participants were recruited from one of two previous surveys carried out by the same authors and separated into consulters or non-consulters for both conventional and alternative healthcare. Participants were given a healthcare seeking interview which assessed healthcare use and frequency, access to healthcare and satisfaction with their healthcare. The structured interview for bowel symptoms was also administered to give a functional diagnosis based on the Rome I criteria (Drossman et al., 1994). This structured interview also accounts for aspects related to quality of life and extent of symptoms. In addition, participants were given the Composite International Diagnostic Interview (World Health Organisation, 1997), a structured measure designed to assess past and current psychological disturbance.

Drawing on data from previous work, van Tilburg et al. (2008) considered the prevalence and types of CAM used in IBS and FBD in 1012 FBD patients from an 'outpatient' healthcare maintenance organisation in the US (the data having been collated during a previous study (Nyrop et al., 2007). The study was carried out over six months. Participants were assessed for symptom severity at their 'baseline' visit to the clinic using the Irritable Bowel Syndrome Severity Scale (IBS-SS) (Francis, Morris, & Whorwell, 1997), as well as quality of life (using the Irritable Bowel Syndrome Quality of Life scale, IBS-QOL (Patrick et al., 1998), psychological distress (using the Brief Symptom inventory, BSI (Derogatis, 1977) perceived treatment effectiveness and CAM use.

#### **1.6.2.2 Extent of CAM use**

Smart et al. (1986) found significantly more of those with IBS had visited an alternative practitioner compared with the other two groups. Current alternative medicine use was significantly greater in the IBS group with herbal treatments and homeopathy as the most frequently used treatments (Smart et al., 1986). Verhoef et al. (1990) reported that 50%

of CAM users had FBD (compared to 13% of non CAM users) but only 9% had used CAM for the condition they presented to a gastroenterologist with chiropractors (for conditions other than GI), herbalists, naturopaths and reflexologists being the most frequently used CAM therapists. 46% of participants had visited more than one type of CAM practitioner.

Donker et al. (1999) found the IBS patient group had paid more visits to an alternative practitioner than the population group (32% compared with 15%). Koloksi et al. (2003) revealed that 86.5% of the functional GI group had at some time sought conventional healthcare. This figure dropped to 20.8% when participants were asked about seeking alternative healthcare, with only 9% using any CAM in the previous 12 months with the most frequently accessed treatment being visits to a naturopath. van Tilburg et al. (2008) found 35% of those with FBD and 38.4% of those with IBS had used CAM with ginger, massage therapy and yoga being the most popular treatments.

### **1.6.2.3 Reasons for CAM use**

#### *i) Demographics and functional diagnosis*

Being female was the sole significant predictor of CAM use in functionally diagnosed individuals in one study (Koloski et al., 2003). Other studies (Donker et al., 1999; Smart et al., 1986; Verhoef et al., 1990) did not examine the role of gender in CAM use although Donker et al. (1999) reported that most IBS patients were female and had significantly lower levels of education. van Tilburg et al. (2008) also found being female predicted CAM use but in contrast to Koloski et al. (2003) they found higher levels of education were also a predictor of CAM use (van Tilburg et al., 2008). Two studies noted that having a functional diagnosis itself was more likely to result in participants using CAM. Verhoef et al. (1990) reported that a functional diagnosis was an independent predictor of CAM use compared to those with organic GI disorders. Similarly, Smart et al. (1986) reported more patients with IBS than Crohn's used CAM.

*ii) Perception of symptoms*

Donker et al. (1999) reported IBS outpatients also had significantly poorer symptoms (abdominal pain and other symptoms such as tiredness, backache and headaches) than the population group. Koloski et al. (2003) found that physical aspects of IBS were significant predictors of conventional care seeking rather than influencing CAM use. van Tilburg et al. (2008) found a greater perception of symptom severity was associated with CAM use but was not a significant predictor of CAM use in a logistic regression model that examined predictors of CAM use.

*iii) Patient perception of conventional treatment*

Smart et al. (1986) found that the IBS group was reported to be more likely to use alternative treatments if they had perceived conventional treatment had failed. Verhoef et al. (1990) observed that only 54% of CAM users with GI disorders (including IBS) were satisfied with conventional treatment compared with 85% of participants that did not use CAM and that GI patients that used CAM were significantly more sceptical of conventional medicine than those that did not use CAM (49% compared to 13% of non CAM users). Further analysis revealed associations between a functional diagnosis and scepticism towards conventional medicine, and the finding that these variables both (independently) significantly predicted the use of CAM. In relation to communication between conventional practitioner and patient, this study also identified that CAM users were less satisfied with 'answers' from conventional practitioners than non CAM users (77% v 91%). Koloski et al. (2003) found dissatisfaction was a non-significant influence on CAM use, although there was a reported difference between CAM users and non-users. van Tilburg et al. (2008) found no significant association between CAM use and satisfaction with physician care during their primary visit and that CAM users did not rate their conventional prescription medication as being less effective than non-CAM users.



#### *iv) Positive aspects of CAM treatments and therapies*

Only one study reported possible positive aspects of CAM as being a reason for IBS patients to use CAM. The results from Koloski et al. (2003) suggest a desire to treat the GI problem with a more natural approach, to consider the potential for alternative treatments to work and personal recommendation were all factors (albeit not significant) that influence CAM use. However, Donker et al. (1999) reported that 92% of CAM users felt that the treatment had helped them.

#### *v) Psychosocial factors*

Verhoef et al. (1990) showed that stressful life events in the previous year were a significant predictor of CAM use in those with functional GI disorders. Donker et al. (1999) reported that those with IBS had higher scores on the GHQ compared with the population group. There were also differences in the BIOPRO scores between the two samples. Those with IBS had more concerns about the future, self confidence, social interactions and relationship issues. In terms of health behaviour, the IBS group reported more occupational absence in the two months prior to the study. Having IBS resulted in significantly more visits to the family GP, a physical therapist and a GI specialist. The significant differences in healthcare seeking between the two groups suggest that those with IBS may have potentially more psychological disturbances as measured by the GHQ and increased social difficulties. In turn, these factors seem to be associated with influencing CAM use in this patient group (Verhoef et al., 1990). Koloski et al. (2003) reported noticeable, although not significant, differences between both sets of healthcare consulters (CAM and conventional treatment) and non-consulters in psychological disturbance and perception of symptoms. van Tilburg et al. (2003) found CAM users had significantly reduced IBS-QOL scores than non-users. Similarly there were differences between CAM and non-users on the somatisation, anxiety and depression subscales of the BSI. Logistic regression analysis revealed that only anxiety turned out to be a significant predictor of CAM use.

### **1.6.3 Discussion**

#### ***1.6.3.1 Summary of main findings***

A systematic review of the literature surrounding the use of complementary treatments in those with IBS revealed a small number of studies. These ranged from patient group-healthy control population comparisons, to comparisons of those with IBS who used CAM and those that did not. The findings suggest that those with IBS and who use CAM seem to report (or perceive) more severe symptoms, and may experience mild to moderate psychological problems and social issues. There is also some indication that dissatisfaction with conventional care is an important and additional factor in whether someone with IBS will turn to CAM (Smart et al., 1986; Verhoef et al., 1990) although Koloski et al. (2003) did not find dissatisfaction to be a significant factor influencing CAM use and van Tilburg et al. (2008) found no significant difference in ratings of prescription medication between CAM users and non-CAM users. As a group, the studies indicated prevalence of CAM use at between 9 and 38.4%, less than the 50% CAM use reported in a study examining the prevalence of CAM use in GI illnesses (Kong et al., 2005).

Collectively, the studies reviewed provide an indication that the reasons for CAM uptake in those with IBS show some similarities to patterns of use observed in non illness specific CAM research. All of the studies also had an overwhelming female representation which is consistent with estimates of prevalence in that a greater proportion of females than males seek healthcare for IBS/functional GI symptoms (Andrews et al., 2005; Hungin et al., 2005). Although consistently, a greater proportion of females than males use CAM in general (e.g. Astin, 1998), only two studies (Koloski et al., 2003; van Tilburg et al., 2008) found that being female was an independent predictor of CAM use in those with a functional GI diagnosis.

A distinctive factor with CAM use in IBS compared with CAM use in general populations is the number and duration of experienced symptoms. Within each study there were differing levels of focus on

symptom experience or perception of symptoms as this seems to be a key feature of IBS in terms of chronicity, fluctuation and extent of symptoms (Drossman et al., 1999). Smart et al. (1986) considered other factors more important than symptom duration in predicting CAM use in IBS as more patients with IBS were currently using CAM than the Crohn's group (who have similar symptoms) (Smart et al., 1986), however Verhoef et al. (1990) did not consider participants' reported symptoms. Two of the remaining studies (Donker et al., 1999; van Tilburg et al., 2008) found reporting of more severe GI symptoms to be associated with CAM use as were reduced ratings of quality of life (van Tilburg et al., 2008). One study (Koloski et al., 2003) found increased perception of symptoms to be more predictive of conventional care seeking rather than CAM. These findings appear consistent with research into IBD as increased symptom perception (Scott et al., 2003) and reduced reported quality of life can lead to CAM use in IBD patients (Langmead et al., 2002).

The studies reviewed suggest psychological factors will influence CAM use in those affected by IBS and FBD. This appears to be consistent with much of the research into CAM use in both general (Astin, 1998; Eisenberg et al., 1998; Testerman et al., 2004; Thomas et al., 2001; Vincent, Furnham & Willsmore, 1995) and IBD populations (Hilsden et al., 1998). The studies reported that stressful life events (Verhoef et al., 1990), higher GHQ scores (Donker et al., 1999) and higher levels of anxiety (van Tilburg et al., 2008) were all associated with CAM use in those with IBS. Furthermore, social factors also seemed to have some influence on CAM use. Donker et al. (1999) reported those with IBS had concerns regarding the future, reduced self confidence, problems with social interactions and more relationship issues. It should be noted however, that many studies into CAM use in general populations have not examined such psychological factors although the findings in this review do concur with what is known about possible psychological influence on IBS (section 1.1.1.1).

### **1.6.3.2 Limitations of review**

Across the five reviewed studies, there were common themes why those with IBS turn to CAM although aspects of the various methodologies were heterogeneous meaning it is difficult to generalise findings. There also appears to be a substantial gap in the literature regarding why those with IBS use CAM. Mention should also be made of the reviewed studies being conducted in different countries in that there may be differences in healthcare service provision compared with that available in the UK which also raises the potential for cultural differences within participant groups. Consequently, the impact and understanding of these influences on CAM use is hindered somewhat by the lack of research. Furthermore, the variation in participant numbers in each of the studies is a further area of concern. In addition, two studies (Donker et al., 1999; Verhoef et al., 1990) had relatively small numbers of participants with IBS/FBD. There is also some ambiguity concerning the extent of a functional diagnosis (Verhoef et al., 1990) and if all participants had IBS or different functional diagnoses (such as functional dyspepsia) (Koloski et al., 2003). Group comparisons in each study were also different. Both Verhoef et al. (2003) and van Tilburg et al. (2008) surveyed those with FBD and IBS patients and compared CAM users with non-CAM users. Smart et al. (1986) compared IBS patients with other GI patient groups, while both Donker et al. (1999) and Koloski et al. (2003) compared an IBS group with a control group of healthy participants.

The findings here suggest a perception by some of those affected by IBS that conventional medicine has perceived shortcomings which can lead to CAM use. This can range from unhappiness with communication (Verhoef et al., 1990) to feeling that conventional treatment had failed (Smart et al., 1986) and CAM users feeling more dissatisfied with conventional medicine than CAM (Koloski et al., 2003). However it should be remembered that the nature of IBS and the range of symptoms make the disorder difficult to treat thus the relief that conventional treatment can offer may be limited by the action of pharmacologic treatment targeted towards the most troublesome symptom. Regardless

of the reasons for patient concern, there appears to be some degree of dissatisfaction with conventional medicine but some uncertainty remains about how it is operationalised, measured and whether it is due to issues with treatment or the consultation.

Furthermore, both 'failure' of (Smart et al., 1986) and 'dissatisfaction' with conventional treatment (Koloski et al., 2003) appear to be dimensions of the same construct in that they refer to treatment, the consultation or both. In the studies reviewed, measurement of these factors varied. Koloski et al. (2003) conducted a healthcare seeking interview, Smart et al. (1986) asked participants if they would use alternative treatment if they had perceived conventional treatment to have failed them and Verhoef et al. (1990) administered a questionnaire assessing scepticism towards conventional medicine. van Tilburg et al. (2008) considered the first visit to the healthcare organisation as well as perceived effectiveness of prescription medicine. Moreover, four of the studies reviewed here (Donker et al., 1999; Koloski et al., 2003; Smart et al., 1986; Verhoef et al., 1990) focused solely on CAM consultations thus neglecting 'off the shelf' products from their analysis.

#### ***1.6.3.3. Implications for the thesis***

Only a small number of studies were identified for inclusion in this review based upon the identified criteria. It is evident from the review that the majority of studies lacked a theoretical foundation. It could be surmised from these findings that the implementation of a more robust theoretical framework would have enabled a deeper understanding of psychological factors that could have potentially been targeted to improve management of IBS. Consequently, further research is needed to fully explore factors that influence CAM use in IBS. CAM use is clearly extensive in an IBS context and represents a need for effective treatment. Future studies may focus on why people with IBS are using CAM (both via a practitioner and 'off the shelf') with reference to symptom perception. Assessing the influence of such illness related perceptions could provide greater understanding of the role of these constructs in influencing CAM use in

IBS. Furthermore, treatment beliefs are also important influences on whether CAM is actively sought as a treatment option. Such treatment beliefs could be conceptualised as people's concerns regarding the effects of conventional medical treatments and positive beliefs about CAM.

Illness perceptions have been shown to be important factors in IBS and may have a role in CAM use and influence health related quality of life and are worthy of further exploration. Attention may focus on symptom perception and differing dimensions of perceptions people have about their IBS treatment and how this may influence use of CAM. There is also further scope for investigation into aspects of quality of life and how this may be influenced by CAM use. In future group comparisons, a standard pattern of analysis between CAM-users and non-users may be adopted, where differences in beliefs between such groups have been observed (Hilsden et al., 1998; Vincent & Furnham, 1995; Verhoef et al., 1990). Conducted within those affected by IBS, future research may take account of these considerations as the area warrants extensive further study to understand the importance of illness perceptions and treatment beliefs in IBS. Subsequently, such findings may be used as a guide to influence further study or potentially inform future management interventions based on targeting such psychological factors.

#### **1.6.3.4 Conclusions**

In summary, the findings from this review show the extent of CAM use to be close to 38.4% of those with IBS and FBD. Several factors appear to influence CAM use. CAM-users perceive their symptoms as being more severe when compared with non-users, they may report more severe quality of life, and may have underlying psychological issues such as anxiety. With conventional treatment often limited to the relief of one or two symptoms of IBS, the need for a greater understanding of illness perceptions in IBS would be beneficial. Many of the issues considered in the reviewed studies such as dissatisfaction, quality of life, and anxiety related to the condition could potentially be addressed by future changes

in the approach of conventional medical consultations (e.g. van Dulmen et al., 1996; 1997). Future studies may consider such issues, while considering a systematic and theoretical approach to measurement of these factors to improve the scope of findings using existing reliable and valid measures where possible. The application of a theoretical framework to research in this area may also aid translation to practical measures of intervention.

### **1.7 Chapter summary and aim of thesis**

This chapter has outlined the symptoms, prevalence, impact and diagnostic process in IBS. Aetiology has been considered in relation to a biopsychosocial conceptualisation of IBS which allows for psychological influences in onset and maintenance of symptoms. The importance of illness perceptions has been considered with reference to their influence on health related quality of life and CAM use. The extensive use of CAM has been considered in IBS and a systematic review was presented which synthesised existing research that has examined influential factors on CAM use in IBS.

Research in non-specific illness populations has focused on explaining the extent of CAM use and established a number of demographic, health related and psychological factors are influential in why people select CAM as a treatment option (Astin, 1998; Bishop et al., 2006). However, in IBS, research into why CAM is used has been limited despite CAM use being prevalent (Kong et al., 2005; van Tilburg et al., 2008). It is important to determine which factors are related to CAM use in IBS and how these factors may influence quality of life. This will give further understanding of the role and importance of cognitive and emotional representations of IBS and their influence on the experience and trajectory of IBS. By enhancing the understanding of these factors in IBS improved management techniques and approaches to treatment may be formed.

Previous work from both IBS and general populations has established:

- Illness perceptions influence health care seeking (including CAM use) and quality of life
- Beliefs about both conventional medicine and CAM will influence CAM use
- The perceived illness experience of CAM-users may be more severe than those not using CAM

From the systematic review presented in this chapter, it was further ascertained that in individuals affected by IBS, CAM use is influenced by:

- Perception of IBS symptoms
- Negative beliefs about conventional medical treatment
- Positive beliefs about CAM

Current research has lacked structured examination of how illness perceptions and treatment beliefs may be structured, organised and shown to influence CAM use, in addition to how these factors may influence quality of life according to whether CAM is used or not used for IBS symptoms. This provides a strong rationale that exploration of these psychological factors in those affected by IBS is warranted. Furthermore, CAM use in those affected by IBS, is also clearly a legitimate area of investigation for health psychology research as it appears to be used extensively and is influenced by psychological factors.

This thesis therefore examines psychological aspects related to IBS within a theoretical framework allowing for comparison between those that use CAM to relieve their symptoms and those that do not use CAM treatments. It is envisaged that the illness and treatment beliefs that influence CAM use, coping and quality of life may be identified to further the understanding of these concepts in those affected by IBS and may have influence on future management strategies for those presenting with IBS.



Furthermore, it is evident that investigation of illness perceptions and treatment beliefs in IBS would benefit from a systematic and theoretical approach, as research to date, has investigated many similar concepts, but using different measurement instruments and approaches. The following chapter outlines the reasoning for and implementation of the theoretical approach adopted by the research presented in this thesis.

## Chapter 2

### Theoretical framework

*This chapter outlines and justifies the theoretical framework adopted in the research presented in this thesis. An 'extended' version of the common-sense model (CSM) that incorporates illness perceptions and treatment beliefs is proposed as the most suitable theoretical framework within which to examine these factors in IBS and their relationship with CAM use and reported quality of life. The CSM is outlined with reference to measurement issues, and empirical evidence for the components and pathways in the proposed model. Existing applications of the CSM with respect to IBS and use of CAM are also considered.*

#### 2.1 Theory-based research in health psychology

Chapter one contended that future research into CAM use in IBS would benefit from the adoption of a systematic and theoretical approach in future investigations. Within the field of health psychology research, theoretical models such as social cognition models have been widely and successfully utilised to explain health and illness phenomena. These models have assisted in isolating variables that influence outcome or health and illness related behaviour and have been used to guide interventions and self-management strategies (Brewer, Chapman, Brownlee & Leventhal, 2002; Conner & Norman, 2005). A number of studies have utilised such social cognition models as the Health Belief Model (Becker, 1974), the Theory of Reasoned Action (Ajzen & Fishbein, 1980) and the Theory of Planned Behaviour (Ajzen, 1991) as frameworks to understand underlying processes of health-related behaviour (e.g. Conner & Norman, 2005). The application of a theoretical framework to the research presented in subsequent chapters would provide benefits in understanding specific health related behaviour in IBS (e.g. CAM use) and may lead to identification of illness perceptions and treatment beliefs that subsequently have a strong influence on quality of life judgements. One model that may facilitate explaining both CAM use and the influence

of illness perceptions on quality of life in IBS is the common-sense model (CSM) of illness representation (e.g. Leventhal et al., 1992) and this approach was selected as being the most appropriate theoretical framework for the research presented in this thesis.

The CSM has had success in explaining the influence of illness perceptions on health-related behaviours such as adherence to medication (Brewer et al., 2002; Horne & Weinman, 2002; Llewellyn, Miners, Lee, Harrington & Weinman, 2003), attendance at rehabilitation programmes (French, Cooper, & Weinman, 2006; Whitmarsh, Koutani, & Sidell, 2003), and physical and psychological outcomes (Carlisle et al., 2005; Kaptein et al., 2006; Rutter & Rutter, 2002; 2007) in a number of chronic illnesses.

## **2.2 The common sense model of illness representation**

Chapter one outlined the importance of illness perceptions in IBS and the subsequent influence on quality of life (Lea & Whorwell, 2004; Rutter & Rutter, 2002; 2007), although there is limited knowledge about which aspects of illness perceptions are most important. Illness representations have also been shown to be influential in the use of CAM in general populations (Bishop et al., 2006; 2008; Searle & Murphy, 2000). The common-sense model (CSM) of illness representations (also referred to as the self-regulatory model, e.g. Leventhal, Brissette, & Leventhal, 2003), has offered a theoretical framework for the study of how illness representations (or perceptions) influence illness outcomes (such as quality of life) via adoption of coping strategies across a wide range of chronic illnesses (e.g. Brewer et al., 2002; Glattacker, Opitz, & Jäckel, 2010; Gray & Rutter, 2007; Hagger & Orbell, 2003). It is argued that this model is the most appropriate to address the research aim outlined in the previous chapter.

Fundamentally, the CSM (Leventhal et al., 2003) is a multi-stage process of self-regulation (see figure 2.1) where individuals firstly respond to a health threat by forming emotional and cognitive representations based

on threats to health, with the goal of returning to a state of normality (i.e. without illness). The second stage involves the adoption of coping strategies to deal with a health threat. Thirdly, a process of appraisal is performed to assess the effectiveness of adopted coping strategies have performed in dealing with threats to health (Leventhal et al., 2003). Representations of illness are said to influence coping, which in turn, is then 'appraised.' In this context, coping is said to mediate (i.e. explain) the relationship between illness representations and outcome appraisals (Hagger & Orbell, 2003; Hale, Trehane & Kitas, 2007). The CSM is described as a 'dynamic' model, as illness representations are said to be 'updated' as new information about the illness is obtained and coping strategies are evaluated for effectiveness in dealing with the health threat. Furthermore, there have been more recent attempts to extend the explanatory capabilities of the model by including representations of treatment (i.e. treatment beliefs, Horne & Weinman, 2002). CSM research has also led to the development of both health-based intervention and self-management recommendations designed to target problematic illness representations in chronic illness (e.g. Cameron & Jago, 2008; McAndrew et al., 2008). Identification of such factors would be beneficial to both theory and practice in IBS, to enhance understanding of the role of illness and treatment representations in IBS and to suggest potential pathways for possible future intervention or self-management programmes. Furthermore, the examination of distinct coping strategies and how these are directed by illness perceptions in CSM research is argued to be a crucial aspect of seeking to improve patient outcomes (Leventhal et al., 1998).

### ***2.2.1 Illness representations***

Illness representations are formed from different sources of 'lay' information when individuals are faced with an illness threat (Petrie & Weinman, 2006). Representations may be formed from information gained from external agents (such as health care professionals) and may be updated with appraisal information from coping strategies (Leventhal et al., 1992; 1998; 2003). Representations may be formed from both

'abstract' (lay and external information) and 'concrete' (e.g. symptoms) sources (Leventhal et al., 1998). Leventhal et al. (1998) outline five distinct but interrelated components of illness perceptions related to possible causes; identification with symptoms (illness identity); consequences of the illness; the duration of the illness (timeline) and the extent to which the illness can be controlled or cured (Leventhal et al., 1992; 1998).

The 'illness identity' component of the CSM accounts for representations relating to labelling the illness (e.g. IBS) and information about symptoms of the illness, for example experiencing bowel pain (Petrie & Weinman, 2006). The 'causes' component represents an individual's beliefs regarding possible causal factors of their illness (Hagger & Orbell, 2003; Leventhal et al., 1998). Causes may be perceived as biological, e.g. due to the immune system, germs or viruses; psychological e.g. stress, overwork and personality factors; behavioural e.g. smoking, poor diet or environmental e.g. due to pollution or chemical influence (Moss-Morris et al., 2002).

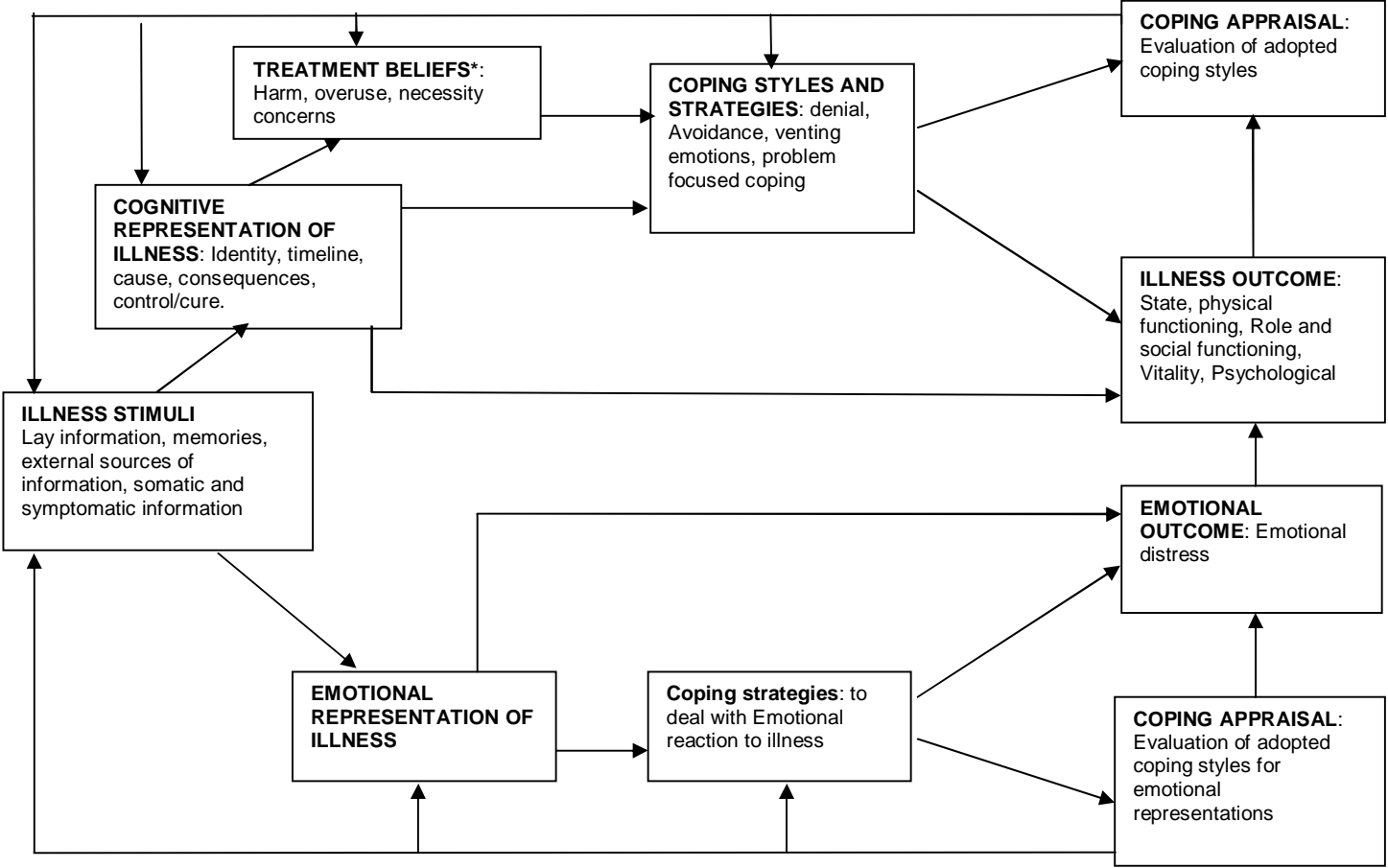
Illness 'consequences' are concerned with the perceived impact the illness will have for the individual in terms of their day to day life and functional capacity (Petrie & Weinman, 2006). The consequences component also accounts for a series of comparative estimations of how the illness has made things worse since onset (e.g. Hagger & Orbell, 2003; Moss-Morris et al., 2002). The 'timeline' component refers to the perceived trajectory of the illness and whether it is likely to be acute or chronic as well as considering the timeline of symptoms (Leventhal et al., 1998). In addition, Moss-Morris et al. (2002) proposed that timeline perceptions may be thought of in terms of chronicity of the illness and whether symptoms are likely to be cyclical which suggests there will be periods of relief but awareness that symptoms will return.

The cure/control perceptions refer to beliefs about whether the illness may be cured or if there is a feeling of efficacy in being able to deal with

the illness based on the performance of coping behaviour (Leventhal et al., 1992; 1998). This component has been subsequently dichotomised into two separate constructs (Moss-Morris et al., 2002): the extent to which the individual feels able to control the illness (personal control) and the extent of whether treatment is perceived as being able to control the illness (treatment control) (Petrie & Weinman, 2006). 'Illness coherence', i.e. the extent to which illness is understood in a coherent manner, was subsequently added to the illness representation components (Moss-Morris et al., 2002).

Leventhal et al. (1992; 1998; 2003) further proposed the CSM is a 'parallel processing' model meaning that emotional responses to illness (e.g. fear or anxiety) are generated alongside cognitive representations (Hale et al., 2007). These responses are instrumental in the formation of emotional representations, which have influence on emotional outcomes related to the illness. However research into emotional representations has been limited in comparison to cognitive representations (Hagger & Orbell, 2003), but, as the CSM stipulates (figure 2.1), emotional representations are important factors in responding to health threats and have important implications for emotional outcomes in the self-regulatory process (Hale et al., 2007; Leventhal et al., 2003).

**Figure 2.1 Flow diagram of an extended version of Leventhal et al's. (1992; 1998) Common-Sense Model of Illness Representations (adapted from Hagger & Orbell, 2003 and Horne, 1997)**



\* Shows the theorised role of treatment beliefs in the extended model

### **2.2.1.1 Evidence for the role of illness representations in IBS and CAM use**

The CSM offers a way to systematically conceptualise the illness-related perceptions in those affected by IBS and observe which perceptions may be influential in CAM use and on quality of life. Although there is limited research utilising the CSM framework in IBS, there is evidence for a role of the different components of illness perceptions in IBS. For example, individuals with IBS may identify specific factors as instrumental in onset or flare-ups of IBS including anxiety, depression (Lacy et al., 2007) and stress (Casiday et al., 2009; Hungin et al., 2005). Receiving a definite IBS diagnosis (NICE, 2008) may result in certain enhanced CSM representations as a lack of a clear diagnosis of IBS can prove frustrating (Casiday et al., 2008). Providing illness-related education may also enhance control over IBS symptoms, as it has been suggested that education provision may result in reduced use of health care services (Ringström et al., 2009; 2010). Those affected with IBS have also been shown to have more bodily preoccupation (Gomborone et al., 1995) and, if their causal cognitions differ from those of their GP, they will tend to use more health care services than if doctor-patient concordance exists (van Dulmen et al., 1996; 1997; 1998). The CSM also refers to emotional representations of illness threats (Hagger & Orbell, 2003; Hale et al., 2007; Leventhal et al., 2003). Emotional representations appear especially relevant in IBS as such representations may influence 'catastrophising' and beliefs that IBS is a more serious condition (Drossman et al., 1999; Lackner et al., 2004). Such catastrophising thoughts may then influence poorer emotional outcome in those with IBS. It also is possible that greater emotional distress caused by IBS may be a driving factor for individuals to initiate use of CAM.

Research exploring CAM use in IBS has yet to adopt a theoretical framework (e.g. van Tilburg et al., 2008; Verheof et al., 2003; section 1.6.3). Bishop et al. (2006) and Searle and Murphy (2000) have shown that illness representations are important in CAM use and suggest the CSM is a useful framework in exploring CAM use in general populations.



However, the research presented in this thesis is unique in applying the CSM to CAM use in those affected by IBS. Existing research that has utilised the CSM has explored these phenomena, IBS and CAM use, as separate entities. However, these studies demonstrate there is a credible and coherent rationale for the use of the CSM dimensions of illness representations in the examination of the representations of illness in IBS and how representations may influence CAM use and reported quality of life.

### ***2.2.1.2 Measurement of illness representations***

The most widely utilised quantitative measures of illness representations are the Illness Perception Questionnaire (IPQ, Weinman, Petrie, Moss-Morris & Horne, 1996) and the revised Illness Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002). The IPQ-R has also been compressed into a shorter version, the brief-IPQ-R (Broadbent, Petrie, Main & Weinman, 2006) to ease responder burden. The IPQ is a quantitative measure of the five CSM representation components of identity, timeline, consequences, cause and cure/control. These five components have shown consistency over a number of illness populations in both meta-analysis (Hagger & Orbell, 2003), and in the development of the IPQ (Weinman et al., 1996). The IPQ-R (Moss-Morris et al., 2002) was developed following refinement and revision of the CSM constructs measured by the IPQ. Illness coherence, the division of timeline representations into cyclical and chronic dimensions and a number of additional causal items were added (Moss-Morris et al., 2002). There was also development of the cure/control dimension into separate treatment and personal control scales.

One important addition to the IPQ-R was that of the component of emotional representations (Hagger & Orbell, 2005; Hale et al., 2007; Moss-Morris et al., 2002). As previously noted, the CSM stipulates that individuals form parallel cognitive and emotional representations of a health threat (Leventhal et al., 2003). As with the IPQ, the IPQ-R has demonstrated largely consistent associations between the components

across a number of illness populations (Fowler & Baas, 2006; Moss-Morris et al., 2002). Stronger emotional representations are related to stronger perceptions of consequences and stronger timeline beliefs (chronic and cyclical), and negatively related to both personal and treatment control (Moss-Morris et al., 2002). These relationships are again consistent with the theoretical stance of the CSM (Leventhal et al., 2003) as this implies that a greater level of control over illness and treatment is intuitively associated with less illness severity, lower reported consequences and less emotional distress.

Research adopting the CSM framework has added support to the theoretical components within the model by demonstrating that the constructs measured by the IPQ and IPQ-R are related in logically consistent ways but remain sufficiently theoretically distinct (Hagger & Orbell, 2003; Moss-Morris et al., 2002; Weinman et al., 1996). Moss-Morris et al. (2002) demonstrated that timeline scales, emotional representations and consequences were all positively related. The two control scales and coherence scale were negatively correlated with the identity, consequences, emotional representations and timeline scales, which is consistent with CSM theory (Moss-Morris et al., 2002). A confirmatory factor analysis of the IPQ-R based on 660 women in a cervical screening context, has further added theoretical consistency and validity of the IPQ-R (Hagger & Orbell, 2005). The treatment and personal control components, along with the illness coherence scale, were negatively related to other scales on the IPQ-R, whereas the remaining scales were all positively related (Hagger & Orbell, 2005). The interrelations between the components of the IPQ have been further demonstrated as theoretically consistent in a meta-analysis of 45 studies that utilised a CSM approach (Hagger & Orbell, 2003). Subsequent studies have added support to these findings (Carlisle et al., 2005; Fowler & Baas, 2007; Hagger, Chatzisarantis, Griffin & Thatcher, 2005; Gray & Rutter, 2007; Kaptein et al., 2006). Such studies are evidence that illness perceptions are observable components that can be reliably captured by the IPQ and IPQ-R.

### **2.2.1.3 Application of the CSM to IBS**

Two studies (Rutter & Rutter, 2002; 2007) have explored components of the CSM in an IBS sample. Rutter and Rutter (2002), using a cross-sectional design, found relationships amongst illness representations as measured by the IPQ that were similar to previous research (e.g. Weinman et al., 1996). Illness identity was positively related to illness consequences and timeline perceptions. Conversely, illness identity was negatively related to the cure/control scale. The timeline scale however, was positively related to both the consequences scale and the cure/control scale (Rutter & Rutter, 2002), suggesting greater beliefs in curing or controlling IBS manifest after a longer perceived duration of IBS.

An important omission from the two existing CSM studies in IBS (Rutter & Rutter, 2002; 2007) is that of examination of patients' emotional representations of IBS. Given the potential for those with IBS to 'catastrophise' (Drossman et al., 1999; Lackner et al., 2004), the research presented in this thesis included a measure of the component of emotional representations as measured by the IPQ-R.

The majority of CSM studies have been conducted using cross-sectional designs (Hagger & Orbell, 2003; Rutter & Rutter, 2007; Searle, Norman, Thompson and Vedhara, 2007) meaning assessment of representations over time is overlooked. A longitudinal study that considered IBS illness representations over time found no difference in measures of the IPQ over two time points in a twelve month period (Rutter & Rutter, 2007). This is a theoretically contentious point, as the CSM denotes that illness representations are updated with new information over time and therefore subject to change (Leventhal et al., 2003). The lack of change may be a measurement artefact in that changes in representations may be subtle or take place over a longer period. Alternatively, IBS illness representations may actually be stable in the populations sampled. However, in patients recovering from traumatic injury, it has been that all IPQ-R components apart from the two timeline scales, differed

significantly over six months in 114 participants with traumatic injuries (Lee, Chaboyer & Wallis, 2010). Similarly, Kaptein et al. (2010) found in 241 osteoarthritis outpatients over a six year period that timeline chronic and illness coherence scores significantly increased, whereas personal control and emotional representations scores decreased. Patients showing negative changes in illness perceptions also had poorer outcome over the six year period and this may be due to disease progression (Bijsterbosch et al., 2009). Foster et al. (2008) observed change in the IPQ-R component scores of 810 individuals with low back pain, although this study set out to examine whether such changes were related to both positive and negative outcomes over six months rather than change in IPQ-R components in isolation. Some longitudinal CSM research however, has not explored changes in representations over time (Llewellyn et al., 2007; Treharne et al., 2008).

CSM based research has not been limited to research in the quantitative domain. Qualitative research has also considered the process of change in illness representations over time. Goodman, Morrissey, Graham and Bossingham (2005) conducted an Interpretative Phenomenological Analysis (e.g. Smith, Jarman & Osborn, 1999) of semi-structured interviews which explored the illness representations of 36 individuals diagnosed with Systemic Lupus Erythematosus. Participants' representations of their illness appeared to change at specific points in time or in stages rather than being due to 'updating' of representations with new information. This may, in part, be related to illness trajectory. Therefore it would be beneficial to explore IBS illness representation components longitudinally to investigate possible schematic changes in representations over time.

#### **2.2.1.4 Application of the CSM to CAM use**

As the previous chapter indicated, research exists that points to illness perceptions influencing CAM use (Bishop et al., 2007; Vincent & Furnham, 1996). Three studies have examined components of the CSM in CAM use. Beliefs in a psychological cause have been shown to

influence adherence to homeopathy (Searle & Murphy, 2000), whereas Bishop et al. (2008) found weaker relationships between illness perceptions and repeated CAM use. Bishop et al. (2006) found stronger beliefs in an emotional cause, greater illness coherence and stronger perceptions of consequences all predicted CAM use in a population of CAM users (Bishop et al., 2006).

In summary, a body of research provides support for theoretically consistent and clear dimensions of illness representations (Hagger & Orbell, 2003, Hale et al., 2007). Given the importance of illness representations in IBS and CAM use, the evidence presented here demonstrates why the application of the CSM to examine illness representations in this research was justified.

### ***2.2.2. Influence of illness representations on coping strategies***

According to the CSM, illness representations direct coping strategies to deal with health threats (Leventhal et al., 1998; 2003). Coping may consist of cognitive acts, strategies, procedures or behaviours that may help the individual manage health threats in an attempt to maintain or return to a state of being free from the threat through self-regulation. Coping may be classified as functional (adaptive) or dysfunctional (maladaptive) (Carver, Scheier & Weintraub, 1989; Lazarus & Folkman, 1984). Coping strategies are then appraised for effectiveness and information is 'fed back' to the representation stage where representations may be updated (Hagger & Orbell, 2003; Hale et al., 2007; Leventhal et al., 2003).

#### ***2.2.2.1 Coping strategies and measurement of coping***

In the context of the CSM, coping strategies can be conceptualised as 'if-then' rules (Leventhal et al., 1998; 2003). The 'if' component refers to the formation of perceptions of the health threat (e.g. identity, timeline, consequences) and what might be expected in terms of outcome after the coping strategy had been implemented. The 'then' is the act of performing the strategy or procedure. For example, an individual who

has a sudden onset of pain such as a headache will use different sources of information to form a representation of the health threat (the 'if'). This may include severity and past experience which may be used to guide an appropriate coping response to the health threat (Leventhal et al., 1998; 2003), which, in the case of a headache, may be to take pain reducing medication (the 'then'). If the pain medication is successful, the reduction of pain would be provided as feedback and the coping strategy appraised favourably. Information about the type of pain and the success of the coping strategy would then provide the basis for representations to be updated (Leventhal et al., 1998).

In many cases adoption of adaptive or functional coping styles may facilitate an improvement in symptoms. Maladaptive or dysfunctional coping may result in denial of a problem or an attempt to mentally block out symptoms. Further categorical distinctions formed from empirical investigation into the measurement of coping has cited further domains labelled as, for example, problem focused, emotion focused and behaviour focused coping (Carver et al., 1989). Coping has been conceptualised and measured in many ways (Carver & Connor-Smith, 2010), however, the CSM has often examined specific coping behaviours or focused on coping checklist measures such as the COPE. Carver et al. (1989) formulated 15 coping procedures for the COPE measure that included behavioural disengagement, active coping, use of religion, venting of emotions and denial. Based on such distinctions, a number of instruments exist to capture generic coping strategies (Schwarzer & Schwarzer, 1996) and several studies using the CSM have opted to use the COPE (Carver et al., 1989) and the shortened Brief-COPE (Carver, 1997) to capture coping procedures. These studies have included relatives of patients with schizophrenia (Fortune, Smith & Garvey, 2005), head and neck cancer patients (Llewellyn et al., 2007) and individuals affected by IBS (Rutter & Rutter, 2002; 2007) and have explored relationships between the components of the CSM (Hagger & Orbell, 2003). Such checklists may however be less effective in capturing the finer aspects of coping. However, Leventhal et al. (1998) argue the term

coping 'procedure' more accurately reflects behaviours performed to return to normality when faced with a health threat.

Searle et al. (2007) refer to such checklist measures as measuring 'coping cognitions.' This may be contrasted to specific coping behaviours, which may consist of such behaviours as adherence to conventional medication, making dietary changes or conducting exercise. Several types of coping behaviour have been utilised in CSM research. These have included adherence to medical treatment (e.g. Brewer et al., 2002; Horne & Weinman, 2002), number of visits to doctors (Hagger & Orbell, 2003), adherence to homeopathic treatment (Searle & Murphy, 2000) and repeated use of CAM (Bishop et al., 2008).

A useful distinction between more general coping strategies and coping behaviours is supported by evidence from the coping cognitions and coping behaviours of those affected with diabetes (Searle et al., 2007). Illness perceptions as measured by the IPQ-R predicted coping cognitions and coping behaviours. Coping cognitions however, did not mediate (i.e. explain) the relationships between representations and coping behaviour. There was also no relationship between coping behaviours and coping cognitions (Searle et al., 2007). In the context of this research, use of CAM may be considered a specific coping behaviour (Suarez & Reese, 2000) and coping cognitions (strategies) were explored within individuals performing a specific coping behaviour (CAM use).

#### ***2.2.2.2 Relationships between illness representations and coping***

The CSM stipulates that illness representations will guide cognitive or behavioural coping procedures to deal with health threats (Leventhal et al., 2003). The strength of the representation exacts a proportionate response in terms of a coping strategy or procedure (Leventhal et al., 1992; 1998; 2003). In one of the two studies conducted utilising the CSM in participants with IBS (Rutter & Rutter, 2002), there were direct relationships between representations and dimensions of coping as

measured by the COPE (Carver et al., 1989). Rutter and Rutter (2002) found several correlations between illness perceptions and coping strategies, although these associations tended to be weak. Stronger timeline beliefs resulted in greater acceptance of IBS. Stronger beliefs in a psychological cause were related to greater behavioural disengagement and greater use of alcohol to cope with IBS. Stronger external cause representations of IBS were associated with more positive reinterpretation and restraint coping. Perceptions of stronger consequences were related to a greater likelihood of venting emotions, restraint coping, less acceptance and mental and behavioural disengagement. Conversely, greater control/cure representations resulted in positive associations with active coping, positive reinterpretation and planning. Rutter and Rutter's (2007) second study using the CSM framework in IBS, did not report relationships between representations and coping.

The links between representations of illness and coping procedures have been supported by a number of cross-sectional and longitudinal studies in other chronic illnesses. Greater illness identity and stronger timeline beliefs were weakly positively related to avoidant and resigned coping. Stronger consequences were moderately positively related to avoidant and resigned coping, while stronger perceptions of control were moderately negatively related to avoidant and resigned coping in a sample of women with rheumatoid arthritis (Carlisle et al., 2005). In a longitudinal study of head and neck cancer patients, Llewellyn et al. (2007) found moderately strong positive relationships between illness identity and the coping procedures of self-distraction and venting emotions, which also demonstrated a positive association with illness consequences. Greater timeline beliefs were positively associated with greater planning. Stronger emotional representations were positively related to more substance use, self-distraction, planning and denial (Llewellyn et al., 2007).



Hagger and Orbell's (2003) meta-analysis of 45 CSM studies found significant associations between illness representations and coping procedures over a number of illnesses. Control and coherence dimensions have been found to be positively related to more adaptive coping procedures (Hagger & Orbell, 2003). Stronger representations of illness identity, timeline and consequences of illness are typically positively related to maladaptive coping or demonstrate a negative association with more adaptive forms of coping (Hagger & Orbell, 2003). Searle et al. (2007), examining individuals with diabetes, found several illness representations were associated with coping procedures and behaviours although there was no relationship between coping behaviours and coping cognitions. This finding seems to support the notion that coping procedures, such as 'active' coping may be viewed as cognitive expressions of coping which may be separate from specific coping behaviours (Searle et al., 2007). Illness perceptions however, showed stronger relationships with coping cognitions than many of the coping behaviours such as medication and dietary changes (Searle et al., 2007). The influence of illness perceptions on coping behaviours also appears consistent when analysed outside of the quantitative paradigm. Meyer, Leventhal & Gutmann (1985) interviewed 230 patients diagnosed with hypertension and found evidence that to reduce risk of the health threat representations are produced to form strategies to cope with the health threat. In those with hypertension this appears to be strongly influenced by prior illness experience (Meyer et al., 1985).

Therefore it can be concluded that illness representations classified as more serious (e.g. stronger consequences) are more likely to be positively associated with less effective coping procedures or strategies (e.g. denial) and negatively associated with adaptive coping strategies. In the context of the aims of this research, the intention was to examine the relationships between representations and coping strategies in addition to assessing the influence of representations on a specific coping behaviour.

### **2.2.3 Appraisal of coping procedures**

The final stage of self-regulation in the CSM is the appraisal stage (Leventhal et al., 2003). During appraisal the effectiveness of each coping strategy is effectively 'appraised.' This is where information is fed back to reinterpret the representation to determine if an alternative coping procedure needs to be adopted to deal with the health threat (Leventhal et al., 1998; 2003). Within CSM research, the 'appraisal' of coping has largely been assessed via quantifiable measures of study 'outcome' rather than examining appraisal per se (Hagger & Orbell, 2003). Measures of reported quality of life have been used as outcome measures in several existing CSM studies including illnesses where aetiology has yet to be established, such as IBS (Rutter & Rutter, 2002; 2007), chronic fatigue syndrome/myalgic encephalomyelitis (Gray & Rutter, 2007) and fibromyalgia (Glattacker et al., 2010) in addition to potentially life-threatening diseases such as head and neck cancer (Llewellyn et al., 2007). Given the documented impact of IBS on quality of life (Lea & Whorwell, 2004; Lackner et al., 2004) and the important influence of illness representations on quality of life (Petrie & Weinman, 2006), a measure of quality of life was considered to be appropriate for use in this research. However, one possible confounding factor is that an individual's perception of how they perceive their quality of life may change through the course of chronic illness. This represents a problem of 'response shift' and may potentially explain changes in quality of life ratings rather than any change in illness status per se (Ring, Höfer, Heuston, Harris, & O'Boyle, 2005; Schwartz & Sprangers, 1999).

Furthermore CAM-users with IBS have been shown to report poorer quality of life than those not using CAM (van Tilburg et al., 2008). Differences in illness and treatment beliefs between CAM-users and non-users, was documented in the previous chapter (section 1.1.5). This research consequently presents a unique exploration of pathways of the CSM between two groups of participants that have IBS, namely CAM-users and non-users.

Leventhal and Colman (1997) argue that multi-dimension illness specific measures of quality of life are preferable in capturing quality of life judgements. Use of such instruments enables pathways to be examined from illness representation to formation of quality of life judgements (Leventhal & Colman, 1997). This argument is consistent with illness representations being influential on quality of life in IBS (Lackner et al., 2004; Rutter & Rutter, 2002; 2007). This provides further strength for the decision to use a measure of quality of life as an 'outcome' in this research (section 3.3).

#### ***2.2.3.1 Relationship of illness representations with illness outcomes***

Research using the CSM framework has established links between illness representations and illness outcomes (Hagger & Orbell, 2003; Leventhal et al., 2003; Rutter & Rutter, 2002; 2007). Figure 2.1 illustrates the direct links between illness representations and outcomes as well as indirect links between representations and outcomes via coping strategies. These CSM pathways are said to represent a mediational model (Baron & Kenny, 1986). Mediation, in its simplest form, occurs when a third variable explains the relationship between two other variables. In the context of the CSM, illness representations influence outcome via coping (where coping acts as a mediating variable). Despite the existence of statistical procedures for mediation testing (e.g. Baron & Kenny, 1986) formal testing of mediation has not always been conducted in CSM research (Hagger & Orbell, 2003), meaning processes determining the influence between illness representations and outcome are not consistently determined by statistical testing.

One of two studies that tested for mediation in an IBS sample was Rutter and Rutter's (2002) study of the illness cognitions of 209 members of a UK IBS self help network. The authors reported relationships between several illness perceptions and with outcome. Greater beliefs about serious consequences of IBS and beliefs about a lack of control over their IBS both contributed to lower quality of life scores. Beliefs about

serious consequences also contributed to higher scores in anxiety and depression. Lower illness identity (i.e. number of symptoms) resulted in greater satisfaction with health. The study also found evidence that certain coping styles mediated between illness representations and outcome which was tested via regression based path analyses (Rutter & Rutter, 2002). Greater 'acceptance' was found to mediate between weaker beliefs about illness consequences and better reported quality of life. With cure/control also included in the model, 32% of the variance in quality of life was predicted. An active coping style mediated between stronger cure/control beliefs and greater satisfaction with health. With external causes and illness consequences included in the statistical model, 28% of the variance in satisfaction with health was predicted. Venting emotions mediated between stronger beliefs in a psychological cause and anxiety and between more severe consequences and anxiety, predicting 41% of the variance in anxiety. Restraint coping was positively related with illness consequences, but negatively related to depression scores demonstrating a further mediation effect. Also included in this statistical model, lower control/cure beliefs were related to the mediator 'behavioural disengagement' which resulted in a positive relationship with greater depression scores. The model predicted 30% of the variance in depression and also included non-significant potential mediators 'emotional support' and 'suppression of emotions' (Rutter & Rutter, 2002). This cross-sectional study illustrates that in IBS there is evidence of mediation of coping procedures between pathways from representations to outcome.

A subsequent longitudinal study by the same authors (Rutter & Rutter, 2007) found that over three time points (over 12 months) the most consistent predictor of outcomes (anxiety, depression, quality of life and satisfaction with health) was a belief in severe consequences of IBS which was consistent over three time points. Other significant predictors of outcome were a belief in a psychological cause at time one and two and predicted anxiety at time three, while beliefs related to chronicity at time two predicted anxiety and satisfaction with health at time three.

Cure/control beliefs at time one and two predicted improved quality of life at time three. The same beliefs at time one predicted anxiety and satisfaction with health at time three. Including all the illness perception scales in the analyses explained between 24 and 38% of the variance in outcome. In contrast to other studies (e.g. Fortune et al., 2005), Rutter and Rutter (2007) found no evidence of coping acting as a mediator between illness representations and outcome over three time points over 12 months. Similarly, in a group of rheumatoid arthritis patients, Treharne et al. (2008) found no evidence of praying/hoping acting as a mediator between illness consequences and demographic factors that predicted fatigue over one year.

Studies in other illness groups have also found evidence of a mediating effect of coping, although the studies are typically cross-sectional. Brewer et al. (2002) found evidence of problem-focused coping partially mediating the effect between greater illness consequences and more cholesterol control in hypercholesterolemia patients. Fortune et al. (2005) studied the relatives of patients with schizophrenia to examine the relationships between the relatives' perceptions of psychosis, coping, distress in patients and treatment appraisals. Greater illness identity and stronger carers' perceptions of personal control (of their relative) were related to higher distress. Greater positive reframing, lower levels of reported self blame and greater acceptance mediated these pathways predicting 75% of the variance in distress (Fortune et al., 2005). One further study that set out to examine mediation effects in 42 patients with Parkinson's disease at baseline (time one) and after six months (time two), Evans and Norman (2009) found evidence of mediation at study time one only. Avoidance mediated the pathway between emotional representations and anxiety at time one. Similarly, acceptance-resignation mediated the pathways of both emotional representations and illness consequences on time one depression.

Direct relationships between representation and outcome have been demonstrated in studies across different chronic illnesses that have also

demonstrated an absence of any mediation effect. Heijmans (1998) observed patients with Addison's disease, while Kemp, Morely and Anderson (1999) examined coping in those with epilepsy. Both studies found direct associations between illness perceptions and outcome with little influence of coping strategies with no indication of mediation being present. Kaptein et al. (2006) found no evidence of mediation of coping between illness perceptions and perceived well-being in patients with Huntington's disease. In diabetic patients, Searle et al. (2007) found no evidence of mediation between coping 'cognitions' (as measured by a coping checklist) and coping behaviours (such as exercise and dietary changes). Llewellyn et al. (2007) also found no evidence of coping procedures mediating the relationship between illness perceptions and outcome (quality of life) in head and neck cancer patients. Similarly, Scharloo et al. (1998) examined a number of illness groups including psoriasis and rheumatoid arthritis, and also reported a lack of mediation and limited impact of coping procedures. This suggests that in some instances, illness representations may have stronger direct influence on outcomes irrespective of coping (Hagger & Orbell, 2003).

Conversely, in a separate study involving rheumatoid arthritis patients, Carlisle et al. (2005) found evidence of partial mediation of avoidant and resigned coping between greater reported illness identity, stronger disability ratings and greater reported psychiatric morbidity. The resultant regression analyses predicted between 17 and 36% of the variance in outcome. The disparity between the two studies' results may lie in the way coping was measured. Carlisle et al. (2005) utilised an arthritis specific coping measure, while Scharloo et al. (1998) opted for a generic coping measure. Hagger and Orbell (2003) and Leventhal et al. (1998) argue that measuring coping can be problematic as researchers often use generic coping measures that are removed from the context of the illness. One approach is not to devise domain specific measures of coping but to examine coping strategies at a discrete level in terms of more specific actions or procedures than 'avoidant' or 'problem-focused' coping (Leventhal et al., 1998). In this context, a measure such as the

Brief-COPE may be appropriate. The Brief-COPE captures 14 different scales and includes semi-specific coping procedures such as the use of religion and expressing of emotions (Carver, 1997). As there is evidence for mediation of coping, mainly from cross-sectional designs, this research sought to clarify if such coping strategies demonstrate mediation effects at both a single and subsequent time point.

There is sufficient evidence to demonstrate that CSM constructs, especially illness representations are consistent across a number of illness populations (section 2.2.1). The CSM has also been beneficial in enhancing understanding of the role of illness perceptions in influencing quality of life in chronic illnesses where establishing aetiology has been problematic (e.g. Glattacker et al., 2010; Gray & Rutter, 2007; Rutter & Rutter, 2002; 2007). Moreover, research has identified that stronger symptom based and emotional representation components appear to influence poorer outcomes, whilst enhanced control and coherence components are associated with improved outcomes. In this thesis the role of illness perceptions may be examined by utilising the CSM framework in a sample of individuals who have IBS to assess which perceptions may influence both CAM use and quality of life. There is also sufficient scope to suggest that CAM-users' beliefs (section 1.1.5) differ from those not using CAM, so pathways from representation to outcome may be examined between those that using CAM and those not using CAM.

### **2.3 Extending the common-sense model**

Section 2.2.1 provided evidence to support the use of the CSM to examine CAM use in IBS. However, there has been suggestion that alongside illness perceptions, individuals may also form representations or beliefs regarding their treatment or treatment in general and these beliefs may be important in health related behaviour (e.g. Horne & Weinman, 2002). It has been argued that the inclusion of treatment beliefs into the CSM would enhance the model's explanatory capability and offer additional benefits for targeting illness management or

intervention strategies (Horne, 1997; Horne & Weinman, 2002). There is evidence that concerns about conventional medication may have influence on specific coping behaviours such as patients' self management and adherence to treatment (Horne & Weinman, 1999; 2002) although the associations between treatment beliefs and quality of life over time have been shown to be weak (Llewellyn et al., 2007). Exploring the treatment beliefs of those with IBS in a systematic framework would therefore be beneficial. The Beliefs about Medicines Questionnaire (BMQ), was designed for use as a measure of the cognitive representation of treatment (Horne et al., 1999) and has been employed in a number of studies that have adopted an 'extended' CSM.

Horne and Weinman (2002) examined the illness perceptions and treatment beliefs of individuals with asthma using the IPQ and the BMQ specific version in an 'extended' CSM framework. The BMQ specific version assesses representations of particular medication in terms of necessity of the medication and concerns about taking it. The study found that non-adherence to preventer inhalers was related to low necessity beliefs, concerns about possible side effects and more severe perceptions of the consequences of asthma. However, Llewellyn et al. (2007) found no influence of illness perceptions and treatment beliefs on reported quality of life in head and neck cancer patients six to eight months later. There were however, significant influences of illness perceptions on coping at six to eight months later and of treatment beliefs on coping at one month later (Llewellyn et al., 2007).

Chapter one illustrated that treatment beliefs have also been implicated in the uptake of CAM (e.g. Bishop et al., 2006; 2008). Feeling conventional treatment had failed to cure or relieve illness and having concerns about harmful effects of medication have been associated with CAM use in a sample of participants with a variety of health complaints (Vincent & Furnham, 1996). Patients with inflammatory bowel disease that used CAM were shown to have concerns about harmful effects of medication (Hilsden et al., 1998). Horne et al. (1999) found that



individuals who attended a CAM therapist (herbalist or homeopath) had higher scores of medication harm and overuse on the BMQ. Many affected by IBS have had the condition for many years (Andrews et al., 2005) and are likely to have either a long duration of treatment or many different treatments to control symptoms. With this issue in mind, and in considering the research into treatment beliefs and CAM use, it is plausible to speculate that treatment beliefs may have an important role in CAM use and in influencing reported quality of life in IBS. Therefore the examination of treatment beliefs alongside illness perceptions in those with IBS may potentially elucidate a greater understanding of representations of illness and medication in IBS patients and the factors that initiate CAM use and have an impact on quality of life. Figure 2.1 highlights the potential role and position of treatment beliefs in the CSM, showing the potential influence on coping responses and outcome.

Measurement of treatment beliefs may be further extended to examine beliefs about CAM treatments (Bishop, Yardley & Lewith, 2005; Bishop et al., 2006; Hyland, Lewith & Westoby, 2003). As well as evidence and a rationale for extending the CSM to include treatment beliefs, there is also suggestion that beliefs about CAM may be important in CAM initiation (Bishop et al., 2005; Bishop et al., 2006). CAM-users have more 'positive' views of CAM than non-users (Vincent & Furnham, 1996; Furnham & Kirkcaldy, 1996) and more holistic views about health (Astin, 1998; Testerman, et al., 2004). Beliefs in holistic health have been found to predict CAM use rather than negative beliefs about conventional treatment (Bishop et al., 2006). Kolowski et al. (2003) found patients wanted to treat functional GI problems with a more natural approach and Bishop et al. (2008) found beliefs in holistic health predicted adherence to a CAM treatment regimen.

Such evidence points to CAM beliefs potentially having an important role in CAM use and may be considered an important facet of treatment beliefs to measure in this research. It may also be speculated that CAM-users may get alternative explanations of possible causes of IBS from

CAM practitioners given the differences in philosophy between CAM and conventional treatment (Zolman & Vickers, 1999). Differences in causal explanations may be reflected in CAM-users having different responses to non-users on representations of causes. Although the relationships between treatment beliefs, coping and outcome are less well established than in the case of illness representations, the concept of treatment beliefs is an important element to this research as such beliefs may be important influences on CAM use in IBS.

## **2.4 Comparison of CSM with social cognition models**

Previous sections have demonstrated the benefit of studying illness perceptions across a number of illness domains and how this may be especially applicable to the study of IBS. The CSM is a dynamic model of self-regulation and has been successfully used as a framework to investigate CAM use (Bishop et al., 2006) and in examining pathways between perceptions, coping and outcome in IBS (Rutter & Rutter, 2002; 2007). The CSM however, differs from many of the previously mentioned social cognition models that have been widely used to explore health and illness-related behaviour. The CSM is considered unique in its focus on the role of illness representations and how such representations are formed in response to health threats (Leventhal et al., 2003). The subsequent influence on coping and outcome offers the potential to identify unhelpful representations and coping and the possible development of interventions to improve outcomes (Hale et al., 2007; Rutter & Rutter, 2002). In the context of this research however, it is possible to outline alternative conceptualisations of CAM use in IBS and it is worthwhile to briefly consider two such approaches (the Theory of Planned Behaviour and the Health Belief Model) to highlight the benefits of the CSM framework.

The Theory of Planned Behaviour (TPB) (e.g. Ajzen, 1991) has also been widely used to investigate health and illness-related behaviour. The TPB denotes that intention to perform behaviour and perceived control over the behaviour are the best predictors of an individual

carrying out a particular behaviour (Orbell, Hagger, Brown & Tidy, 2006). Perceived behavioural control, subjective norms (i.e. the views of significant others) and attitudes towards the behaviour are all said to influence behavioural intentions. Like the CSM, the TPB has had limited application in exploring CAM use, although the TPB offers an alternative framework for investigation of why people will use CAM. An intention to use CAM as well as perceived control over using CAM will influence CAM use. Significant others may hold more pro-CAM feelings and beliefs, thus subjective norms may influence intention to use CAM also. Feeling able to pursue CAM treatment (perceived behavioural control) may also have an influence on intention to use CAM. One study (Furnham & Lovett, 2001) that has utilised the TPB to investigate the use of homeopathy found attitudes, subjective norms and perceived behavioural control predicted intention to use CAM. Intentions to use CAM also predicted CAM use. Past behaviour (i.e. those who had used homeopathy or other CAM treatments before) was also found to predict both intentions to use CAM as well as the use of CAM (Furnham & Lovett, 2001).

Therefore the TPB has potential benefit in investigating CAM use, but is limited by the lack of theoretical scope to examine pathways to outcome in terms of quality of life. The TPB was also originally developed to examine social rather than health-related phenomena and may be limited in not being able to explain the more discrete relationships between illness representations and performing certain health-related behaviours. The TPB does not allow such close inspection of illness representations and how these representations may be related to quality of life, whereas contextually the CSM is able to offer examination of these factors. Orbell et al. (2006) compared the CSM and TPB in predicting non-completion of treatment following screening for cervical cancer. The study found that both illness perceptions and TPB constructs predicted attendance/non-attendance for treatment, and that the TPB explained more variance in outcome (attendance/non-attendance) than illness perceptions. However, this study did not include a measure of reported quality of life

as an outcome. Furthermore, Leventhal, Weinman, Leventhal and Philips (2008) argue, comparison between the CSM and TPB should not be limited to comparison of illness perceptions to all of the TPB constructs. Coping for example, in the CSM could be compared to the active parts of the TPB (behaviour). There is further uncertainty in comparing TPB attitudes with illness perceptions when it is likely the two constructs are measuring different concepts (Leventhal et al., 2008). These as yet unexplored avenues add support to the use of the CSM as a theoretical framework for this research.

The Health Belief Model (HBM) also has potential application for explaining CAM use in IBS. The HBM (e.g. Becker, 1974) was originally developed to examine the beliefs that influence the performing of health-related behaviours. Behaviours are based on the individual weighing the need to use a particular mode of treatment for example, against the perception that use of such a service will result in benefits to the individual (Abraham & Sheeran, 2005). In terms of CAM use, the benefits of using CAM would potentially outweigh the costs (such as financial costs). The perceptions of the illness would also be relevant in that such perceptions as symptom severity will influence use of CAM. In the one study to consider CAM use utilising a HBM approach, Wagner et al. (1999) conducted a qualitative study into St John's Wort use in depression. Individuals with less severe symptoms, lower perceived barriers to treatment and increased perception of benefits of St John's Wort (e.g. lack of side effects, using a natural treatment) were more likely to use St John's Wort to treat their depression.

One criticism of social cognition models however, is that they fail to take account of how individuals make inferences or representations about a particular health threat. The process of how such inferences or representations then influence quality of life or the carrying out of a particular health-related care behaviour, such as using CAM are neglected by the social cognition approaches. Given the importance of

such representations of illness in IBS, a theoretical framework was required that focused on the role of illness representations.

A further issue is the lack of conceptualisation of emotional responses to illness. Emotional reactions to IBS have been shown to be important (e.g. Lackner et al., 2004), this is a factor of IBS that is worthy of exploration that social cognition approaches would not enable. There is further criticism that the HBM views individuals as overly rational in terms of their health care decision making, people are said to use cognitive information to make decisions about their health rather than being influenced by emotions (Conner & Norman, 2005). Moreover, social cognition models tend to be viewed as cost-benefit or expectancy-value models, where there is a trade off between costs and benefits of conducting certain behaviour (Conner & Norman, 2005). Whilst the HBM is a potentially important model that may examine CAM use, the HBM is unhelpful in exploring individuals' perceptions of their illness and the pathways to quality of life. These points highlight why the CSM has a relative advantage over some social cognition models (i.e. the TPB and HBM) in addressing the research aims of the thesis.

## **2.5 Application of CSM research findings**

An underlying theme in this chapter has been the recognition that certain representations influence pathways in the CSM that may lead to poorer outcomes or poor coping procedures in chronic illness. Identifying such representations presents an opportunity to identify areas where self-management may be enhanced, adherence to treatment may be improved or symptoms better controlled through addressing unhelpful or problematic (e.g. stronger perceptions of illness consequences) representations. It is clear from research presented in chapter one that the benefits of simple psychological involvement in the treatment process in IBS such as more information about IBS, and reassurance about symptoms may be beneficial (Ringström et al., 2009; 2010). Studies by van Dulmen et al. (1994; 1996; 1997) and Oerlemans et al. (2010) have demonstrated the benefits of doctor-patient concordance on cognitive

aspects of IBS such as agreement on causal factors in reducing use of health care services. Horne and Weinman (2002) suggested focusing on the necessity of asthma preventer medication and providing better information that asthma still requires controlling as it is an ongoing condition even when symptoms are not present (i.e. timeline perceptions). The CSM may also allow other types of intervention to focus on illness or treatment representations that are related to poorer outcomes (Hale et al., 2007; McAndrew et al., 2008).

Petrie et al. (2002) conducted a brief three stage intervention to modify more negative illness perceptions in patients who had suffered myocardial infarction (MI). Patients' responses from the IPQ were used to tailor content designed to challenge negative illness perceptions when providing information about MI and the heart, about risk factors and rehabilitation. Patients that took part were less likely to have future angina attacks, felt more empowered to leave hospital and were quicker in returning to work. This study is a good indicator of both how illness perceptions may be altered for the benefit of patients and the necessity to investigate illness perceptions in illnesses that are problematic to treat, such as IBS. Petrie, Broadbent and Meechan (2003) cite other CSM based interventions in other chronic illnesses such as diabetes, asthma and HIV. These applications suggest CSM research findings are successfully able to be applied to self-management strategies in what appears to be a buoyant area of enquiry and application.

Such interventions have not been limited to the cognitive arm of the CSM. Cameron and Jago (2008) document interventions designed to regulate emotional distress caused by illness. One such example is a writing intervention, whereby the process of writing about individual experience is said to be positively appraised and can help provide understanding and meaning of symptoms which has similarities to work by Pennebaker (1997), where the disclosure of such emotional events has been shown to result in improved health. Similarly Ringström et al's. (2009) IBS school study may prompt the same effect of challenging

emotional representations through better information about IBS to reduce illness-related distress. Ringström et al. (2009) found their IBS school intervention resulted in less use of health care services over time. This suggests that such an intervention may be able to target illness representations effectively into guiding more adaptive coping procedures that could lead to improved quality of life. Furthermore, a structured patient group appears to work better than written information (Ringström et al., 2010).

## **2.6 Chapter summary and research objectives**

This chapter has outlined the CSM of illness representation and why it was the most suitable model to address the research aims. An outline of the model was presented, measurement issues considered and empirical evidence for the CSM outlined. Studies that have used the CSM in IBS and CAM use were outlined, although these have, to date, been in separate contexts and consist of a small number of studies. No studies have examined CAM use in IBS with the CSM as a theoretical framework. This research also sought to extend the CSM (e.g. Horne & Weinman, 2002) to take account of treatment beliefs as well as illness representations in influencing CAM use, coping and outcome.

There have also been a number of issues raised in this chapter that would benefit from investigation and potential clarification in terms of the aims of the study and the theoretical framework. This research will address deficits in existing knowledge regarding illness perceptions in IBS and use of CAM, which may be important in the development of future management interventions. Similarly, there has been a lack of focus on treatment (and CAM) beliefs in IBS and how these may affect coping and outcome. The clarification of the degree of influence illness and treatment representations have on a specific coping behaviour (CAM use) and coping strategies or procedures is examined. Furthermore, CSM pathways will be explored between those with IBS that use CAM and those not using CAM for IBS wherein the potential mediating role of coping between illness perceptions and outcome is examined. The latter

point is, in part, based on theorised differences between CAM-users and non-users in illness and treatment representations and reported quality of life.

A consideration of these issues and a theoretical basis for the research enabled more specific research objectives to be outlined. The overarching research aim was to investigate the illness-related perceptions and treatment beliefs that were influential in CAM use in IBS and to explore the CSM pathways within CAM-users and non-users (i.e. non-users). Within this overarching aim, there were specific objectives formulated to examine the role of illness representation and treatment beliefs in CAM use in IBS. This included consideration of examining CSM components over different time points. The research aims therefore were:

2.6.1. To explore which illness perceptions and treatment beliefs in those affected by IBS are influential in CAM use (chapter 4).

2.6.2. To explore the interrelations between the CSM components in CAM-users and those not using CAM in those with IBS (chapter 5).

2.6.3. To assess any change in illness representations and treatment beliefs over time in CAM-users and non-users with IBS (chapter 6).

2.6.4. To examine if illness perceptions and treatment beliefs influence reported quality of life after a minimum of six months in CAM-users and non-users with IBS (chapter 6).

With a clear theoretical framework outlined and the rationale for such a framework explored, it is necessary to consider the methodological aspects of the research. The following chapter therefore addresses the methodological and analytical positions employed to undertake the investigation of the research aims presented in chapters four through to six with reference to dimensions and components of an extended CSM.



## Chapter 3

### Methodological framework

*This chapter presents the rationale for the methodological approach adopted for the research. The choice of study design and measurement instruments is reviewed and the rationale for a web-based survey data collection method is presented within the empirical context presented in chapter 2.*

#### 3.1 Design

This research set out to examine predictive factors from the CSM in CAM use and which of these factors were influential in outcome, and how these factors differed between CAM-users and those not using CAM (non-users). Previous CSM research (considered in chapter 2) has addressed similar questions using a cross-sectional quantitative approach in a number of chronic illnesses including IBS (Rutter & Rutter, 2002). The design of specialist measures to capture illness perceptions (Moss-Morris et al., 2002), meant that utilisation of such measures would reliably capture participants' illness perceptions and allow comparison with previous research using the CSM framework. To examine potential changes over time, a follow-up study was also conducted which allowed statistical comparison between data collected at study time one and study time two (follow-up) as was consistent with previous work utilising the CSM in IBS (Rutter & Rutter, 2007). Therefore, a quantitative methodology was considered the most appropriate to address the majority of the research aims investigating pathways within the CSM. As considered in the previous chapter, numerous CSM studies have been conducted utilising a qualitative philosophy. Moreover, to cross-validate the apparent importance of illness perceptions, the final research aim required the collection of qualitative data. This aspect of the design is considered in the next section.

### **3.1.1 Philosophical framework**

The research presented in subsequent chapters is primarily theory driven and follows a deductive approach using quantitative web-based survey methodology to investigate the research aims presented at the end of the preceding chapter (section 2.7). It can be argued that the nature of theory limits the methods that can be used to test or examine that theory (Breakwell & Rose, 2006). In the case of the empirical work presented in previous chapters (e.g. Bishop et al., 2006; Rutter & Rutter, 2002; 2007), a quantitative design was deemed the most appropriate method to examine the components of an extended CSM. It was therefore deemed appropriate to test these components statistically in terms of relationships between illness perceptions, treatment beliefs, coping and quality of life (e.g. Rutter & Rutter, 2002; 2007) and to determine which illness perceptions and treatment beliefs would statistically predict CAM use (e.g. Bishop et al., 2006) in those with IBS. The choice of a quantitative methodology was further determined by the following consideration of what constitutes knowledge and how different approaches to gathering knowledge may potentially be harmonised to further the understanding of IBS (e.g. Casebeer & Verhoef, 1997). Moreover, the specific method of data collection is considered here in the context of the theoretical model, past research and electronic methods of data collection.

#### **3.1.1.1 Deductive and inductive approaches to research**

The question of epistemology, that is, what constitutes acceptable knowledge in a particular research domain can be considered in terms of philosophical orientation, an orientation that forms the foundation of the whole research process (Bowling, 2009). Broadly speaking there are two main approaches to epistemology (Bryman, 2008). One perspective is represented by the positivist stance which is characterised by the laws of natural science and establishment of facts (Bowling, 2009; Bryman, 2008). The positivist approach is said to be opposed to more interpretive approaches which seek to ascertain the subjective meaning of social actions (Bryman, 2008). Considering these positions further illustrates

that typically the approach to knowledge in research is demarcated on whether it is either *deductive* or *inductive* in its orientation (Bowling, 2009; Casebeer & Verhoef, 1997). A deductive approach is more readily associated with the scientific method of theory testing via hypothesis formation and an attempt to establish objective, reliable and valid results, to prove objectivity or fact (Casebeer & Verhoef, 1997). This is usually carried out by collecting and using numerical data whilst making statistical inferences from samples that can be generalised to the particular population of interest to the researcher. Inductive approaches however, tend to begin with observations of phenomena which lead to theory development (Bowling, 2009). Inductive research is often associated with qualitative methods that seek to explain patterns and processes involved in a particular phenomenon. The resulting interpretations lead to the development of theories that best explain the phenomena being investigated. Rather than numerical and statistical information being collected and analysed, some form of textual analysis (e.g. interview transcripts) or observations are common forms of data collection (Marks et al., 2005). Portions of text are 'compared' and narrative description is used to try to explain 'what' is being studied in terms of meaning for the individual (Pope, Ziebland & Mays, 2000).

### ***3.1.1.2 Advantages of harmonising deductive and inductive approaches***

The demarcations between approaches in research are typified by different understandings about the basis of knowledge or epistemology. Quantitative designs loosely fit the idea of positivism in that all human experience can theoretically be 'reduced' to numerical form and further explored by the relationships between the numerical values which can both support and generate theory (Bryman, 2004; Casebeer & Verhoef, 1997). Qualitative designs tend to oppose this idea of numerical detail and seek to study the underlying processes, mechanisms and meanings of phenomena to the individual (Bowling, 2009). However, it is argued that these boundaries are superficial and potentially limiting to researchers in that one method can be deemed more suitable in terms of

gathering knowledge than a differing methodology (Bowling, 2009; Casebeer & Verhoef, 1997). This can place unnecessary restrictions on researchers investigating such phenomena as chronic illness (Casebeer & Verhoef, 1997). Bowling (2009) argues that although seemingly diametrically opposed, researchers should seek to establish novel ways to combine these perspectives within research to gain further insight into topics of interest (Bowling, 2009; Casebeer & Verhoef, 1997). In fact, the very tensions within approaches may generate unique insights into studied phenomena (Lingard, Albert & Levinson, 2008). It is now accepted that researchers may conduct experimental or quantitative survey studies whilst collecting material that may be qualitatively analysed. Such qualitative analysis may help to explain processes or outcomes identified by quantitative methods, the meaning of quantitative constructs for individuals or guide future investigations (Casebeer & Verhoef, 1997; O’Cathain & Thomas, 2004).

The research presented in this thesis, although orientated quantitatively, took into account the subjective nature of IBS and the degree to which it affects reported quality of life (Amouretti et al., 2006; Dancey & Backhouse, 1993). Based on the arguments of Bowling (2009) and Casebeer and Verhoef (1997), an open question was included in the survey which stated ‘you may use the space below to comment on anything you would like to say about having IBS.’ Responses to this question were analysed qualitatively, applying a top-down thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006) to provide additional substantiation of components of illness perceptions in participant text. An analysis of these findings are presented in appendix XV. It should be noted that such an approach to research does not represent a multiple or mixed-methods approach, but rather an attempt to obtain qualitative data in a ‘novel’ way. ‘Novel’ is considered in the context of using largely quantitative methodology to obtain qualitative data (Bowling, 2009) to potentially gain deeper understanding of IBS. As noted in chapter two, much of the foundation work into the CSM was conducted using in-depth qualitative interviews (Weinman et al., 1996) and other CSM studies

have adopted a qualitative approach (Goodman et al., 2005; Meyer et al., 1985). It is possible that such qualitative information may prompt further investigation or potentially lead to development in measurement of illness perception components.

### **3.1.2 Data collection**

A web-based survey design was considered the most appropriate method of data collection for this research as the method has been used in previous research into the CSM and CAM use (Bishop et al., 2006; 2008) and the internet offers many other advantages to researchers using survey based methodology (Ahern, 2005; Duffy, 2002). There are several factors that make the recruitment of participants for internet based research a legitimate prospect.

#### **3.1.2.1 The internet: access, health information and e-interventions**

In recent years both internet use and access has increased substantially. The Office of National Statistics (ONS) reported that 73% of households in the UK have access to the internet, an 8% increase on 2008 (ONS, 2010). The number of adults using the internet daily (or almost daily) in the UK is estimated at 30.1 million (ONS, 2010). In the first quarter of 2011, adult internet use was said to be approximately 82% (ONS, 2011). Similar usage is reported for the US and Europe (Internet World Stats, 2011; Madden, 2006). Internet connectivity is also not confined to the more economically affluent or specific ethnic groups and is widespread amongst different cultural and ethnic groups in the UK (Ofcom, 2007). In terms of conducting research online, such data suggest a demographically diverse pool of potential participants have internet connectivity (Birnbaum, 2004; Gosling, Vazire, Srivastava & John, 2004).

Furthermore, the use of the internet as a primary or supplementary source of information for health advice or health related information has become widespread (Bansil, Keenan, Zlot, & Gilliland, 2006; Bundorf, Wagner, Singer, & Baker, 2006; Powell & Clarke, 2002; Scott, Scott, & Auld, 2005). Websites operated by the NHS give advice about particular

symptoms or treatment options. Studies have shown that using internet for health or illness information is common (de Boer, Versteegen, & Wijhe, 2007) with patients essentially becoming consumers of health information online (McMullan, 2006). Patients may also feel empowered by feelings of immediate benefits of obtaining health and illness information instantly (Donnelly, Shaw, & van der Akker, 2008). Such factors arguably make the internet a natural domain for health based research to be conducted as participants become more familiar with such phenomena taking an electronic format (Ahern, 2005; Cantrell & Lupinacci, 2007).

Other developments have taken the form of online health interventions and online support. E-interventions have had an impact in many chronic disorders such as eating disorders (Robinson & Serfaty, 2001; 2003), self management and improving social support in diabetic patients (Glasgow, Barrera, McKay, & Boles, 1999) and breast cancer patients (Winzelberg et al., 2003). In terms of support provision, individuals with chronic illnesses, such as IBS, have been shown to use internet based forums as a means of support, sharing information and experiences regarding their IBS (e.g. Coulson, 2005). A large number of illness specific websites also exist on the internet, often run by charities that offer information and support to individuals via electronic support information or self management programs or through online community message boards, such as the IBS network in the UK. It is illness or health related websites where researchers often seek to recruit participants for research participation (Bishop et al., 2006; Duffy, 2002). These developments in internet familiarity, connectivity and the online provision of health care, support networks and information offer extensive opportunity to recruit participants and conduct research online.

### **3.1.2.2 Web-based surveys**

The increase in electronic media over the last two decades has opened up a new domain for researchers. Surveys can now be completed by participants using their computer thus removing the need to see the

researcher, to speak to them or to return a completed questionnaire in the post. Such methods have been used successfully in an increasing number of studies (Ahern, 2005; Cantrell & Lupinacci, 2007) and a number of online Psychology research directories exist that detail current web-based studies. Surveys can be sent to potential participants via their email address (in the form of an attachment or invitation to contact the researcher) or via linking from web-pages on the internet or email (Duffy, 2002). The latter is often referred to as “internet mediated research” (e.g. Hinchcliffe & Gavin, 2008) as the “internet” takes the place of the researcher in administering and providing information about the research. Studies carried out in this manner usually attract participants by posting details about the survey on other web pages that are visited regularly by the target population. Of these two possible recruitment methods, a direct link to the study website is regarded as more favourable (Duffy, 2002). The research presented here worked in a similar way, albeit utilising a web-based approach similar to Bishop et al. (2006) who conducted their study online using elements of an extended (dynamic) CSM to determine factors important in CAM use.

### **3.1.2.3 Benefits of web-based surveys**

There are several reasons why web-based research should be considered a legitimate research tool. Evidence presented in section 3.1.2.1 suggests individuals will routinely seek out illness or health related information on the internet (Bansil et al., 2006; Bundorf et al., 2006). There are other practical benefits to the researcher such as access to ‘specialist’ samples (section 3.1.2.3.1) and easy electronic transmission of data into statistical packages for analysis. Potentially large numbers of participants may be recruited and disclosure may be enhanced by the perception of anonymity in using the internet.

#### **3.1.2.3.1 Access to specialist samples and increased disclosure**

There is also argument that the internet offers a unique opportunity to gain access to ‘specialist’ samples of participants that may not be accessible via more traditional approaches (Ahern, 2005; Duffy, 2002;

Gosling et al., 2004; Hiskey & Troop, 2002). In the case of face-to-face interviewing a high response rate may be obtained, however certain factors, such as personal issues, may not be reported due to lack of anonymity (Bowling, 2009). There is also the possibility that the interviewer's presence may effectively 'lead' participants into answering in a particular way (Boynton & Greenhalgh, 2004). Face-to-face interviewing may also be less financially viable and more time consuming than some other methods. Many of these potentially negative issues related to this form of data collection may be addressed by using a web-based survey. Web-based survey research may be considered cheaper, less intrusive and less time consuming than other more 'traditional' methods of data collection (Ahern, 2005).

#### ***3.1.2.3.2 Economic and participant response benefits of online research***

A further implication of surveys carried out by telephone call or by post is cost. In the case of the former, one notable expense is that respondents very often may not be available for interview, calls may be terminated during the interview, remain unanswered or the caller may be involved in a long (and therefore more expensive) exchange of dialogue (Boynton & Greenhalgh, 2004). Telephone interviewing can be productive for shorter, uncomplicated surveys that will not take up too much of the participant's time (Bowling, 2009) but in general this method still has an impact on participant's time and financial cost to the researcher. Some of these shortcomings may be addressed by conducting postal surveys. Self-administered questionnaires, sent to potential participants in the post can arguably reduce any social desirability and interviewer bias (Bowling, 2009). One possible method of approaching a large scale sample is to send out a questionnaire in the post – with a prepaid reply envelope – for the participant to respond to at their convenience. The method can be seen as more economical in terms of expenditure on stationery and postage as opposed to potential travel costs (as with face-to-face interviews) and costs of repeated telephone calls (telephone



interviews). There is also suggestion that participant disclosure is likely to be greater due to the greater level of anonymity involved in postal questionnaires (Oppenheim, 1992).

Postal surveys however, may suffer from poor response rates as participants may decide not to take part or simply forget to return their questionnaires (Boynton and Greenhalgh, 2004). Again, this may be addressed by conducting a web-based survey. Participants have the convenience of being able to participate in the research at any time of day and evidence suggests completion is either more likely in an online format (Kongsved, Basnov, Holm-Christensen & Hjollund, 2007) or no worse than paper and pencil format (Wu et al., 2009).

#### ***3.1.2.3.3 Practical benefits to the researcher***

Previous commentators have suggested that potentially large numbers of participants can be reached in a relatively short time span with using web-based surveys (Birnbaum, 2004; Duffy, 2002). The apparent increased anonymity of the internet makes research participation more likely (Gosling et al., 2004). Barry (2001) argues that increased participation in research on the internet comes from a feeling of familiarity with internet pages, itself coming from experience of general internet use. This can create a situation in which the participant feels comfortable in responding to questions at their own pace (Barry, 2001).

Web-based surveys have increased over the last 15 years (Cantrell & Lupinacci, 2007), something that is mirrored by the advent of e-companies offering 'ready made' survey software for researchers making the process of administering and collecting data relatively uncomplicated. Conducting surveys using the internet can be a simple and cost effective alternative to other methods of survey administration for researchers allowing potentially large numbers of participants to be recruited and allowing contact to be made with participants for follow-up studies via email (Ahern, 2005; Gosling et al., 2004). The fact that large numbers of participants may be recruited may also establish greater generalisation of

findings (Gosling et al., 2004). A further benefit of internet surveys is that participant responses can usually be downloaded in numerical form and input into statistical software programs with minimum effort and can reduce potential data entry errors (Ahern, 2005).

### ***3.1.2.3 Participant recruitment in web-based surveys***

The favoured approach for contacting participants on the internet is to post a clickable link (along with some information) to the study on a website that is populated by a sample of the target population (Cantrell & Lupinacci, 2007; Duffy, 2002). This may take the form of a discussion forum or a website offering some sort of advice or support. Cantrell and Lupinacci (2007) suggest this issue is considered fully by the researcher when designing the study, as it can result in recruitment problems if not administered properly. As the researcher is not present during web-based studies as there is no direct contact with participants, there may be little they can do to influence participation. However, if they have participant details such as if they have placed an advertisement asking for potential participants to contact the researcher if they are interested in the study, they can send out reminders to participants to take part via email (Duffy, 2002). However, one downside to this approach is that it can be time consuming for the researcher to correspond directly with large numbers of participants. Therefore, this study opted to rely on advertisements on websites and discussion forums to attract potential participants. Furthermore, in specific illness populations, individuals may be motivated to take part in research as they feel as though they are 'part' of the study. There may also be willingness to take part as participants may feel they are gaining something from taking part in the study such as helping to further understanding of their illness (McColl et al., 2001).

### ***3.1.2.4 Potential issues with web-based surveys***

All aspects of internet research require care and planning. However factors such as security and repeat or nonsense responses require specific attention. As with any personal information researchers need to

take care with personal data and ensure that electronic submission and storage of personal information is secure. There is also potential for websites to be targeted by repeat or nonsense responses making data meaningless (Birnbaum, 2004; Gosling et al., 2004). However, through the use of a specific illness population and careful advertising of the survey, responses such as this were not an issue with the research presented in this thesis. Almost all of these concerns were addressed by the use of an existing online survey host company where issues of secure storage and transmission of data are taken care of. The researcher can make sure that they alone have access to the data (Duffy, 2002). The online survey host used in this study was also able to note the IP (internet provider) address of each response. This was for the sole purpose of eliminating possible repeat responses from the identical IP addresses. IP addresses are allocated to individual users by internet providers to enable communication between computers on the internet. In this study it was utilised solely to potentially identify multiple responses from the same computer or participant.

Furthermore, there has been speculation about the limitations and potential weaknesses of research carried out via the internet (Ahern, 2005, Birnbaum, 2004). However, empirical data have demonstrated many of these concerns to be increasingly unfounded. Gosling et al. (2004) investigated several preconceptions regarding the potential for poor quality or non-probabilistic survey data collected on the internet. Firstly, internet samples are regarded as more diverse than originally thought, although not yet fully representative of the general population. Second, there have been concerns that internet data do not yield reliable and valid data in established psychological measures (Gosling et al., 2004). Such concerns however appear unfounded. Research has shown that psychometrically sound measures are not affected by data collected online in a culturally diverse sample (Graham & Papandonatos, 2008) and in comparisons of internet and mailed questionnaires (Birnbaum, 2004; Ritter, Lorig, Laurent, & Matthews, 2004).

Findings from studies utilising different presentation formats online also seem to demonstrate consistency across formats (Gosling et al., 2004). Investigation into standardised psychological measures has shown little or no difference between online and paper and pencil samples. Vallejo, Jordan, Diaz, Comeche, and Ortega (2007) compared online and paper responses to the General Health Questionnaire-28 (Goldberg & Hillier, 1979) and the Symptom-Check-List-90-Revised (Derogatis, 1977), both tools used for screening of psychopathology. The study found consistency between the methods of administration, where any differences found were minor (Vallejo et al., 2007). Similarly in using the Short form-36 (Ware & Sherbourne, 1992), to compare paper and internet responses of in women referred for mammography, Basnov, Kongsved, Bech, and Hjollund (2009) found consistency across paper and online methods of administration. These studies strengthen the argument that the internet is a viable tool for administration of survey based research.

#### ***3.1.2.5 Summary of issues related to conducting web-based surveys***

It is clear there are justifiable reasons for using the internet to conduct research. There is potential for easy access to participants that may be out of reach of more traditional methods of data collection as well as the potential to contact large numbers of participants who can take part in research at their own convenience. The internet has also grown into a tool for both information provision and even electronic intervention in many illnesses or health issues. Research into establishing the reliability and validity of existing measures online is promising in that there appears to be little or no difference in web-based populations. Other concerns seem to be giving way to a body of literature that suggests potential obstacles can be overcome by the implementation of relatively straightforward procedures such as checking for repeat responses and ignoring incomplete or nonsense replies. There are numerous online survey hosts that simplify survey administration and data collection and researchers can now be much more confident that their data are

comparable with existing work from more traditional methods of survey administration.

Considering the aspects that have been highlighted in the preceding sections, it was determined that both the initial cross-sectional study as well as the follow-up study would be conducted using survey methodology which is common with several other CSM based studies (chapter two). The benefits of conducting web-based research have also been considered and in the context of the CSM, web-based research has been previously conducted (Bishop et al., 2006; 2008). These factors demonstrate that a web-based survey is both appropriate and effective to address the research objectives of the thesis.

### ***3.1.3 Identification of variables for measurement***

Inherent in the CSM is the assumption that certain variables are present to be able to assess the model. In this study, the core components of the CSM were measured which were, namely, illness perceptions and coping. As chapter two argued (section 2.2.3), an illness-specific measure of quality of life was considered a suitable outcome and treatment beliefs (regarding conventional medicine and complementary medicine) were included as an extension of the model based on previous work (Bishop et al., 2006; Horne et al., 1997; Horne & Weinman, 2002). Measurement of CAM use was also considered. The measures considered in relation to the CSM constructs outlined in chapter two are considered fully in section 3.3.

### ***3.1.4 Presentation of survey and response format***

It is generally accepted that questionnaires should be presented in an appealing, structured way and usually in sections (Bryman, 2008). An aesthetically pleasing questionnaire is more likely to be completed than one that looks uninteresting or confusing (Boynton & Greenhalgh, 2004; Keeter, Kennamer, Ellis, & Green 2001) and this extends to having a straightforward and clear layout (Puleo et al., 2002). Factors such as this are easily implemented using web-based surveys and require minimum

expertise if using an online survey host. Likewise the structure of surveys is also important. Generally an introduction to the research (i.e. information about the study) is considered best practice with some non-intrusive questions to start off the survey (Bowling, 2009; Rattray & Jones, 2007; Sapsford, 1999). This can be followed by the main body of the survey, with the detailed demographics at the end of the survey as, if placed at the beginning they can contribute to study attrition (Bowling, 2009). At the end of the survey, further information may be volunteered by the researcher about the study and participants are generally thanked for their participation. As considered earlier, there can also be an 'open' section for additional comments or responses that may be analysed qualitatively (O'Cathain & Thomas, 2004). The end of the survey is an appropriate place to ask participants if they would be interested in taking part in any further studies, with the participant offering some form of contact to the researcher. In the case of web-based studies, contact is often made via email between researcher and participant (Ahern, 2005; Duffy, 2002).

The response formats of the selected questionnaires are outlined in section 3.3. Many of the response formats used in this study come from validated measures and take the form of a Likert type scale, usually with a mid point. Participant responses are coded numerically to give a level of agreement or disagreement with particular statements. It is also common to treat these data as parametric (interval) data when the measure is regarded as reliable and valid (Bowling, 2009; Polgar & Thomas, 1995) thus ensuring more powerful statistical analysis using parametric tests where appropriate (Rattray & Jones, 2007).

Additional questions may focus on such issues as if (and how long ago) a diagnosis took place, or how long someone might spend with their Doctor. Such questions may form an important part of subsequent analysis of data, or they may help explain characteristics of the sample and can be used as non-threatening introductions to more in-depth questions (Bowling, 2009; Rattray & Jones, 2007). Both Likert type and

open response formats are usually easy for participants to understand and follow, and by offering a mid-point in Likert scales allows participants to remain undecided, but still gives the researcher a 'total' score to examine (Bowling, 2009).

As considered previously, detailed participant demographics relating to participants are better positioned towards the end of a survey, thus avoiding the potential for study attrition (Bowling, 2009). Although there is no definite guide to what should be included, generally participant gender, age, income and education are asked. Further questions may enquire about ethnic background, religious beliefs, employment and comorbidity if dealing with a specific illness group, factors which have been shown to be influential in CAM use in previous studies (chapter two). Demographic information can also act as a means of comparison with existing work and may help to argue findings have wider application beyond each study sample (Bryman, 2008). Such claims have particular relevance to internet based studies (Birnbaum, 2004; Gosling et al., 2004).

### ***3.1.5 Study design***

The preceding sections have recognised the major issues in structuring a series of questionnaires and how these factors may affect the response rate. It has also considered the benefits and limitations of different methods of administering questionnaires and it was decided that the survey should be administered via the internet. The instruments described in the following sections of this chapter have been selected on the basis of being psychometrically sound measures of each of the relevant components (chapter two) of the CSM. These will be used to examine the research objectives outlined in chapter two.

The study was developed taking into account the points considered earlier, including the order of questionnaires, response formats, the length of the survey overall and how the study looked in terms of

presentation to participants. The structure of the survey is outlined in figure 3.1.

Participant recruitment took place via advertisements placed on the internet inviting potential participants to take part in the research rather than asking them to contact the researcher first to assist the response rate and make data collection quicker. Moreover, by using mostly established measures in the research that have undergone thorough testing and development it was thought this would minimise any problems and aid a smooth completion of questionnaires by participants.

In considering previous CSM research it was thought both a cross-sectional (chapters four and five) and a follow-up study (chapter six) would best address the research objectives effectively. The initial cross-sectional study consisted of a large scale web-based survey. All questionnaires were presented to participants via the internet using an online survey host. The main predictor (and explanatory) variables are outlined in subsection 3.3 and consisted of measures of illness perceptions, treatment beliefs (including beliefs about CAM) and coping. There were two main outcome variables consisting of a dichotomous measure of CAM use for IBS (yes or no) and a measure of quality of life specific to IBS (the IBS-QOL, Patrick et al., 1998).

### **3.2 Sample size**

To determine an appropriate sample size (Lerman, 1996), a statistical power calculation was conducted based on the intended use of logistic regression described in section 3.6.2. A power calculation is able to provide researchers with a suggested minimum number of participants required to detect statistical significance in a population. The suggested sample size is based on information including desired significance level (usually  $p < .05$ ), number of variables to be analysed and an acceptable level of power (usually .8 or 80%, the chance of committing a type II error).



### **3.2.1 Determination of sample size**

A statistical power calculation was used to determine the minimum sample size. Statistical power works in reverse to the usual  $\alpha$ -value of .05 (.05 demonstrating the likelihood a researcher is to make a type I error or false positive). The concept of 'power' allows the researcher (based on previous research and theory) to 'expect' an effect to be detectable in the sample population (Field, 2009; Tabachnick & Fidell, 2007). A calculation of sample size or 'power' can be conducted to establish the minimum number of participants required to find an expected effect in a sample at a power size of .80 (usually denoted by  $\beta=.80$ ) which is sometimes expressed as 80%. This effectively means that there is a .2 or 20% chance of committing a type II error, that is a rejection of a potentially significant result when it exists in the population. The G-Power<sup>1</sup> program (Faul, Erdfelder, Lang, & Buchner, 2007) was used to determine the number of participants on an 'a priori' basis to find an 'expected' effect. Assuming much of the analysis would be exploring inter-relationships between components of the CSM, a decision was made to primarily focus on the number of factors that would predict CAM use in those with IBS to determine the required sample size.

Thus a power calculation was conducted with 22 predictor variables, namely 11 scales of the IPQ-R, the 2 scales of the BMQ and the 3 scales of the CAMBI. Also included were approximately six demographic variables (such as age, gender and dichotomous measure of prescription medication) a minimum sample size of 163 was required for logistic regression analysis (to predict CAM use), with alpha set to .05 and a power of .80 would give a critical value of 'F' in the regression model of:  $F(22, 140) = 1.62, p < .05$ . Further to the reasons considered earlier in relation to a web-based study being the most favoured approach, the minimum recommended sample size of 163 from the power calculation, suggested that a web-based study would be appropriate to gain this number of participants as a minimum.

---

<sup>1</sup> This software is available as a free download at:  
<http://www.psych.uni-duesseldorf.de/aap/projects/gpower/>

### **3.2.2 Obtained sample size**

In both phases of the study, participants were all adults aged 18 or over that have IBS or IBS symptoms. As stated, recruitment took place via the internet. Phase one of the study attracted 2887 visits to the study website, with 1246 participants commencing the study. Approximately 53% of those who commenced the study completed all the questionnaires meaning a final sample of n=653 participants for the cross-sectional part of the study (presented in chapters 4 and 5). At the end of the study, interested participants were given the option to take part in a follow-up study by leaving an email address as a point of contact. Participant details for the follow-up study are presented in chapter six.

### **3.3 Measures/materials**

The structure of the survey was broadly organised into four main sections based on consideration of the preceding discussion regarding surveys. This followed the pattern of: i) non-intrusive background questions (e.g. regarding diagnosis of IBS and time with symptoms), ii) questionnaires based on the CSM, iii) questions about CAM use (if applicable) and iv) demographic questions.

#### **3.3.1 Background questions**

The first section of the survey was designed to ask participants some non-intrusive questions about their IBS (e.g. Bryman, 2008). This included if they had been diagnosed by a health care professional and approximately how long ago this was. They were also asked how long they had been with symptoms of IBS. As the survey was web-based, 'branching' was used so participants were not presented with unnecessary questions (e.g. asking participants about how long ago they were diagnosed if they had not actually been diagnosed).

#### **3.3.2 Predictive/explanatory measures**

The survey was largely made up of established questionnaires related to components of the CSM. These measures were included to capture

participant perceptions of their IBS, their treatment beliefs, their beliefs about CAM, how they coped with IBS, their reported quality of life and if they used CAM to relieve their IBS. Further questions asked about which CAM treatments had been used. Specific details of each of the measures are presented in the following subsections.

### ***3.3.2.1 Illness perceptions***

The illness perception questionnaire revised version (IPQ-R; Moss Morris et al., 2002) was used to measure the main components of illness perceptions identified by Leventhal et al. (1998; 1992). The IPQ-R is a reliable and valid measure of nine components of illness perceptions, having been used in several illness populations such as asthma patients, those with chronic pain and in a cervical screening context (e.g. Hagger & Orbell, 2005; Moss-Morris et al., 2002) (see chapter 2) and has been used in studies to determine CAM use (Bishop et al., 2006; 2008). As chapter two illustrated, the IPQ-R is a revision of the original five-component IPQ (Weinman et al., 1996) which itself measured the key components of the CSM namely: identity (symptoms that are attributed to the illness), timeline (beliefs regarding the duration of the illness), cause (beliefs about what caused the illness), consequences (personal significance of the illness) and cure/control (the likelihood of the illness being controlled or cured). The nine-component IPQ-R includes the addition of a scale of emotional representations related to illness, something not considered by the IPQ but part of the CSM in that both cognitive and emotional responses to a health threat work in parallel to maintain a state of normality (Leventhal et al., 1998). The IPQ-R contains a revised causal scale, including eight additional items and the 'control' dimension was split into patient control and treatment control. The IPQ-R also has an additional timeline scale that measures the cyclical nature of illness. There is empirical support that both the IPQ and IPQ-R are structurally related to coping (Hagger & Orbell, 2003; Rutter & Rutter, 2002), CAM use (Bishop et al., 2006; 2008) and quality of life (Rutter & Rutter, 2002; 2007) (see chapter 2).

The measure was amended slightly as Moss-Morris et al. (2002) recommend that the word 'illness' be changed to the illness under investigation, therefore the word 'illness' was substituted with 'IBS' throughout the questionnaire (Moss-Morris et al., 2002). Furthermore, at the present time, although many illness specific identity scales exist, there is no domain specific scale for IBS. The identity scale is based on fourteen symptoms of which participants respond 'yes, this symptoms is related to my IBS' or 'no, this symptom is not related to my IBS'.

The Timeline acute/chronic scale is measured by six items to determine perception of an acute or chronic timeframe for IBS. Items in this scale include 'My IBS will last a short time' and 'My IBS is likely to be permanent rather than temporary'. A second Timeline scale (to assess beliefs about the cyclical nature of illness) consists of four items including 'The symptoms of my IBS change a great deal from day to day' and 'My IBS is very unpredictable'.

A further six items on the IPQ-R measure 'consequences' that is, the perceived seriousness of the illness for the individual. This scale includes items such as 'My IBS has major consequences on my life' and 'My IBS is a serious condition'. There are two 'control' scales on the IPQ-R – personal control and treatment control. Six items measure personal 'control' which concerns how much control the individual feels they have over their illness. Items in this scale include 'There is a lot I can do to control my symptoms' and 'I have the power to influence my IBS'. A further five items measure treatment 'control' which relates to perceptions of how medication can help control symptoms and illness. Treatment control items include 'My treatment can control my IBS' and 'The negative effects of my IBS can be prevented (avoided) by my treatment'.

A further five items measure patient 'coherence' of illness in terms of the degree to which individuals feel they understand their condition. Items include 'The symptoms of my IBS are puzzling to me' and 'I have a clear

picture or understanding of my IBS'. Six items measure 'emotional representations' which ask about how IBS makes participants feel emotionally. Example items include 'I get depressed when I think about my IBS' and 'My IBS makes me feel angry'. All the aforementioned scales are formed numerically by firstly reverse scoring appropriate items (from the measure guidelines) and then summing the scores for each item.

The final scale is that which measures perceived 'causes' which consists of eighteen items listing a number of possible causes such as 'stress or worry', 'diet or eating behaviour' and 'my personality'. Moss-Morris et al. (2002) recommend performing principal components analysis (PCA) on larger sample sizes to see which items can be statistically grouped together. PCA is a procedure that allows compression of individual questionnaire items into 'components' or groups of items that may then represent a scale, the groupings themselves are based on items being strongly correlated (Field, 2009; Tabachnick & Fidell, 2007). The PCA for the causes scale is presented in chapter four.

### **3.3.2.2 Beliefs about conventional medication**

As the preceding chapter illustrated, there is both theoretical and empirical evidence that treatment beliefs can fit into an 'extended' CSM (Bishop et al., 2006; Horne & Weinman, 2002). One reliable and valid measure to assess such beliefs is the Beliefs about Medicines Questionnaire (general version) (Horne, Weinman, & Hankins, 1999) which was designed to capture the beliefs of the individual in relation to conventional medication being harmful or overused. This measure is deemed psychometrically sound having been used with a variety of illness populations (Horne et al., 1999; Horne, 1997) and has been shown to be relevant in predicting CAM use (e.g. Bishop et al., 2006).

The Beliefs about Medicines Questionnaire (BMQ-General; Horne et al., 1999) was used to measure beliefs about conventional treatment for IBS. This version of the BMQ (there also exists a specific version which was

not used in this study) is an eight item, two scale measure of general treatment beliefs and was presented to all participants. Again, this measure has been validated by the authors (Horne et al., 1999) and used in subsequent studies utilising an 'extended' CSM (e.g. Bishop et al., 2006). The BMQ-General consists of two scales of four items each that focus on beliefs about harm and overuse of medicine in general. The harm scale includes the items 'all medicines are poisons' and 'most medicines are addictive'. The overuse scale includes items such as 'Doctors use too many medicines' and 'natural remedies are safer than medicines'.

### **3.3.2.3 Beliefs about CAM**

There has been extensive work on the attitudes and beliefs of those individuals who use CAM (Astin, 1998; Eisenburg et al., 1998; Vincent & Furnham, 1996) but little of this has been carried out using standardised health psychology measures (Bishop, Yardley, & Lewith, 2004). Bishop et al. (2005) argue that there are three key dimensions involved in beliefs about CAM. These dimensions consist of beliefs in holistic health (CAM users often believe in healing the whole body), beliefs about natural aspects of treatment (CAM is often seen as more 'natural') and participation in treatment (CAM users often want to be seen as active partners in any treatment regime). One recently developed measure that captures these three dimensions is the Complementary and Alternative Medicine Beliefs Inventory (CAMBI, Bishop et al., 2005) and over a number of studies has been shown to have stable psychometric properties in general illness populations (Bishop et al., 2005; 2006; 2008).

The CAMBI (Bishop et al., 2005) was used to measure three dimensions of beliefs about complementary medicine. The measure consists of three scales regarding 'naturalness' of treatments, beliefs about holistic health and patient/client participation in treatment. The 'natural aspects of treatment' scale comprises six items and assess beliefs people have about natural treatments and consists of such items such as 'Treatments

should have no negative side effects' and 'Treatments should only use natural ingredients'. The holistic health beliefs scale comprises five items that assess beliefs relating to the human body being treated as a 'whole.' This scale contains items such as 'I think my body has a natural ability to heal itself' and 'Health is about harmonising your body, mind and spirit'. The third scale, participation in treatment, also comprises five items that consist of statements such as 'Patients should take an active role in their treatment' and 'Treatment providers should treat patients as equal partners'.

### ***Scoring the IPQ-R, BMQ and CAMBI scales***

Aside from the IPQ-R identity scale, where the number of 'yes' items are totalled to give a total score for illness identity, the majority of the remaining items on the IPQ-R are assessed using a five point Likert type scale ranging from 'strongly agree' to 'strongly disagree'. The items in each scale are summed to give a total score, however to account for missing data Moss-Morris et al. (2002) have provided researchers with SPSS syntax that allows for up to two items of data to be missing in a six-item scale and one missing item of data in a four-item scale. A number of items on the measure also required reverse scoring. High scores on the identity, consequences and timeline (chronic and cyclical) dimensions represent stronger beliefs about the number of symptoms attributed to the IBS, the chronic nature of IBS, cyclicity of the condition, and negative consequences of the IBS illness. High scores on the personal control, treatment control and illness coherence scales represent positive beliefs about the controllability of the illness and greater personal understanding of the condition.

For each of the two scales of the BMQ, the four items are summed to give a total score for that particular scale. For reasons of consistency and to account for missing items, the SPSS syntax used in calculation of the IPQ-R scores was adapted for use with the BMQ. If participants had at least three responses in each scale, then a total score was computed. Any participants with less than 3 responses were coded as missing data.

On both scales, higher scores indicate stronger beliefs in harm and concerns with conventional medicine.

The CAMBI is a seventeen item measure of beliefs towards complementary treatments and was measured using a 5 point Likert scale. Items in the three scales are totalled giving a score for each. As with the IPQ-R and the BMQ, SPSS syntax was used to incorporate participants with up to two missing items on the 'natural treatments' and 'holistic health' scales and one missing item on the 'patient participation' scale. Participants with more than three items of missing data in each scale were coded as missing. Higher scores on each of the scales indicate more positive beliefs about CAM.

#### **3.3.2.4 Brief-COPE**

Chapter two highlighted the Coping Orientation of Problems Experienced (COPE) (Carver et al., 1989) as one method used to measure coping in CSM research and has been used in studies with IBS (Rutter & Rutter, 2002; 2007). With a number of questionnaires already present in the research, an alternative measure, the Brief-COPE (Carver, 1997), was used in this research due to concerns about response burden. The Brief-COPE was devised from many of the same items as the original COPE and covers fourteen scales covering the scope of the different forms of coping and featuring some revisions to the original COPE measure (Carver, 1997). This measure has also been utilised in CSM research previously (e.g. Llewellyn et al., 2007).

The Brief-COPE (Carver, 1997) is a shorter, refined version of the original 60 item COPE, with no apparent decline in validity or reliability. The measure consists of twenty eight items which make up fourteen scales (two questions assess each scale) that encompass questions surrounding problem-focused or emotion-focused coping styles although some scales in the measure focus on other aspects of coping that may be considered as maladaptive/dysfunctional or adaptive/functional. These coping strategies include the using humour, or the use of



substances such as alcohol or drugs (Carver, 1997). The scales consist of Self-distraction, Active coping, Denial, Substance use, Emotional support, use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humour, Acceptance and Religion. A new scale added to the Brief-COPE that was not present on the original COPE measure was named 'Self blame' (Carver, 1997).

### ***Scoring the Brief-COPE***

Each item on the Brief-COPE is measured on a four-point Likert scale ranging from 'I haven't been doing this at all' to 'I've been doing this a lot' in relation to each of the 28 statements. Carver (1997) states there is no overall coping score as researchers are encouraged to explore each type of coping. Scores for each coping 'style' are summed from each pair of items giving a total score for each of the fourteen scales. Higher scores on the 14 Brief-COPE scales indicate a greater likelihood to adopt a particular style of coping, be it potentially adaptive or maladaptive.

### ***3.3.3 Outcome measures***

There were two main outcome measures in the research consisting of a measure of CAM use (section 3.3.3.1) and a measure of health related quality of life (section 3.3.3.2). Within the former, questions regarding number of CAM treatments were asked for those that had used CAM. It should also be noted that 'CAM use', in the framework of the CSM, would be seen as a specific coping behaviour, however in the context of the statistical analysis conducted (see sections 4.2.5.4 & 4.3.6) it was considered an outcome variable.

#### ***3.3.3.1 CAM use***

Use of complementary and alternative medicines was assessed by firstly asking participants if they have ever used complementary or alternative treatments to relieve their IBS, for which they could answer 'yes' or 'no.' For those answering 'yes', a list of 30 CAM treatments (including acupuncture, herbal treatments and aromatherapy – derived from Furnham, 2000) was presented so participants were able to select

treatments they had used. In case a new or unusual treatment was indicated that was not on the list an option of 'other' treatment was offered where participants could name the treatment they had used to relieve their IBS. This enabled examination of which CAM treatments were most popular and also to calculate the number of CAM treatments used. This variable was also used to group participants into those that indicated they used CAM for their IBS at study time one (CAM-users) and those not using CAM (non-users).

### **3.3.3.2 Quality of life**

As considered in chapter two, there is some discussion about whether researchers should use general or domain specific measures of quality of life. For this study, a domain specific quality of life measure was utilised as firstly, it was thought this would capture information about specific ways in which IBS can impact on an individual's life. Secondly, a domain specific measure was thought to offer something beyond a description of 'feeling worse' and should include such factors as effect on relationships and occupational life (Palsson, 2002). As a domain specific measure of quality of life was favoured (chapter two), the Irritable Bowel Syndrome Quality of Life (IBS-QOL, Patrick et al., 1998) measure was selected as it is psychometrically sound over several studies (Bushnell et al., 2006; Drossman et al., 2000; Patrick et al., 1998). The IBS-QOL also measures a number of scales that can be combined to provide an overall quality of life score that reflects the multi-faceted nature of quality of life in IBS. Further, the measure has also been validated via electronic data capture through a hand held computer device (Bushnell et al., 2006). Importantly, the IBS-QOL contains a 'Dysphoria' subscale which may be utilised as a measure of 'emotional outcome' (according to the CSM) thus enabling the relationships between emotional representations, coping and emotional quality of life to be examined. The IBS-QOL gives a general 'score' from 34 items based on quality of life as rated by participants (i.e. the higher the score, the better the perceived quality of life) which consists of eight subscales – Dysphoria (8 items), Interference with activity (7 items), Body Image (4 items), Health Worry (3 items),

Food Avoidance (3 items), Social Reaction (4 items), Sexual issues (2 items) and Relationships (3 items).

Items that make up the Dysphoria subscale measured the emotional impact of IBS on the individual with example items including 'I feel like I'm losing control of my life because of my bowel problems' and 'I feel my life is less enjoyable because of my bowel problems'. The Interference with activity subscale consists of items that measured the impact of IBS on normal activities and includes such items as 'I feel I get less done because of my bowel problems' and 'I have to avoid stressful situations because of my bowel problems'. Body image assessed the impact of IBS on individual body image with items including 'My bowel problems limit what I can wear', and 'I feel sluggish because of my bowel problems'. Food avoidance assessed the degree to which foods are avoided due to IBS by items that include 'I have to watch the kind of food I eat because of my bowel problems' and 'I feel frustrated that I cannot eat when I want because of my bowel problems'. The health worry subscale measured beliefs about the impact of IBS on health by items including 'I feel vulnerable to other illnesses because of my bowel problems' and 'I worry that my bowel problems will get worse'. The social reaction subscale measured the concerns regarding the reaction of others to an individual's IBS with items including 'I am embarrassed by the smell caused by my bowel problems' and 'I feel like I irritate others because of my bowel problems'. The impact of IBS on 'Sex' is assessed by two items; 'Because of my bowel problems, sexual activity is difficult for me' and 'My bowel problems reduce my sexual desire'. Finally, the subscale 'relationships' assess the impact of IBS on relationships with others and includes the items 'I feel uncomfortable when I talk about my bowel problems' and 'My bowel problems are affecting my closest relationships'.

### ***Scoring the IBS-QOL***

IBS-QOL items are measured using a five point Likert scale ranging from 'Not at all' to 'Extremely' or 'A great deal'. The IBS-QOL is scored by

summing responses which are then averaged for a total score. This score is then transformed into a 0-100 scale where higher scores demonstrate better ratings of quality of life (Patrick et al., 1998; Drossman et al., 2000). The sum of the items is subtracted from the lowest possible score, the result of which is divided by the range of the raw scores. The obtained value is multiplied by 100.

As with the BMQ, IPQ-R and CAMBI, scores were summed to allow for a small amount of missing responses. The Dysphoria and Interference with activity scales, being the two longer scales (eight and seven items respectively) were computed with up to two values missing. The remaining scales were all allowed one missing item. The total QOL score was therefore computed from no less than 24 values out of a possible 34. Each subscale total was computed to allow for examination between CAM-users and those that not using CAM (non-users) on the full range of IBS-QOL dimensions.

As indicated, in terms of examining pathways in the CSM, this research utilised the overall IBS-QOL as a measure of outcome alongside the Dysphoria subscale of the IBS-QOL as a measure of emotional outcome (see chapter 2). A further reason for taking this approach was because of the large number of coping scales involved from the Brief-COPE and potentially the greater significance of uncovering differing coping styles (between CAM-users and non-users) and their interrelationships with perceptions, beliefs and outcome.

### **3.3.4 Demographics**

Detailed demographics were asked at the end of the questionnaire. 'Standard' questions regarding participant age, gender and total household income were asked. Participants were also asked to indicate their level of education ranging from no qualifications to postgraduate qualifications. Further questions that were included asked which religious group participants occupied, their geographical location and comorbidity (i.e. did participants have any other health complaints other

than IBS). Such questions are standard in much social research (Bowling, 2009) and assisted in explaining characteristics of the sample in demographic terms. This was in addition to being able to examine the influence of demographic factors on CAM use in those with IBS.

### **3.4 Procedure**

Details of the study procedure are provided in relation to pilot testing of the survey, advertising the study and ethical details.

#### **3.4.1 Pilot procedure**

The majority of measures in the study had been used on a variety of illness populations previously. Some measures (the IPQ-R, BMQ and CAMBI), have also been used in a web-based surveys previously (Bishop et al., 2006; 2008). Furthermore, as many survey based studies have successfully recruited participants online it was therefore decided to run an initial pilot phase of the survey using people not affected by IBS to assess if online data capture was feasible. This involved completing several test runs of the survey with the assistance of senior colleagues using different computer terminals at different locations. Responses were downloaded from the website into SPSS. Consequently there were no problems with either access to the survey, participation or access to data detected at this stage, so the research proceeded with the posting of advertisements to commence study recruitment.

#### **3.4.2 Advertisement of study**

As the study was web-based, participants were recruited from a number of different health related web pages and discussion forums. The primary source of recruitment was via an online advertisement on the website of the IBS Network<sup>2</sup> which is the largest IBS charity based support network in the UK. The advertisement invited participants to take part in the study, gave some information about the study and

---

<sup>2</sup> The IBS Network is the main IBS self help network in the UK and can be located at [www.theibsnetwork.org](http://www.theibsnetwork.org), as of March 2011 it was re-named, formerly being known as the Gut trust. There was a small charge for this advertisement which was paid for by the University of West London.

contained a direct 'clickable' link to the study website. The IBS Network was selected for several reasons, namely that the website has a high volume of visitors and the organisation has been used to successfully recruit participants in previous studies with a psychological orientation (e.g. Rutter & Rutter, 2002; Dancy & Backhouse, 1993). The IBS Network website does have some commercial partners but this website itself does not contain explicit advertisements of products manufactured by these organisations. At the time the advertisement was placed, it was noted that the organisation also carried advertisements calling for volunteers to take part in a number of randomised controlled trials for newly developed IBS conventional medication.

Additionally, advertisements for the study were also placed on other online GI related discussion forums (with the forum administrator's permission), whereby a direct link to the study website was included in the message posting<sup>3</sup>. One further advertisement for the study was also placed on an online directory of psychological research studies<sup>4</sup>.

The survey was hosted by a specialist internet research company ([www.questionpro.com](http://www.questionpro.com)) who were selected because of a user-friendly website and emphasis on security of responses. Only the primary researcher had access to the responses via username and password.

### **3.4.3 Participant information and ethical information**

On the study website front page, potential participants were greeted by an introductory information page giving necessary ethical information about the study. This included an option to give consent to take part or withdraw from the study as well as notification about rights, such as the right to stop, withdraw or request that data not be used (British Psychological Society, code of ethics and conduct, 2009). Participants

---

<sup>3</sup> Three forums were used to post invitations to participate in the study: the Discovery health forum at: <http://community.homeandhealthtv.co.uk/eve/forums>; the IBS forum at: <http://www.healingwell.com/community/default.aspx?f=26>; and the IBS support group at: <http://www.ibsgroup.org/forums/>

<sup>4</sup> This can be found at [www.onlinepsychresearch.co.uk](http://www.onlinepsychresearch.co.uk)

were also informed that all data and responses were held securely in accordance with the Data Protection Act 1998. The primary researcher's contact details were provided for participants to make contact in the case of any questions regarding the research. As advertisements for the study were placed on websites deemed to be offering support to people affected by IBS, participants were not offered any formal medical advice or support, but the researchers contact details were provided for the benefit of participants if they had any questions or issues raised by the research.

#### **3.4.4 Survey completion**

Participants were guided through the measures on screen with instructions before they began each section and were instructed to click on the 'next' tab when they had finished entering responses for each of the measures listed above. Selective 'branching' was used where possible to avoid the accumulation of unnecessary responses being collected. For example where participants were asked about their use of CAM if they answered 'no' they were asked no more questions about CAM (figure 3.1). A 'yes' response, directed participants to further questions about their CAM use and the type of CAM they had used. Data collection took approximately twelve months between May 2007 and May 2008 although potentially this time may have been reduced for two reasons. Firstly, the original advertisement was not particularly visible on the IBS Network website. Second, the organisation underwent significant re-branding during the data collection period resulting in approximately 2 months of downtime in terms of the advertisement being absent from the website. Following commencement of the new website and replacement of the advertisement in a prominent position on the front page of the website, data collection increased dramatically.

Prior to the end of the study, participants were asked an open 'question' about their IBS: 'You may use the space below to comment on anything you would like to say about having IBS' (see appendix XV). Finally, participants were asked if they would be willing to take part in a follow-up

study and were offered the chance to enter their email address to be contacted to take part. The email addresses that were collected from participants interested in the follow-up study were downloaded and stored separately from the remainder of the data set to avoid any possibility of identification of participants. Participants were finally given a 'thank you' message for taking part in the study. Any participants who contacted the researcher with questions regarding IBS were advised to contact their primary care provider.

### **3.5 Ethical approval**

Ethical approval for all aspects of the study was granted by the (former) Faculty of Health and Human Sciences Ethics Committee at the University of West London (formerly Thames Valley University) before the study commenced.

### **3.6 Statistical methods**

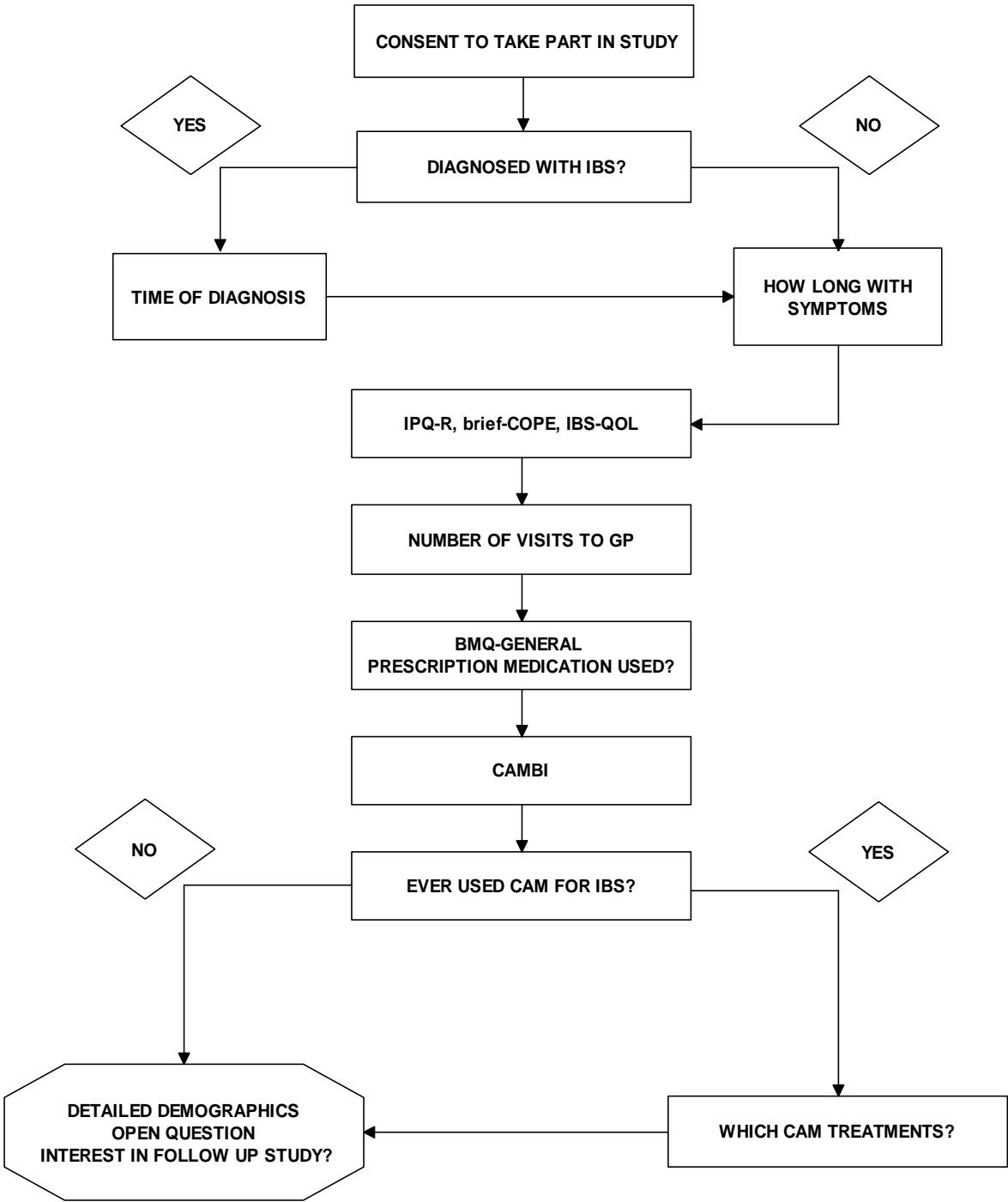
Data were downloaded from the survey website in comma separated variable (CSV) format. Data were then imported directly into Statistics Package for the Social Sciences (SPSS) Release Version (PASW) 17.0 (© SPSS, Inc., 2008, Chicago, IL, [www.spss.com](http://www.spss.com)). CSV files are just one of a number of 'external' files that SPSS recognises and is able to open as a data file (Antonius, 2003). Prior to data screening, variable names were checked and relabelled if required.

#### **3.6.1 Missing data**

Missing data were numerically coded in SPSS as 'missing' (using the digits '999' as a numerical code) and where possible were excluded from the analysis via the 'listwise' deletion option available in SPSS (section 3.3). This meant that if data were missing anywhere for a particular individual, that individual would be excluded from that particular analysis. It should be noted that for some procedures such as logistic regression, SPSS runs a listwise deletion as a fixed default. Specific details regarding missing data are presented in each of the subsequent chapters, four to six.



**Figure 3.1 Flow chart of participant route through the study web pages**



**Explanatory note:** Branching was used to distinguish between those who had and had not been diagnosed. If participants indicated they had been diagnosed, they were directed to a further question relating to the time of diagnosis before they were asked about duration of symptoms. If they had not been diagnosed, participants were not shown the questions about diagnosis and were directed straight to the question about symptom duration. A similar strategy was used when participants were asked about CAM use for IBS. Those that had used CAM were asked about the different forms of CAM they had used prior to the demographics at the end of the study. Those that did not use CAM were directed straight to the demographics section at the end of the study.

### **3.6.2 Distribution of scores**

A large sample size (i.e. over 600 participants) results in statistical methods for determining normality of distributions of variables becoming less reliable. Therefore visual checking of histograms is recommended in such cases (Field, 2009; Tabachnick & Fidell, 2007). Distribution of scales is considered in subsequent chapters with reference to robustness of certain parametric tests to violations of normal distribution.

### **3.6.3 Statistical tests**

A number of statistical tests were required to examine each of the specific research questions (chapter 2) namely, to identify which illness perceptions and treatment beliefs predict CAM use and which coping styles mediate the relationship between illness perceptions (or treatment beliefs) and outcome (quality of life). Further examination of data considered differences between CAM-users and non-users and an examination of relationships (in CAM-users) between illness perceptions, treatment beliefs and number of CAM treatments used.

#### **3.6.3.1 Differences between CAM-users and non-users**

As mentioned parametric testing was favoured as all measures utilised in the research were considered to be reliable and valid tools of measurement, thus generating parametric (interval level) data. Independent *t*-tests were used to test for differences on scale scores between CAM-users and those that not using CAM (non-users) on CSM based variables. The independent *t*-test is able to detect differences in scale variables based on dichotomous group membership and is said to be robust against any violation of normality in scale variables, including increased potential for Type I errors (Vickers, 2005).

#### **3.6.3.2 Predicting CAM use**

Binary logistic regression analysis was used to predict CAM use in those with IBS. Logistic regression is a procedure that can predict group membership from scale and categorical predictors based on the likelihood of membership of a particular group whilst controlling for other

predictor variables in the model (Field, 2009; Tabachnick & Fidell, 2007). Multiple predictors were entered in a block entry binary logistic regression model to assess firstly the impact of illness perceptions, treatment beliefs and CAM beliefs in predicting CAM use (block one) and secondly to examine which demographic factors (block two) predicted CAM use, which also determined if predictors significant in block one were still predicting CAM use when controlling for demographic variables included in the model. This procedure also allowed examination of the importance of each block in terms of variance in outcome predicted. In this context, this test was considered the most appropriate to examine for prediction of CAM use in those affected by IBS.

#### ***3.6.3.3 Diagnostic tests for logistic regression model***

Diagnostic testing was carried out for the logistic regression model and further details are presented in chapter four. Testing was conducted for highly correlated predictor variables, residual outliers and values that may have undue effect on the regression model. Such diagnostic testing is considered normal procedure in regression models with a number of predictor variables (Field, 2009; Tabachnick & Fidell, 2007).

#### ***3.6.3.4 Testing for Mediation***

The CSM proposes that the causal pathways between illness perceptions (or treatment beliefs) and outcome are mediated (i.e. explained) by coping strategies. As chapter two illustrated, illness perceptions influence coping strategies, which are then said to influence outcome. This means the impact of illness perceptions (or treatment beliefs) influences outcome through coping strategies. Therefore a statistical test for mediation may offer support for the CSM and denote which processes (i.e. coping strategies) indirectly influence better or worse reported outcome. A widely used strategy to test for mediation comes from Baron and Kenny (1986) known as the 'causal steps' approach which tests for 'simple' mediation (i.e. with a single predictor, potential mediator and outcome variable). This approach consists of the researcher performing a number of regression analyses and then making

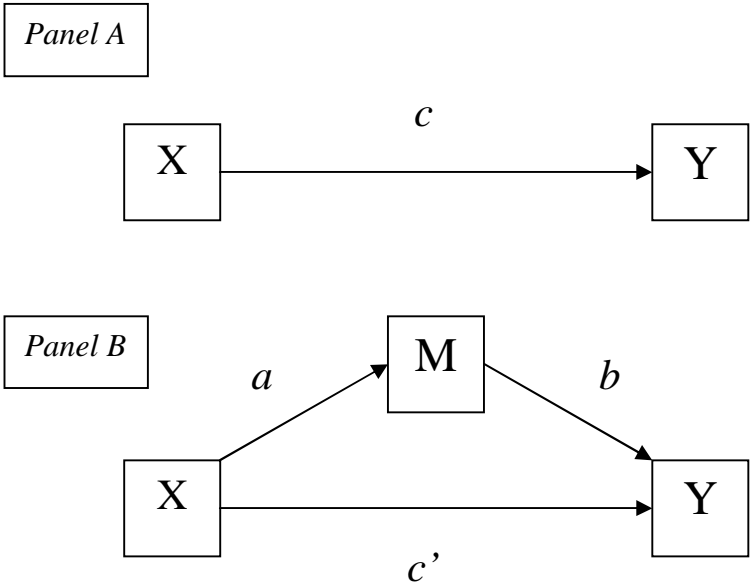
inferences regarding whether mediation is present (Baron & Kenny, 1986; Hayes, 2009; Preacher & Hayes, 2004). This approach to mediation testing is also arguably consistent with the premise of the CSM. It has also been 'recommended' that mediation testing has a sound theoretical basis (Preacher & Hayes, 2008; Shrout & Bolger, 2002).

The determination of mediation is based on four equations or pathways as illustrated in figure 3.2. The first pathway  $c$  is denoted by a significant relationship between predictor and outcome ( $X \rightarrow Y$ ). The predictor variable must then significantly influence the mediator ( $X \rightarrow M$ ). Third, the mediator should significantly predict the outcome ( $M \rightarrow Y$ ) whilst controlling for the predictor ( $X$ ). Finally, the pathway  $c'$  between predictor and outcome is reduced to non-significance in the presence of the mediator, in which case 'mediation' is said to be present. More commonly, pathway  $c'$  is reduced quantitatively but not necessarily in significance (Preacher & Hayes, 2004). This situation is said to denote partial mediation. If the latter situation exists, a further issue for the investigator is to determine the strength (or statistical significance) of the mediation effect without committing type I or type II errors in relation to mediation effects detected (Preacher & Hayes, 2004).

Preacher and Hayes (2004) argue for statistical assessment of whether the difference between  $c$  and  $c'$  (alternatively, the product of  $ab$ ) is significantly different from zero (thus, if different from zero, then mediation or partial mediation is present). One way of testing this is to use a Sobel test (Sobel, 1982) which measures the strength of what is also referred to as the 'indirect effect' (i.e. the difference between  $c$  and  $c'$ ) and can be used to assess the degree of mediation. The Sobel test however assumes the difference in values between  $c$  and  $c'$  to be normally distributed, which can produce questionable interpretation of mediation being present (Preacher & Hayes, 2004). Preacher and Hayes (2004) offer an extension of the Sobel test based on 'bootstrapping' which makes estimates of the significance of the 'indirect

effect' (the effect of predictor, through the mediating variable, on outcome) of the same sample size, but based on the researcher's data. The resulting estimate is more accurate than the Sobel test alone (Preacher & Hayes, 2004). Furthermore, Fairchild, Mackinnon, Taborga and Taylor (2009) offer an additional test to identify the unique portion of variance in the outcome variable accounted for by the mediation effect. Further detail and analyses are presented in chapters five and six.

**Figure 3.2 Illustration of 'simple' Mediation**



In Panel A: path  $c$  is a result of X (predictor) significantly affecting Y (outcome). Panel B: X affects Y indirectly through the Mediator (M) with  $c'$  being less than  $c$  if mediation/partial mediation is present. Adapted from Preacher and Hayes (2004)

In order to test for potential mediating effects of coping between illness and treatment beliefs and quality of life, a number of simple mediation analyses were conducted separately for CAM-users and the non-users (those not using CAM). Firstly, to determine step one of the Baron and Kenny (1986) criteria, Pearson's correlations were examined between

illness perceptions, treatment beliefs and quality of life (and the Dysphoria scale of the IBS-QOL). To examine step two of the Baron and Kenny (1986) criteria, Pearson's correlations were examined between illness perceptions, treatment beliefs and the scales of the Brief-COPE. Significant relationships from these two steps were identified as possibly indicating mediation and so were entered into multiple regression models to analyse the relationships between the identified variables. As Baron and Kenny (1986) suggest, regression models may contain only the three variables of interest (in this thesis, based on CSM theory, see also Carlisle et al., 2005), the predictor (IPQ-R, BMQ or CAMBI scale), potential mediator (individual scales of the Brief-COPE) and outcome variable (IBS-QOL total score or Dysphoria subscale score). Considering the theoretical and statistical grounds for simple mediation testing, it was reasonable to suggest this method of analysis would not result in any increased likelihood of type I errors. Such errors may be commonly associated with performing multiple comparisons on a single dependent variable (e.g. Field, 2009), in using multiple *t*-tests for example. As stated, formal significance testing was conducted where simple mediation effects were detected from the Baron and Kenny steps (Preacher & Hayes, 2004). Further, as considered previously, each statistical model was analysed based on the theoretical suppositions of the CSM (e.g. Leventhal et al., 1998). In many cases, the predictor–outcome relationship was reported on successive occasions (and remained consistent) to highlight the change in 'predictor' Beta coefficient values on addition of a single Brief-COPE scale (chapter five).

### **3.7 Overview and Summary**

This chapter has considered the philosophical orientation of the research presented in subsequent chapters. A number of considerations related to what constitutes acceptable knowledge, how best to test the CSM in this context and the idea of adapting quantitative survey methodology to access qualitative data for analysis all determined the largely quantitative approach of this research. A power calculation and consideration of various research methodologies led to the conclusion that a web-based

study would be appropriate and the most effective and efficient way to gain the required number of participants. Web-based surveys have the additional benefit of relative ease in contacting participants for follow-up studies.

Consideration has been given to how the survey was structured online and how participants were recruited. The measures used were all considered to be reliable and valid measures of key constructs of the CSM (or an 'extended' CSM in the case of the BMQ and CAMBI). General statistical methods have been highlighted such as the key statistical analyses that are presented in later chapters as well as the procedure for testing for mediation according to Baron and Kenny (1986) and Preacher and Hayes (2004). Further statistical details are highlighted in subsequent chapters where appropriate. The following chapter presents the first part of the empirical research establishing which illness perceptions and treatment beliefs were influential in determining CAM use in those with IBS.

## Chapter 4

### **Applying the common-sense model of illness representations to the exploration of CAM use in IBS**

*This chapter presents findings from the web-based cross-sectional survey and thus provides a baseline for the subsequent analyses reported in chapters 5 and 6. Within the ‘extended’ common-sense model of illness representations, the chapter records an exploration of illness perceptions and treatment beliefs which are influential in CAM use and examines differences in representations between CAM-users and non-users.*

#### **4.1 Introduction**

Chapters one and two have shown there are both empirical and theoretical grounds for suggesting components of an extended CSM (e.g. Bishop et al., 2006; Horne & Weinman, 2002) can examine illness perceptions and treatment beliefs that are important in CAM use in IBS. There are no current peer-reviewed published studies that have investigated CAM use in IBS using the theoretical framework of the CSM. Furthermore, only a small number of studies have utilised the CSM framework to investigate CAM use and IBS and these have been conducted separately (Bishop et al., 2006; 2008; Rutter & Rutter 2002; 2007; Searle & Murphy, 2000). It is currently unknown which specific illness perceptions or treatment beliefs will be influential in CAM use in those with IBS. Therefore the research analysis presented in this chapter explored CAM use within the theoretical framework of an extended CSM to address research aim one (2.7.1), which was to explore which illness perceptions and treatment beliefs in those affected by IBS were influential in CAM use

The most recent data on CAM use in IBS suggests between 38.4% and 50% of those with IBS use CAM (Kong et al., 2005; van Tilburg et al.,



2008). Prevalence of IBS is between 10-20% in the UK (Wilson et al., 2004) and with CAM use reported as high as 50%, may suggest conventional medical treatment is not perceived as being effective at controlling IBS symptoms. Chapters one and two provided evidence of the influence of illness perceptions and treatment beliefs on CAM use in general populations (Bishop et al., 2006; 2008; Vincent & Furnham, 1996). Chapter one further illustrated that reporting of more symptoms (i.e. greater illness 'identity' in the context of the CSM) and psychological aspects related to the illness, such as anxiety and reported quality of life to be influential in CAM use (Donker et al., 1999; van Tilburg et al., 2008).

Such illness related perceptions (e.g. perceptions of treatment control) have also been shown to be important factors in symptom experience and maintenance in IBS (Drossman et al., 1999; Gomborone et al., 1995; Rutter & Rutter, 2002; van Dulmen et al., 1996; 1997; 1998). It may be theorised that such illness perceptions will influence whether those with IBS will use CAM. In the context of the extended CSM (figure 2.1), CAM use can be viewed as a coping behaviour (Searle et al., 2007) which will be influenced by representations of illness and treatment.

The main aim of this study was to investigate which illness perceptions and treatment beliefs are influential in CAM use. To fully explore this aim, four specific objectives were addressed:

4.1.1 To assess the prevalence of CAM use in IBS.

4.1.2 To examine which illness perceptions and treatment beliefs were related to use of more than one type of CAM.

4.1.3 To compare the illness perceptions and treatment beliefs of those with IBS in terms of those using and not using CAM.

4.1.4 To examine which illness perceptions and treatment beliefs predicted CAM use in IBS.

## **4.2 Method**

This component of the research was conducted according to the methodology outlined in detail in chapter three (sections 3.2 to 3.6). A web-based survey was conducted which recruited participants with IBS who completed a number of measures that captured illness perceptions and treatment beliefs. Participant responses were analysed for prevalence of CAM and associations with CAM use. Differences in CAM-user representations (compared to non-users) were examined and a logistic regression analysis was performed to predict which participants used CAM for their IBS based on a number of demographic and CSM based predictor variables.

### **4.2.1 Design**

A cross-sectional web-based survey was conducted as this method was reasoned to be the most appropriate to explore the study objectives. Conducting a web-based study offered the opportunity for large scale and diverse participant recruitment as many people use the internet to locate illness or health based information about specific health complaints and may be more likely to be interested in participating in a research study online (section 3.1.2.1). To address the specific objectives of examining components of the CSM, participant data were taken from IPQ-R, BMQ and the CAMBI. Demographic information was also collected (section 3.3.4).

### **4.2.2 Participants**

Six hundred and fifty three participants were recruited online from an IBS support network in the UK and IBS online discussion forums. There were a large number of visits recorded to the study website, albeit not every visit resulted in a completed survey. A completion rate figure was calculated from subtracting the number of completed surveys ( $n=653$ ) from the number of visits to the study website with incomplete survey responses ( $n=1246$ , see also section 3.2). The resulting figure represented a completion rate of 53%.

### **4.2.3 Measures**

The predictor and explanatory variables used in this study were measures of components of an extended CSM and demographic factors. As stated in the preceding chapter (see section 3.3.2), the Illness Perception Questionnaire Revised version (IPQ-R; Moss-Morris et al., 2002) was used as a measure of illness perceptions (which captures both cognitive and emotional aspects of illness). The Beliefs about Medicines Questionnaire general version (BMQ-general; Horne et al., 1999) was utilised to capture general beliefs about conventional medicines. The Complementary and Alternative Medicine Beliefs Inventory (CAMBI; Bishop et al., 2005) was used to capture beliefs about CAM. Participants were also asked for demographic information, including questions about how long they had IBS and if they had been diagnosed (section 3.3.4).

In terms of an outcome variable for the logistic regression analysis (section 4.2.5.4), participants were asked if they had used CAM to relieve their IBS. If they replied 'yes' they were asked which CAM treatments they had used (section 3.3.3.1). The number of CAM treatments used by each participant, who had indicated they had used CAM, was summed to help address research objective 4.1.2.

### **4.2.4 Procedure**

The survey was constructed on the internet using an online survey host. Participants were recruited online via advertisements placed on an IBS self-help network webpage and other IBS related online discussion forums (section 3.4). The advertisement (and message board postings) contained a direct 'one-click' link to the study website. Participants completed responses using their computer mouse and were guided through the study webpage via 'next' icons at the foot of each page of the survey. Full details of the study procedure are provided in section 3.4.

#### **4.2.5 Statistical methods**

Scale scores were computed for the IPQ-R, BMQ and CAMBI (section 3.3.2). Scales were evaluated by screening for outlying values and distributions of scale variables were assessed (Tabachnick & Fidell, 2007). Principal Components Analysis was conducted on the IPQ-R causal items to reduce the single eighteen items to identifiable scales for ease of entry into statistical analysis (section 4.2.5.3). Inferential statistical testing was conducted to assess differences between CAM-users and non-users (those not using CAM) using unrelated *t*-tests, illness perceptions and beliefs that are related to CAM use (Pearson's correlations) and factors that predicted CAM use in those affected by IBS using a logistic regression analysis (section 3.6).

##### **4.2.5.1 Computing instrument scales**

Prior to inferential statistical testing, the IPQ-R, BMQ and CAMBI scales were computed (section 3.3.2) which allowed for small numbers of missing values on each item. For the purposes of addressing the third question in this study (section 4.1), that is, to assess objective 4.1.2, a new variable was created to reflect the amount of CAM treatments that had been used. This variable was created by summing the number of specific CAM treatments (as well as any treatments documented in the 'other treatment' category, each of which counted as one treatment) as indicated by each of the participants that had used CAM.

##### **4.2.5.2 Data screening**

Data were screened for outlying values that may have unduly influenced inferential statistical tests (Tabachnick & Fidell, 2007, see also section 3.6). Prior to statistical testing illness perceptions and treatment belief IPQ-R, BMQ and CAMBI scales were screened for bivariate outliers (CAM-users and non-users). Outliers were detected in several variables visually by using box-plots. Outlying values were examined for any consistent patterns (e.g. the same participants or possible response set). All values however were found to be within the correct range of scores. To reduce the influence of outlying values on statistical findings, each

outlier was manually adjusted to make them 'less extreme' (Field, 2009; Tabachnick & Fidell, 2007), a process labelled 'winsorizing' (Erceg-Hurn & Mirosevich, 2008). The adjustment of outliers was attempted by adding or subtracting two standard deviations to (or from) the mean to replace outlying values (Field, 2009). Initial trials with this method proved unsuccessful as 'new' values did not fit appropriately with the range of scores in many cases. Satisfactory results were found by altering each outlying score to the next non-outlying value (Field, 2009). This method ultimately can reduce the size of standard errors and thus provide a more accurate measure of confidence intervals (Erceg-Hurn & Mirosevich, 2008) meaning results can be more successfully generalised.

The distributions for the IPQ-R, BMQ and CAMBI scales were assessed prior to further analysis (Tabachnick & Fidell, 2007). This was conducted visually by observation of histograms for both the CAM-users and non-users. Observation of histograms was conducted as in larger sample sizes (e.g. over 200) statistical testing of normality (e.g. the Shapiro-Wilk test) are especially sensitive to slight deviations from normality (Field, 2009; Tabachnick & Fidell, 2007). Examination of the histograms for the IPQ-R, BMQ and CAMBI scales revealed six scales that demonstrated skewed distributions. The two IPQ-R timeline sub-scales (chronic and cyclical), and emotional representations revealed a negative skew as did the illness coherence scale for CAM-users. CAM-users' scores in the CAMBI natural treatments and participation in treatment sub-scales also showed minor positive and negative deviations respectively.

#### ***4.2.5.3 Principal Components Analysis of IPQ-R causal items***

Principal Components Analysis (PCA) was conducted on the IPQ-R causal items. The large sample size of this study denoted that this was the best strategy to collapse the 18 items into smaller sub-scales and is consistent with previous research (e.g. Moss-Morris et al., 2002). PCA enabled causal items which were highly correlated to be grouped into 'new' scales (Tabachnick & Fidell, 2007).

In the performance of PCA, IPQ-R causal items were initially screened for identifiable correlations present in the data as a means of testing the data for suitability for PCA (Tabachnick & Fidell, 2007). SPSS provided a Kaiser-Meyer-Olkin (KMO) statistic of sampling adequacy which represented the ratio of the squared correlations between variables (scale items) to the squared partial (i.e. controlling for the effect of other variables) correlation (Field, 2009; Tabachnick & Fidell, 2007). A KMO statistic of sampling adequacy should be above .5 (from a range of 0-1), suggesting that data in this study (KMO=.86) were compact enough to yield a reliable set of components (Field, 2009; Tabachnick & Fidell, 2007). Further exploration of data suitability for PCA resulted in a Bartlett's (Chi-square) statistical value of  $\chi^2 = 3043.42$ ,  $df = 136$ ,  $p < .001$  meaning the data contained correlations suitable for detection through PCA. Bartlett's test of Sphericity should result in a significant value ( $p < .05$ ) to confirm data has identifiable correlations suitable for PCA (Field, 2009).

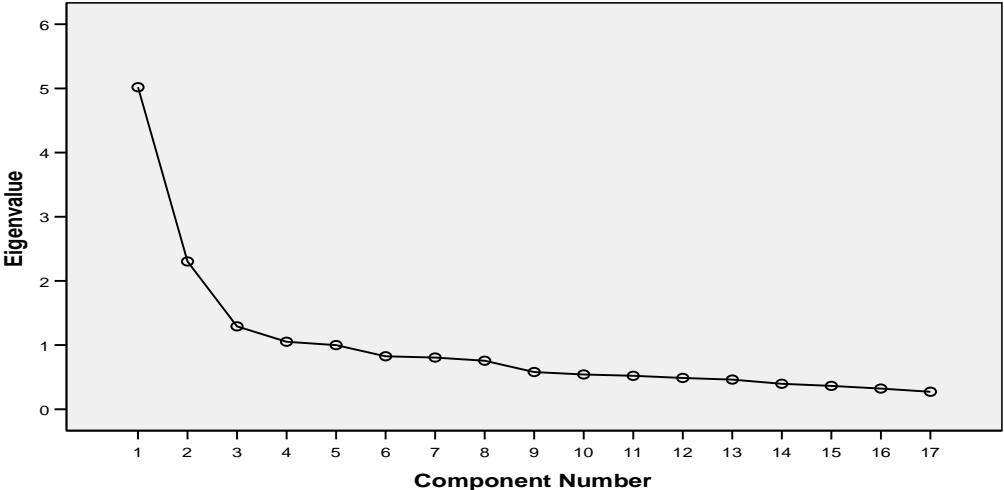
The number of components that were extracted and retained following PCA was determined by a combination of statistical criteria and subjective judgement of the researcher (e.g. Field, 2009). Oblimin rotation of the factor solution was selected as it was probable that there would be some degree of correlation between groups of causal items of the IPQ-R. Oblimin rotation allows for some correlation between resulting components (Field, 2009; Tabachnick & Fidell, 2007). Following PCA using Oblimin rotation, a three component resolution to the IPQ-R cause scale was determined. Firstly, the Scree plot (figure 4.1) was examined to determine the point of inflexion of the graph. Second, the number of components with an Eigenvalue (expressing the amount of variance explained by that component) greater than one were observed. Third, individual causal items were considered if items loaded onto more than one component. This assisted the researcher in making a judgement about which items were inherently related and how many factors there should be in the final solution. Finally, internal reliability

(Cronbach's alpha) was considered. A Cronbach's alpha value closer to 1 (ranging from 0 to 1) means greater internal reliability in a scale. Generally, minimum values of .6 to .7 are deemed acceptable (Bryman, 2008; Field, 2009); however there is some argument that uniform values of alpha may be problematic. Scales consisting of many items often give larger alpha values than scales with fewer items. Kline (1999) argues that values below the often accepted norm of .7 can be deemed acceptable due to the variation in psychological constructs and number of items that make up measure scales (Kline, 1999). As there was little variation in the numbers of items in each component from the PCA, the recommendations on Cronbach's alpha values from Bryman (2008) and Field (2009) were implemented.

Table 4.1 shows the percentage of variance in scores from each of the three components. Causal item two, referring to 'heredity' did not load strongly on any of the components and so was excluded from further analysis. Component one accounted for 29.82% of the variance and items associated with a psychological cause. This component was thus labelled 'Internal causes' as the items reflect aspects that are all under the individual's control. The alpha value was also acceptable at .86, and between the CAM-users and non-users participants' alpha reached acceptability at .88 and .84 respectively. Component two accounted for 13.95% of the variance and contains items that can be considered external to the individual such as 'a germ' or 'virus' and 'poor medical care in the past.' This component was thus labelled 'External causes' and had an acceptable alpha value of .64, with similar alpha values for CAM-users (.61) and non-users (.67). The third component accounted for 7.34% of the variance with an acceptable alpha value of .68 and consisted of items that could be classed as 'risk factors' such as 'smoking' or 'accident or injury.' The alpha values for CAM-users (.67) and non-users (.70) also suggested acceptable internal consistency for these scales.

As illustrated in table 4.1 a number of items loaded onto more than one component, namely items 1, 4, 8, 13, and 18. An item was judged to be loading on a particular component if the figure was greater than the corresponding loading on a different component. Each item also had to theoretically 'fit' with the other items in the component, which was assessed by observing the causal items from the IPQ-R. Again, this was consistent with previous work with the IPQ-R (Moss-Morris et al 2002). Consideration of Cronbach's alpha for each component were deemed acceptable with all scales having internal reliability of .61 or greater. As Oblimim rotation was conducted, correlations between components were assessed to check they were not too highly correlated where it could be inferred components would be measuring the same construct (Field, 2009; Tabachnick & Fidell, 2007). The 'internal' and 'external' causes components were weakly positively correlated (.10). The 'internal causes' and 'risk factors' components showed a weak negative correlation (-.34). The 'external' causes and 'risk factors' components demonstrated a similar pattern (-.25). These low coefficients and direction of the negative relationships were sufficient to infer relative independence of the three casual components derived from the PCA.

**Figure 4.1 Scree plot derived from Principal Components Analysis of causal items from IPQ-R**





#### **4.2.5.4 Statistical tests**

Section 3.6.3 outlined the rationale for conducting inferential parametric tests. The consistent reliability and validity of the measures used in this study and the large sample size enabled parametric testing to be carried out. To ensure greater accuracy, statistical tests were run on a list-wise basis. This meant that any participant with missing data on any of the variables included in a particular test was omitted from the analysis (see section 3.6.1).

Firstly, prevalence of CAM use was assessed comparing frequencies of those who had used CAM and those who had not. This was explored further by gender and by type of CAM. To address the second question, a new variable was computed (applicable only to CAM-users) that reflected the total number of CAM treatments used, as many participants had indicated they had used more than one type of CAM to relieve their IBS symptoms. This variable was created by summing the number of CAM treatments that had been used (in addition to the 'other' category) to enable associations to be explored between illness perceptions, treatment beliefs and number of CAM treatments used. To examine this question a Pearson's correlation was conducted. Even though a small number of variables demonstrated a slight deviation from normality, a Pearson's correlation was conducted as this test is regarded to be robust against the violation of non-normality with sample sizes greater than 40 (Field, 2009). There is also argument normality in variable distributions is unnecessary in calculating Pearson's  $r$  (Nefzger & Drasgow, 1957).

To address the question of whether the CAM-users and non-users (participants who have not used CAM) differed on measures of illness perceptions and treatment beliefs independent  $t$ -tests were conducted (section 3.6). The  $t$ -test was employed as it is considered to be robust against violations in the assumption of normal distributions between grouping dependent variables (Vickers, 2005) without giving rise to an increased likelihood of Type 1 errors. Where results were significant, effect sizes were calculated using Pearson's  $r$ , which offered a

standardised estimate of the magnitude of differences between each of the paired group means (Field, 2009). In using Pearson's  $r$  as a measure of effect size, Field (2009) states that effect size values are typically classified as small (.1), medium (.3) or large (.5).

**Table 4.1 Pattern coefficients resulting from Principal Components Analysis on IPQ-R causal items**

<i>IPQ-R Causal item</i>	<i>Internal Cause</i>	<i>External Cause</i>	<i>Risk Factors</i>
C12 – Emotional state	<b>.87</b>		
C10 – Family problems/worry	<b>.82</b>		
C9 – Mental attitude	<b>.77</b>		
C1 – Stress/worry	<b>.75</b>	-.22	
C11 – Overwork	<b>.69</b>		
C17 – Personality	<b>.65</b>		
C8 – Own Behaviour	<b>.54</b>		-.23
C7 – Pollution in environment		<b>.65</b>	
C6 – Poor past medical care		<b>.62</b>	
C3 – Germ or virus		<b>.66</b>	
C18 – Altered immunity		<b>.65</b>	-.23
C5 – Chance or bad luck		<b>.38</b>	
C13 – Ageing	.27	<b>.31</b>	-.28
C14 – Alcohol			<b>-.84</b>
C15 – Smoking			<b>-.84</b>
C16 – Accident/Injury			<b>-.65</b>
C4 – Diet or eating habits	.34		<b>-.38</b>
Eigen Value	<b>5.07</b>	<b>2.37</b>	<b>1.25</b>
% of variance	<b>29.82</b>	<b>13.95</b>	<b>7.34</b>
Cronbach's alpha Whole sample	<b>.86</b>	<b>.64</b>	<b>.68</b>
CAM-users	<b>.88</b>	<b>.61</b>	<b>.67</b>
Non-users	<b>.84</b>	<b>.67</b>	<b>.70</b>

Component/Factor loadings are indicated in bold. Factor loadings less than .2 are not reported which is consistent with samples of this size (e.g. Field, 2009).

A binary logistic regression analysis was performed to illustrate which factors predicted CAM use, whilst controlling for other variables in the model (Tabachnick & Fidell, 2007). The dichotomous dependent variable in this study was determined from participants being asked if they had used CAM to relieve their IBS ever (Yes or No). The logistic regression model was constructed to allow inclusion of illness

perceptions and treatment beliefs with the minimum amount of demographic variables. It is common with this particular statistical procedure to use a 'minimum' amount of predictor variables (Tabachnick & Fidell, 2007). To minimize the number of demographic variables in the regression model, variables that were either heavily biased in one category or had very low numbers of information in particular categories were not included in the analysis. Therefore, gender, diagnosis of IBS, religious affiliation, ethnicity, geographical location and employment status were all excluded from the regression model. The demographic predictor variables that were retained were income, education, age, time of diagnosis and co-morbidity reported (yes/no). Binary logistic regression allowed construction of a statistical model that could predict the dichotomous outcome of CAM use or no CAM use (see section 3.6) by entering variables hierarchically in two blocks. This allowed the effect of demographic variables on CSM measures to be observed statistically. Following examination of the findings, diagnostic procedures were performed to assess for multicollinearity, outlying and residual values as well as any cases with undue influence on the model (Tabachnick & Fidell, 2007).

### **4.3 Results**

This analysis examined which illness perceptions and treatment beliefs in IBS were influential in CAM use. This was achieved by taking participant measures from instruments designed to capture illness perceptions (IPQ-R), treatment beliefs (BMQ-general) and beliefs about complementary medicines (CAMBI). Participants were asked about CAM use and demographic information was collected.

The results are presented according to the four objectives in section 4.1. Firstly, the prevalence of CAM use was examined (objective 4.1.1). Secondly, the relationship of the IPQ-R, BMQ and CAMBI scales with number of CAM treatments used in the CAM-users was tested (objective 4.1.2). Thirdly, differences between CAM-users and the non-users on scales of the IPQ-R, BMQ and CAMBI (and age) were considered

(objective 4.1.3). Finally, a logistic regression analysis of illness perceptions and treatment beliefs and demographic factors in predicting CAM use in IBS was performed (objective 4.1.4).

#### **4.3.1 Participant demographics**

The age range of participants was 18-83, with 83.6% ( $n=546$ ) being female with 8 missing cases in this category. The mean age overall was 37.41 years ( $SD=12.95$ ). The mean age for males was 41.97 ( $SD=14.13$ ) years, which was higher than females where the mean age was 36.48 years ( $SD=12.53$ ). A further breakdown of age by gender and CAM use is illustrated in table 4.2.

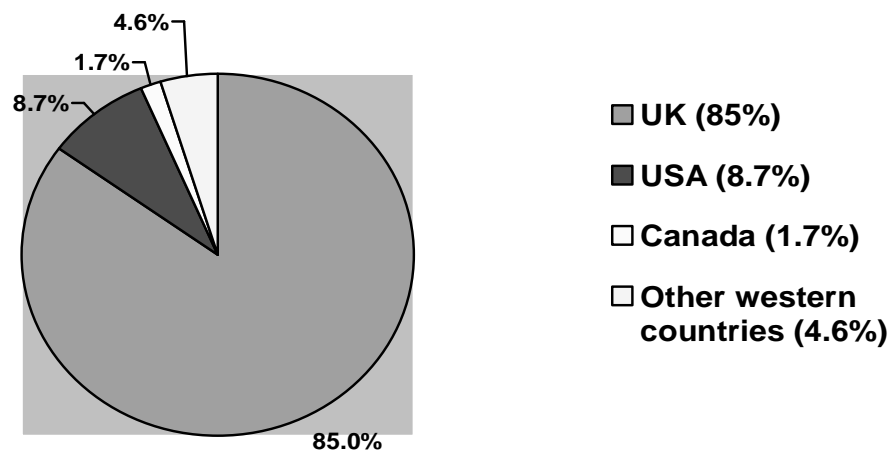
**Table 4.2 Participant mean ages, split by gender and CAM use**

	CAM use Mean (SD)	
	Yes	No
<b>Male</b>	41.61 (13.98)	42.31 (14.41)
<b>Female</b>	36.63 (12.29)	36.26 (12.89)
<b>Total</b>	37.35 (12.60)	37.47 (13.42)

Key categorical demographics are illustrated in table 4.3. Participants were asked if they had been diagnosed with IBS by a health care professional, with most participants (93.7%,  $n=610$ ) stating they had been diagnosed with IBS. Two hundred and forty nine (40.8% approximately) participants had been diagnosed over 5 years ago, with approximately 24.9% ( $n=124$ ) being diagnosed in the last 12 months to asking. Furthermore, over half (62%,  $n=402$ ) of participants stated that they had been living with IBS symptoms for over 5 years (table 4.3). When asked if they were taking prescribed medication for their IBS, approximately 56% ( $n=362$ ) stated 'yes' with 285 stating 'no'. Table 4.3 also illustrates that approximately 71.4% ( $n=455$ ) were employed with

the largest percentage of approximately 23.6% ( $n=137$ ) of participants indicating they had £20,000-£29,000 (or equivalent) household income. Approximately 78% of participants had educational qualifications ranging from GCSEs or 'O' levels to first degree. There were more participants that reported suffering from other conditions (co-morbidity) (58.2%,  $n=380$ ) than reported no co-morbidity (41.1%,  $n=273$ ).

**Figure 4.2 Pie chart illustrating geographical location of participants (percentage of the whole sample)**



In terms of geographical location, most participants were from the UK (85%), 8.7% were from the US and 1.7% from Canada (figure 4.2). Other countries accounted for less than 1% of the sample individually and 4.6% overall. In terms of ethnic groupings, approximately 94% were white British, white Irish or other white background. Religious groupings were either mainly 'Christian' (52%) or 'none' (34%) with other religious groups represented by small numbers of participants. The large proportion of Christian and no-religion in the sample perhaps reflect that the majority of participants were of a white ethnic background, many of whom were British or Irish.

#### **4.3.2 Extent of CAM use in IBS**

Approximately 57% of participants ( $n=373$ ) reported that they had used CAM to relieve the symptoms of IBS either currently or in the past and many had used more than one form of CAM (*figure 4.3*). CAM use in males accounted for 15.3% of CAM-users, with females accounting for 84.7%. Table 4.3 also offers a demographic breakdown of CAM use by frequency. Notably, selected categories in income and time of diagnosis demonstrated higher CAM use. This will be explored further in subsection 4.3.6. Over twenty three percent (23.6%) of CAM-users had visited a CAM practitioner at least once in the last 12 months. Approximately 75% of the CAM group had purchased their own CAM 'off the shelf' and 34.9% had been directed to take CAM by a CAM practitioner. The most popular CAM treatments with CAM-users were herbal treatments (used by 45.3% of CAM-users), massage (27.9%), aromatherapy (24.7%) and Bach flower remedies (22%). Approximately 20% of participants each used homeopathy, meditation, yoga, talk therapies (e.g. counselling) and relaxation techniques. Fifteen percent of CAM-users used acupuncture and nutritional therapy. Approximately 13% indicated use of hypnosis and reflexology to relieve their IBS symptoms (*figure 4.3*).

#### **4.3.4 Age, IPQ-R, BMQ and CAMBI scale associations with number of CAM treatments used**

To assess relationships between illness and treatment representations and CAM use, the total number of CAM treatments used was calculated from summing the number of treatments used by each participant in the CAM group. This was to enable further exploration of these data. Table 4.4 illustrates the Pearson's correlations for age, the scales of the IPQ-R, BMQ and CAMBI with the number of CAM treatments used in the CAM group.

A number of components in the 'extended' CSM were found to be related to number of CAM treatments used. Age was positively related to number of CAM treatments used ( $r=.12$ ,  $p<.05$ ), as was beliefs in

overuse of medicines ( $r=.15$ ,  $p<.01$ ). The strongest correlation was between the BMQ harm scale and number of CAM treatments used ( $r=.28$ ,  $p<.001$ ) suggesting stronger beliefs in potential harm of conventional medicines led to more CAM use. Holistic health beliefs ( $r=.24$ ,  $p<.001$ ), beliefs about active participation in treatment ( $r=.10$ ,  $p<.05$ ) and that treatments should be natural ( $r=.24$ ,  $p<.001$ ) were all positively correlated with an increasing number of CAM treatments. There were no significant associations between dimensions of the IPQ-R and number of CAM treatments used.

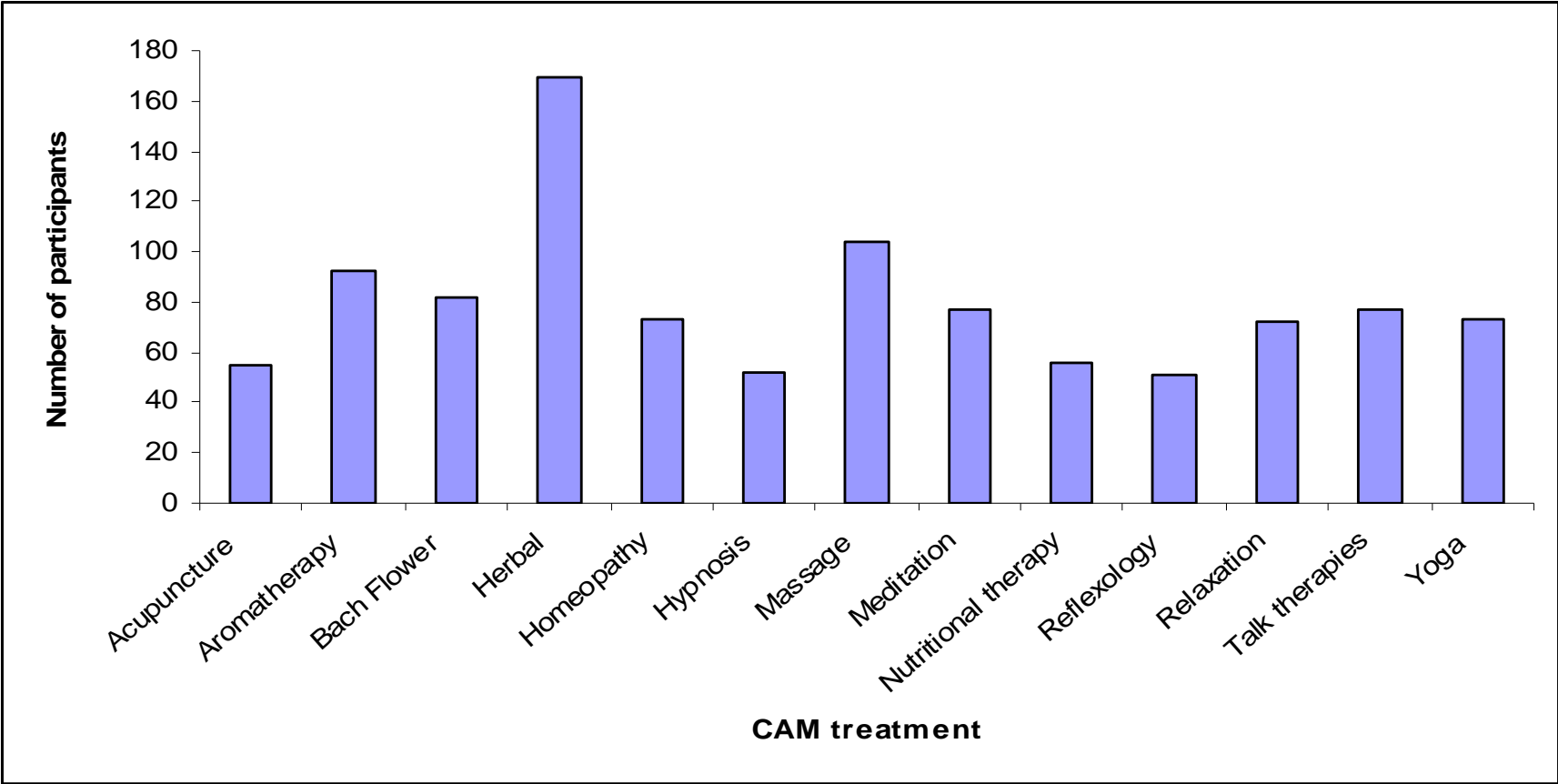
**Table 4.3 Key participant demographic data by category and extent of CAM use (n=653)**

<i>Variable</i>	<i>Category</i>	<i>Number (%)</i>	<i>CAM use%*</i>		
			<i>Y</i>	<i>N</i>	
<b>Gender</b>	Male	99 (15.3)	49.5	50.5	
	Female	546 (84.7)	58.6	41.4	
<b>Diagnosis</b>	Yes	610 (93.7)	57.9	42.1	
	No	41 (6.3)	46.3	53.7	
<b>Time diagnosed</b>	Less than 12 months	152 (24.9)	43.4	56.6	
	1-2 years	69 (11.3)	56.5	43.5	
	2-3 years	71 (11.6)	54.9	45.1	
	3-4 years	37 (6.1)	73.0	27.0	
	4-5 years	32 (5.2)	62.5	37.5	
	Over 5 years	249 (40.8)	64.7	35.3	
	<b>Time with symptoms</b>	Less than 12 months	33 (5.1)	48.5	51.5
		1-2 years	45 (6.9)	42.2	57.8
2-3 years		74 (11.4)	47.3	52.7	
3-4 years		53 (8.2)	58.5	41.5	
4-5 years		41 (6.3)	56.1	43.9	
Over 5 years		402 (62.0)	61.2	38.8	
<b>Currently taking prescribed medication</b>		yes	362 (56.0)	61.8	38.2
		no	285 (44.0)	53.9	46.1
<b>Employed</b>	yes	455 (71.4)	52.2	47.8	
	no	182 (28.6)	59.3	40.7	
<b>Income</b>	up to £9999	58 (10.0)	63.8	36.2	
	£10,000 - 14,999	69 (11.9)	39.1	60.9	
	£15,000 - £19,999	53 (9.1)	73.6	26.4	
	£20,000 - £29,000	137 (23.6)	60.6	39.4	
	£30,000 - £39,999	97 (16.7)	53.6	43.4	
	£40,000 - £49,999	67 (11.5)	53.7	46.3	
	£50,000 and above	100 (17.2)	58.0	42.0	
	<b>Education</b>	GCSE's, O' levels or equivalent	164 (25.5)	53.7	46.3
A Levels or equivalent		167 (25.9)	62.9	37.1	
First Degree (BA, BSc)		174 (27.0)	59.2	40.8	
Postgraduate qualification		86 (13.4)	61.6	38.4	
No qualifications		53 (8.2)	41.5	58.5	
<b>Co-morbidity reported</b>		Yes	380 (58.2)	58.9	41.1
	No	273 (41.8)	54.6	45.4	

\* Percentages are corrected for missing values



Figure 4.3 Bar graph illustrating reported use of most popular CAM treatments in CAM-users with IBS (n=373)



**Table 4.4 Pearson correlations of IPQ-R, BMQ and CAMBI scales with number of CAM treatments used (n=361)**

<i>Scale</i>	<i>Pearson Correlation with number of CAM treatments used</i>
Age	.12*
Identity	.04
Timeline Chronic	-.04
Timeline Cyclical	.10
Consequences	.08
Personal control	.10
Treatment control	.09
Illness coherence	.01
Emotional representations	.05
Internal cause	.07
External cause	.08
Cause - risk factors	.09
BMQ Harm	.28***
BMQ Overuse	.15**
CAMBI Natural treatments	.21***
CAMBI treatment participation	.10*
CAMBI holistic health	.24***

\*p<.05 \*\* p<.01 \*\*\*p<.001

#### **4.3.5. Group differences in age, IPQ-R, BMQ and CAMBI scales**

Table 4.5 shows descriptive statistics for illness perceptions and treatment beliefs scale variables and *t*-tests for differences between the CAM-users and non-users. Several BMQ, CAMBI and IPQ-R scales were significantly different according to whether CAM was used or not. Furthermore, Levene's test revealed those scales that were significantly different based on CAM use/no-CAM use did not violate the assumption of equal variances in each group. Table 4.5 also demonstrates all the scales had acceptable alpha values above .6 when examined according to the two groups, CAM-users or non-users. Figures 4.4 and 4.5

illustrate bar graphs to show significant mean differences visually with error bars highlighting plus or minus one standard deviation relative to each group mean.

#### **4.3.5.1 Age and IPQ-R sub-scales**

A significantly stronger illness identity ( $M=6.40$ ,  $SD=2.76$ ) was found in those with IBS in CAM-users than in non-users ( $M=5.60$ ,  $SD=2.76$ ),  $t(608)= -3.54$ ,  $p<.001$  suggesting CAM-users experienced more symptoms from the general symptom list from the IPQ-R. A stronger perception of a cyclical timeline was found in the CAM-users ( $M=15.34$ ,  $SD=2.71$ ) than non-users ( $M=14.76$ ,  $SD=2.89$ ),  $t(608)= -2.56$ ,  $p<.05$ . CAM-users ( $M=22.39$ ,  $SD=4.28$ ) also reported perceived stronger consequences of their IBS scoring significantly higher on perceptions of consequences of their IBS than non-users ( $M=20.90$ ,  $SD=4.63$ ),  $t(608)= -4.08$ ,  $p<.001$ . Non-users' emotional representations of their IBS were significantly lower ( $M=21.54$ ,  $SD=5.31$ ) than CAM-users ( $M=22.87$ ,  $SD=4.92$ ),  $t(608)= -3.21$ ,  $p<.01$ . These figures are shown in table 4.5.

There were several IPQ-R scales that were not significantly different based on grouping participants into CAM-users and non-users. All but one of these scales also satisfied assumptions of equal variances when compared as groups using Levene's test. There were no significant differences between CAM-users ( $M=37.11$ ,  $SD=12.63$ ) and non-users ( $M=37.33$ ,  $SD=13.52$ ) in terms of age,  $t(608)= .21$ ,  $p>.05ns$ . There was also no difference between CAM-users ( $M=24.96$ ,  $SD=3.81$ ) and non-users ( $M=24.65$ ,  $SD=3.75$ ) in perceptions of chronicity of IBS,  $t(608)= -1.03$ ,  $p>.05ns$ . In terms of perceptions about control, non-users ( $M=19.41$ ,  $SD=4.36$ ) showed no significant difference when compared to CAM-users ( $M=19.65$ ,  $SD=4.65$ ) on ratings of personal control,  $t(608)= -.60$ ,  $p>.05ns$ . On ratings of treatment control, there was also no difference between CAM-users ( $M=14.40$ ,  $SD=3.93$ ) and non-users ( $M=14.22$ ,  $SD=3.81$ ),  $t(608)= -.56$ ,  $p>.05ns$ . Testing the three causal dimensions of the IPQ-R also revealed no significant differences between the two groups. There was no significant difference between

CAM-users ( $M=21.82$ ,  $SD=6.35$ ) and non-users ( $M=21.16$ ,  $SD=5.78$ ) on perceptions of internal causes (e.g. stress),  $t(608)= -1.31$ ,  $p>.05ns$ . Similarly, CAM-users ( $M=14.86$ ,  $SD=3.84$ ) and non-users ( $M=14.84$ ,  $SD=4.02$ ) were not significantly different on ratings of external causes of their IBS (e.g. viruses),  $t(608)= -.08$ ,  $p>.05ns$ . This was also the case for perceptions of risk factors (e.g. smoking), where CAM-users ( $M=9.41$ ,  $SD=3.14$ ) and non-users ( $M=9.80$ ,  $SD=3.10$ ) showed no significant differences,  $t(608)= 1.50$ ,  $p>.05ns$ . Levene's test revealed that the illness coherence scale was the only scale to not have equal variances between the two groups ( $F=6.91$ ,  $p<.01$ ). The difference between CAM-users ( $M=14.17$ ,  $SD=5.42$ ) and non-users ( $M=13.92$ ,  $SD=4.76$ ) on this scale was also not significant:  $t(591.08)= -.60$ ,  $p>.05$ .

#### **4.3.5.2 BMQ and CAMBI sub-scales**

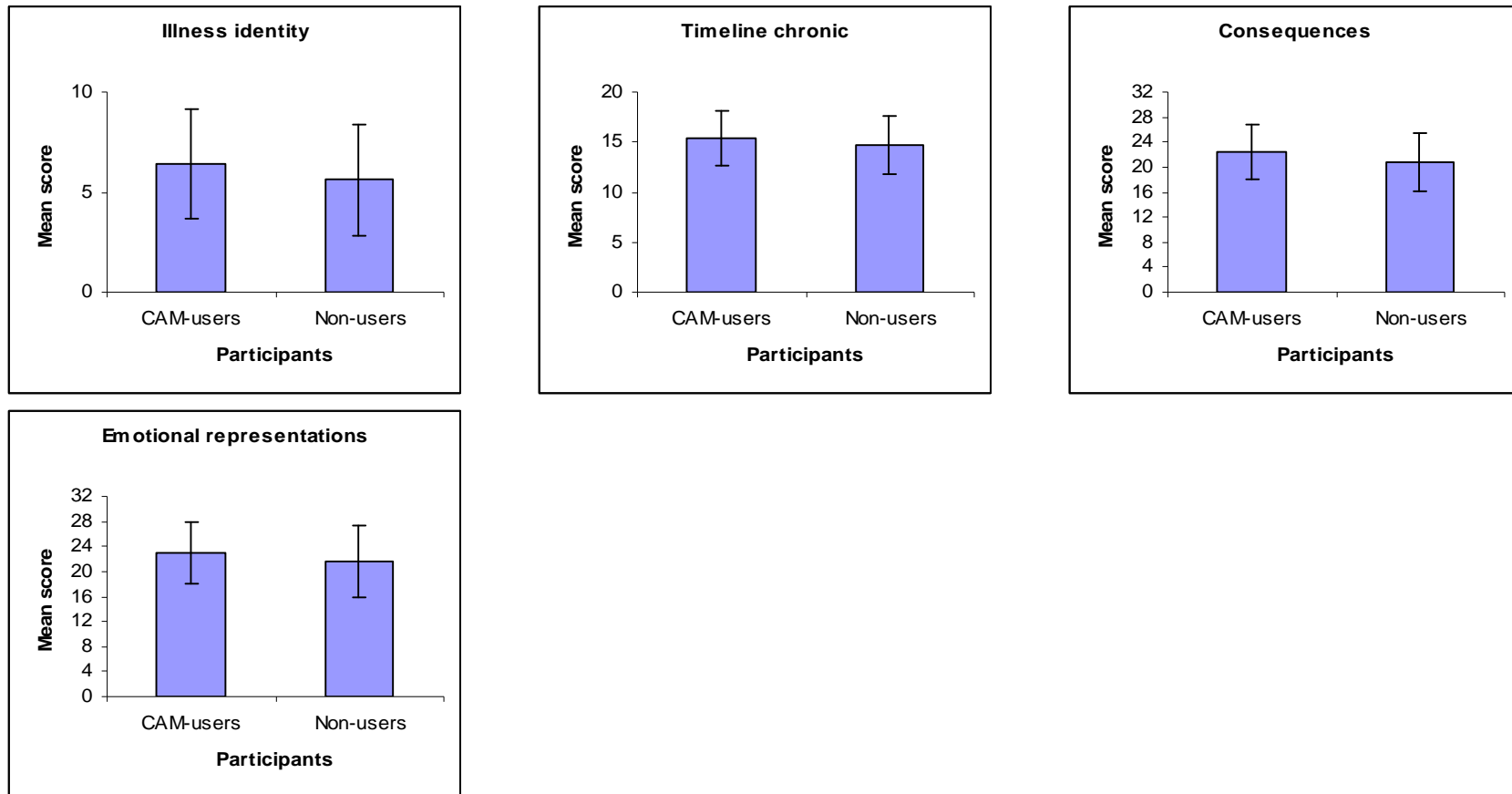
Table 4.5 shows CAM-users had stronger beliefs in possible harmful effects of conventional medicines ( $M=13.00$ ,  $SD=3.14$ ) compared to the non-users ( $M=11.91$ ,  $SD=3.14$ ),  $t(608)= -4.18$ ,  $p<.001$ . CAM-users had significantly more positive beliefs about natural treatments ( $M=22.08$ ,  $SD=3.43$ ) than non-users ( $M=21.40$ ,  $SD=3.28$ ),  $t(608)= -2.49$ ,  $p<.05$ . This was also the case for beliefs regarding participation in treatment, where CAM-users had significantly stronger beliefs regarding 'patient' or client participation in treatment ( $M=19.66$ ,  $SD=2.67$ ) than non-users ( $M=19.02$ ,  $SD=2.73$ ),  $t(608)= -2.89$ ,  $p<.01$ . Non-users also had significantly less strong beliefs about holistic health ( $M=21.25$ ,  $SD=3.64$ ) than CAM-users ( $M=22.07$ ,  $SD=3.48$ )  $t(608)= -2.81$ ,  $p<.01$ . Finally, the BMQ overuse scale also revealed no significant differences between CAM-users ( $M=10.13$ ,  $SD=2.87$ ) and non-users ( $M=9.80$ ,  $SD=2.87$ ),  $t(608)= -1.43$ ,  $p>.05ns$ .

**Table 4.5 Descriptive statistics and *t*-tests for differences on scale variables between CAM-users and non-users with IBS**

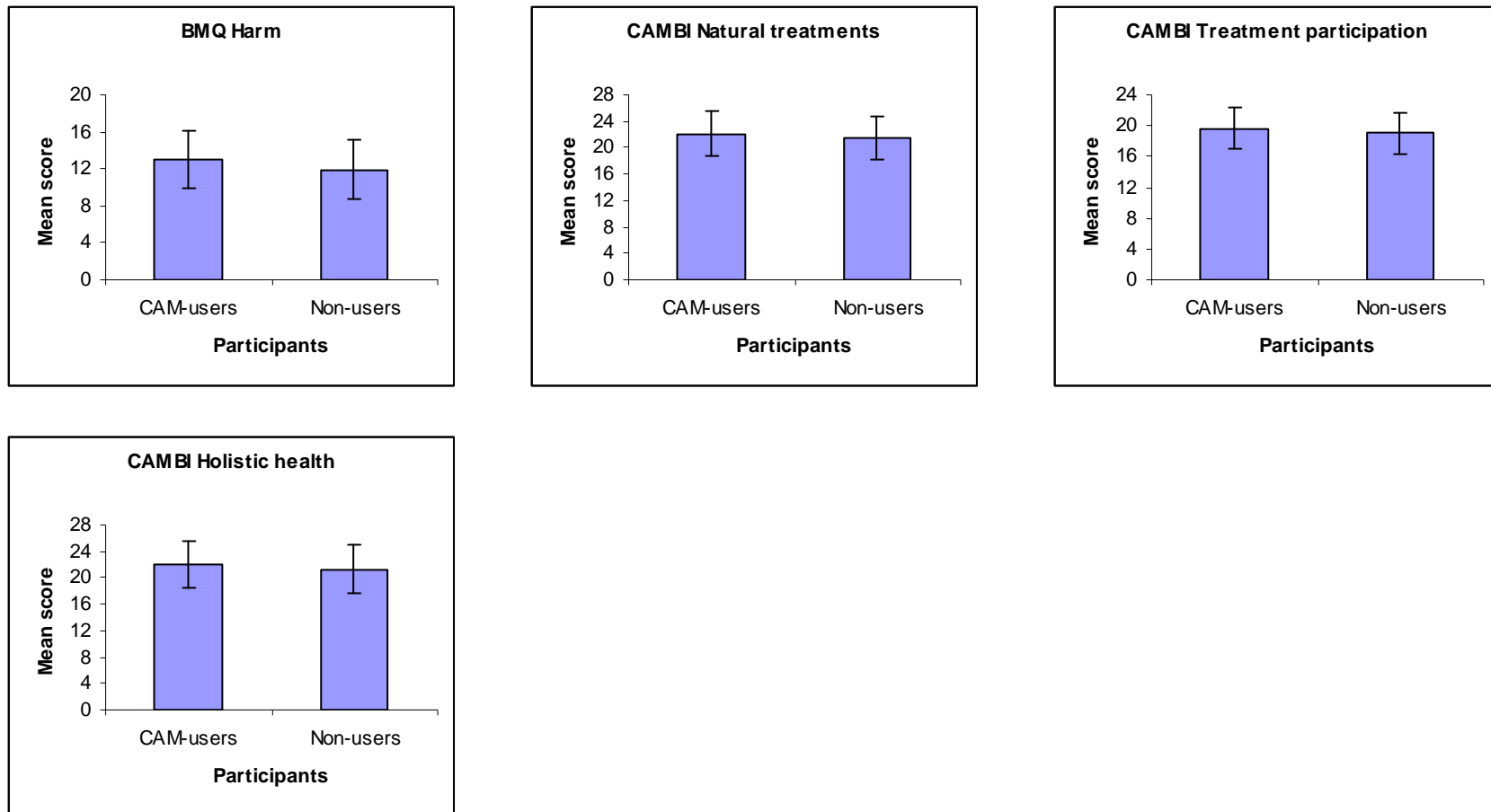
<i>Variable</i>	<i>CAM use y/n</i>	<i>Cronbach's alpha</i>	<i>Mean</i>	<i>SD</i>	<i>t-value (effect size 'r')</i>
Age	No (n=260)	N/A	37.33	13.52	.21
	Yes (n=350)	N/A	37.11	12.63	
Identity	No	N/A	5.60	2.76	<b>-3.54*** (r=.13)</b>
	Yes	N/A	6.40	2.76	
Timeline Chronic	No	.83	24.65	3.75	-1.03
	Yes	.81	24.96	3.81	
Timeline Cyclical	No	.68	14.76	2.89	<b>-2.56* (r=.10)</b>
	Yes	.64	15.34	2.71	
Consequences	No	.82	20.90	4.63	<b>-4.08*** (r=.15)</b>
	Yes	.81	22.39	4.28	
Personal control	No	.84	19.41	4.36	-.60
	Yes	.84	19.65	4.65	
Treatment control	No	.84	14.22	3.81	-.56
	Yes	.78	14.40	3.93	
Illness coherence	No	.90	13.92	4.76	-.60
	Yes	.92	14.17	5.42	
Emotional representations	No	.89	21.54	5.31	<b>-3.21** (r=.13)</b>
	Yes	.87	22.87	4.92	
Internal cause	No	.84	21.16	5.78	-1.31
	Yes	.88	21.82	6.35	
External cause	No	.67	14.84	4.02	.08
	Yes	.61	14.86	3.84	
Cause - risk factors	No	.70	9.80	3.10	1.50
	Yes	.67	9.41	3.14	
BMQ Harm	No	.77	11.91	3.14	<b>-4.18*** (r=.17)</b>
	Yes	.75	13.00	3.18	
BMQ Overuse	No	.77	9.80	2.87	-1.43
	Yes	.73	10.13	2.87	
CAMBI Natural treatments	No	.83	21.40	3.28	<b>-2.49* (r=.10)</b>
	Yes	.84	22.08	3.43	
CAMBI treatment participation	No	.73	19.02	2.73	<b>-2.89** (r=.11)</b>
	Yes	.69	19.66	2.67	
CAMBI holistic health	No	.71	21.25	3.64	<b>-2.81** (r=.11)</b>
	Yes	.69	22.07	3.48	

\**p*<.05 \*\**p*<.01 \*\*\**p*<.001 (Effect sizes *r*=.1 weak, *r*=.3 moderate, *r*=.5 strong)

**Figure 4.4 Bar graphs illustrating significant differences between CAM-users and non-users on IPQ-R scales**



**Figure 4.5 Bar graphs illustrating significant differences between CAM-users and non-users on BMQ and CAMBI scales**



In comparing significant differences between CAM-users and non-users, CAM-users' scores reflected reporting of stronger illness perceptions and more negative beliefs about harm of conventional medical treatment. CAM-users did, however, report significantly more positive beliefs on the CAMBI scales. A measure of effect size (Pearson's  $r$ ) was calculated for each of the significant differences on scales between CAM-users and non-users. The effect sizes reported (table 4.5) were mostly small which is most likely to be a product of the large sample size in this study. As sample sizes increase, typically, measures of effect size will decrease (Clark-Carter, 2007).

#### ***4.3.6 Predicting CAM use from demographic factors and scales of the IPQ-R, BMQ and CAMBI***

Binary logistic regression was conducted to examine which demographic factors and scales of the IPQ-R, BMQ and CAMBI may predict CAM use. As stated, certain demographic variables were omitted from the analysis on the basis of being heavily weighted in one or more sub-categories (section 4.2.5). SPSS version 17 also conducts logistic regression on a 'list-wise' basis. This resulted in participants being excluded from the analysis if there were any missing values on variables included in the regression model. This resulted in  $n=513$  for this analysis. Categorical predictor variables were selected with the first category in each case as the reference point using the 'indicator' option for categorical variables in SPSS.

A summary of the regression coefficients which predicted CAM use can be found in table 4.6. The final regression model was able to predict which participants would use CAM and those that were not CAM-users in 63.4% of the sample. This meant that 36.6% of participants were misclassified as either being a CAM-user when they did not use CAM or the opposite was true. Variables were entered in two blocks. Demographic and clinical factors were entered in block one and IPQ-R, BMQ and CAMBI scales were entered in block two.



#### **4.3.6.1 Relative contribution of demographic and CSM variables**

Block one, which contained demographic and clinical factors was able to predict between 9.2 and 12.4% of the variance in CAM use. To assess how well the logistic regression model fitted the data a number of criteria were assessed (Field, 2009; Tabachnick & Fidell, 2007). First, the Omnibus test was assessed to detect a relatively low, but statistically significant, value of Chi-square ( $\chi^2$ ) which would indicate a good fit for the regression model. The Omnibus test was significant, meaning the logistic regression model was a good fit for the data ( $\chi^2(18) = 49.52, p < .001$ ). The Hosmer and Lemeshow (2000) test was also examined which assessed linearity between scale predictor variables and the log-likelihood of the outcome, if linearity was present, the resulting value of  $\chi^2$  would be statistically non-significant. In this case, the Hosmer and Lemeshow test resulted in a non-significant result: ( $\chi^2(8) = 11.85, p > .05$ ) meaning that the required linearity between scale predictors and log-likelihood of the outcome was present.

The addition of the IPQ-R, BMQ and CAMBI in block two added approximately 10% to the variance predicted by the model overall. The combined blocks were able to predict between 17.0% and 22.9% of the variance in CAM use. Both the omnibus ( $\chi^2(34) = 95.68, p < .001$ ) and the Hosmer and Lemeshow tests ( $\chi^2(8) = 8.14, p > .05$ ) indicated the regression model was a good fit for the data. From these tests it was inferred that the required linearity between scale predictors and logit of the outcome was present for both blocks in the model.

#### **4.3.6.2 Contribution of demographic variables**

Examination of demographic predictor variables indicated that participants with income ranging from £10,000-£14,999 (compared to income of up to £9,999) were more likely not to be CAM-users with an odds ratio (OR) of .30. In terms of education, participants with 'A' levels or equivalent were more likely to be CAM-users than participants with GCSE/ 'O' level qualifications (OR = 1.89) as were participants with

postgraduate qualifications compared to GCSE/ 'O' levels ( $OR = 2.34$ ). Being diagnosed either 3-4 years ago ( $OR = 3.62$ ) or over 5 years ago ( $OR = 3.19$ ) (compared to being in the last 12 months) was also an indicator of whether someone would use CAM. Interestingly, the use of prescription medication and reporting co-morbidity were not significant predictors of CAM use (block one, table 4.6). Having no qualifications (compared to GCSEs or O' levels) resulted in a lesser likelihood of participants using CAM ( $OR = .93$ ), however the confidence intervals for the education category 'no qualifications' crossed the value of '1', making this particular odds ratio less reliable, therefore this finding should be interpreted with caution.

#### **4.3.6.3 Contribution of illness and treatment representations**

The combined model of blocks one and two resulted in the scales of identity, timeline cyclical, illness consequences, risk factors and beliefs about harm being constant as predictors of CAM use whilst controlling for demographic factors (table 4.6). The illness identity scale contributed an odds ratio of 1.07 meaning for every additional symptom reported participants were 1.07 times more likely to use CAM. The cyclical timeline scale of the IPQ-R resulted in an odds ratio of 1.08. This indicated that for every unit increase in perceptions regarding a cyclical timeline of IBS, participants were 1.08 times more likely to use some form of CAM. The 'illness consequences' scale was also a significant predictor of CAM use with an odds ratio of 1.07. This indicated that for every unit increase in the scale of illness consequences, there was 1.07 times greater likelihood that CAM would be used.

Beliefs in risk factors causing IBS (such as dietary factors or smoking) resulted in an odds ratio of .93. Every unit increase of risk as a cause resulted in participants being .93 times less likely to use CAM to relieve their IBS. Beliefs that conventional medicines can cause harm produced an odds ratio of 1.09, meaning that for every unit increase on the harm scale the likelihood of using CAM increase in odds by a factor of 1.09. In general, the odds ratios of demographic factors were larger than those of

the IPQ-R, BMQ and CAMBI scales indicating a larger individual contribution by the demographic factors to the predictive ability of the model.

#### ***4.3.7 Accuracy of logistic regression model***

There are several assumptions in logistic regression that were assessed to test if the model was a good fit for the data (Field, 2009; Tabachnick and Fidell, 2007). Firstly, multicollinearity amongst predictor variables should be absent. This means there should be no high correlations between predictor scale variables. This was assessed by running the analysis as a multiple regression procedure where the 'collinearity diagnostics' in SPSS could be assessed. This option gave a variance inflation factor (VIF) which should fall below 10 (e.g. Field, 2009). All relationships between scale predictor variables were safely in the parameters of this criterion as the VIF minimum and maximum values had a range of 1.09 to 2.07.

Second, residual values were assessed for potential outliers. Such values can affect the accuracy of the regression model so it is advisable to check the final solution for such values (Tabachnick & Fidell, 2007). It is expected that approximately 5% of values should have a z-score (a standardised residual value) of two or more. The logistic regression model presented here indicated only a small number (less than 1%) of values had a z-score outside this parameter, suggesting that there were no values causing undue influence on the model. There were however, two z-scores with a value greater than three. In any sample, it would be expected that 1% of values would fall into the category of having a standardised residual value of three or more (Field, 2009). Even though having two values with a z-score outside this parameter, this fell within accepted parameters for normally distributed residual values in regression (Field, 2009). Further diagnostic statistics were checked to ensure there was no undue influence on the model of these or other values.

**Table 4.6 Summary of logistic regression analysis of IPQ-R, BMQ, CAMBI scales and demographic factors in predicting CAM use in IBS**

Variable	Odds Ratio	95% Confidence Interval	
		Lower bound	Upper bound
<b>Block One</b>			
Prescribed medication (yes)	.75	.50	1.14
Age	1.00	.99	1.02
Income up to £9,999 (reference category)			
Income £10,000-14,999	<b>.30*</b>	.12	.73
Income £15,000-£19,999	1.17	.44	3.08
Income £20,000-£29,999	.69	.31	1.56
Income £30,000-39,999	.53	.23	1.22
Income £40,000-£49,999	.42	.17	1.06
Income £50,000+	.70	.30	1.66
Education: GCSE/O'levels (reference category)			
Education: A'levels	<b>1.89*</b>	1.07	3.32
Education: First degree	1.69	.95	2.98
Education: Postgrad	2.34	1.12	4.89
Education: No qualifications	<b>.93*</b>	.38	2.28
Diagnosed last 12 months (reference category)			
Diagnosed 1-2 years	1.86	.92	3.77
Diagnosed 2-3 years	1.84	.94	3.58
Diagnosed 3-4 years	<b>3.62*</b>	1.43	9.14
Diagnosed 4-5 years	1.88	.715	4.94
Diagnosed over 5 years	<b>3.19*</b>	1.86	5.49
Co-morbidity reported (yes)	1.23	.82	1.85
<b>Block Two</b>			
<b>IPQ-R scales:</b>			
Identity	<b>1.10*</b>	1.02	1.19
Timeline acute/chronic	.99	.93	1.06
Timeline cyclical	<b>1.08*</b>	1.00	1.16
Consequences	<b>1.07*</b>	1.00	1.14
Personal control	1.01	.95	1.08
Treatment control	1.06	.98	1.14
Illness coherence	1.01	.96	1.05
Emotional representations	1.02	.97	1.08
Cause Internal	1.02	.98	1.06
Cause external	.98	.92	1.05
Cause risk factors	<b>.92*</b>	.85	1.00
<b>BMQ Scales:</b>			
Medication harm	<b>1.10*</b>	1.01	1.20
Medication overuse	1.00	.91	1.09
<b>CAMBI scales:</b>			
Beliefs in Natural treatments	1.00	.92	1.07
Participation in treatment	1.01	.92	1.10
Holistic health Beliefs	1.02	.94	1.10

\* p<.05

The regression model was also assessed using three influence statistics, namely Cook's distance, DFBeta values and leverage (or hat) values (Field, 2009). Cook's distance measures influence of individual cases on the regression model, where cases with little individual influence on the model should fall below 1 (Field, 2009). All cases were found to fit with these criteria. Second, DFBeta values were assessed. DFBeta assesses the regression model without individual cases present and gives a value based on the difference between cases being present and then being removed from the model. Values greater than 1 indicate a large influence on the model (Field, 2009). All DFBeta values were found to be within acceptable criteria. Finally, Leverage (or hat) values were assessed. Leverage assesses the influence of outcome cases on the predicted values. Cases should be no greater than the number of predictors plus one, divided by the sample size ( $(k+1/n)$ ), where  $k$  is the number of predictors and  $n$  the sample size ( $(22+1/513 = 0.05)$ ). Leverage values should not fall any higher than three times this value (Field, 2009). One value was found to marginally exceed this value. However considering the other diagnostic statistics were reasonably sound, this case was kept in the model. Moreover, it should be noted that larger values were not necessarily reliable judges of influence as they are measured using the outcome rather than the predictors as with other influence statistics (Field, 2009). The lack of influential cases in the regression model provides a clear indication that no cases were placing undue influence on the regression model therefore the regression model can be regarded as a good fit for the data.

#### **4.4 Discussion**

The aim of this analysis was to examine the illness and treatment representations in participants with IBS to seek to determine influential factors in the use of CAM. This was conducted within the theoretical framework of an extended CSM. Four specific aims were addressed. Firstly, the prevalence of CAM was explored. Secondly, the illness and treatment representations were assessed for associations with more than

one CAM treatment. Thirdly, differences between the CAM-users and non-users on measures of illness and treatment representations were observed. In addition, a logistic regression analysis was conducted to assess factors that predicted CAM use in IBS.

#### ***4.4.1 Prevalence of CAM use in IBS***

More than half of participants with IBS had used CAM to relieve their symptoms, and many had used multiple forms of CAM, of which numerous treatments appeared to be 'off the shelf' products. Overall, CAM use was higher in this study (57%) than reported in previous studies in IBS which has ranged from 38.4% to 50% (Kong et al., 2005; van Tilburg et al., 2008), and would seem to be comparable with CAM-user data from the general population (Eisenberg et al., 1998; Thomas et al., 2001).

The most popular CAM therapies for IBS were herbal preparations, massage, aromatherapy, and Bach flower remedies. The latter three treatments are perhaps not normally associated with IBS relief and not widely investigated as treatments. This may be suggestive of beliefs about IBS being caused or IBS being related to stress, so these treatments may primarily be taken to relieve stress rather than IBS. Taking such a treatment for IBS may be indicative of certain causal beliefs in these participants as stress as a cause of, or influence on, IBS and such associations in those with IBS have been noted in previous work (Casiday et al., 2008; Hungin et al., 2005). The discrepancy of percentages between consulting a practitioner (23.6%) and being directed to take CAM by a practitioner (34.9%) is notable. This may be due to participants asking for advice in some form of CAM retail outlet rather than undergoing a formal consultation with a CAM practitioner.

##### ***4.4.1.1 IPQ-R, BMQ and CAMBI scale correlations with number of CAM treatments used***

The second objective (4.1.2) this analysis addressed was concerned solely with CAM-users and examined relationships between scale

variables (from the IPQ-R, BMQ and CAMBI and participant age) with the number of CAM treatments used by participants. Participant age was positively related to number of CAM treatments used which is arguably a logical association in a group of CAM-users. Both BMQ scales were positively related with number of CAM treatments, the harm scale having the stronger association of the two. More CAM treatments appeared to be used if CAM-users have stronger beliefs about harm or overuse of conventional medication. The number of CAM treatments also increased together with more positive beliefs about CAM. All the CAMBI scales were positively related to number of CAM treatments used although the treatment participation scale to a lesser extent than the natural treatments and holistic health scales.

These findings are consistent with other studies suggesting that positive beliefs about CAM are related to CAM use in the general population (Astin, 1998; Bishop et al., 2006). In considering beliefs about conventional medicine, there have also been associations between negative beliefs about conventional medications with CAM use in IBS and the general population (Hilsden et al., 1998; Vincent & Furnham, 1996). It appears from this analysis, that both dimensions of conventional treatment beliefs (as measured by the BMQ-General) may influence decisions in more than one type of CAM being used for IBS. However, it should be noted that these relationships between treatment beliefs and number of CAM treatments used are only exploratory and only offer an indication of why individuals may use different forms of CAM after they have already instigated CAM use. It is also evident that none of the IPQ-R scales were significantly related to number of CAM treatments used which may suggest perceptions related to IBS are less influential in whether or not more than one type of CAM would be used once a decision to initiate CAM use has been made. This is consistent with findings from Bishop et al. (2008) who found no illness perceptions were associated with continued use of CAM. However, Searle and Murphy (2000) found evidence of causal beliefs influencing adherence to homeopathic treatment in a small sample of users that attended a

homeopath. It should be noted however, that both of these studies focused on continued use of particular CAM treatments rather than CAM in general. The concordance with Bishop et al's (2008) findings in relation to adherence to CAM, might suggest treatment beliefs become more important predictors of adherence (or continued CAM use) after treatment is initiated. This would be consistent in studies that have utilised an extended CSM to examine adherence of conventional medication (e.g. Horne & Weinman, 2002).

#### ***4.4.1.2 Differences between CAM-users and non-users with IBS on scale variables***

The third objective (4.1.3) explored by this study was to examine differences between CAM-users and non-users on the IPQ-R, BMQ and CAMBI scales as well as participant age. This study found no differences between CAM-users and non-users in age. In terms of illness perceptions, CAM-users had a significantly greater number of IBS symptoms, stronger perceptions of a cyclical timeline and consequences of their IBS. The emotional representations of CAM-users were significantly higher than the non-users, indicating that CAM-users with IBS reported greater emotional distress related to their IBS. These findings seem logically consistent with previous work (e.g. Lackner et al., 2004), although to date little investigation has been conducted on the influence of emotional representations on CAM use. Both Bishop and Lewith (2010) and Testerman et al. (2004) reported that CAM-users from the general population may report lower health status. Donker et al. (1999) also found that those with IBS report poorer health in comparison to the general population and this seems to influence health care seeking, including CAM use. Similarly, Verheof et al. (1990) found CAM-users with functional bowel disorders reported poorer health status than non-users. There were no differences between the CAM-users and non-users on scores for the causal scales of the IPQ-R. This may suggest some consensus regarding causal factors for IBS between the two groups of participants.



Understanding of IBS (illness coherence) also did not differ between CAM-users and non-users. This may suggest that this particular sample has similar understanding of their illness regardless of whether CAM is used or not. This is further compounded by the fact the sample came from participants using the internet, many of which came to the study website via a self help network website. It could be theorised that this sample of participants may be well informed about their condition. In general, up to eighty per cent of those with IBS have been shown to have knowledge about their condition (Ringström, et al., 2009) and some will use online forums and websites for support and information about IBS (Coulson, 2005) and health and illness in general (section 3.1.2.1).

CAM-users reported significantly stronger beliefs in the possibility of harmful effects caused by conventional medicines than non-users. This is consistent with previous work (Hilsden et al., 1998; Vincent & Furnham, 1996). Horne et al. (1999) found that participants using homeopathic treatments had significantly greater concerns about both harm and overuse of conventional medicines than non-users. However, in this study there were no differences between CAM-users and non-users in ratings of overuse of medication. This may indicate that perceptions of harm caused by conventional medical treatments for IBS may be a more important influence on CAM use than a perception of medication being over used.

Many studies have emphasised more positive beliefs about CAM as a more prominent reason for CAM use in the general population (Testerman et al., 2004; Furnham & Kirkaldy, 1996) and in functional GI complaints (Koloski et al., 2003). CAM-users in this study illustrated more positive beliefs regarding natural treatments, patient participation in treatment and holistic health than non-users and these factors were also positively related to a greater number of CAM treatments being used. Previous work utilising an extended CSM framework has shown beliefs in holistic health to be related to use of number of CAM treatments (Bishop et al., 2006). As this study did not assess any treatment representations

prior to CAM use, it is difficult to ascertain whether the more positive beliefs about CAM by CAM-users, are a result of their own experience of CAM or if such beliefs were instrumental in commencing CAM treatment.

#### ***4.4.1.3 Predicting CAM use in IBS from the CSM and demographic items***

The final objective (4.1.4) addressed in this analysis was to determine which components of the extended CSM and demographic factors predicted CAM use. Several demographic factors were influential in CAM use although reporting co-morbidity was not a significant predictor of using CAM.

Having an income in the category of £10-14,999 (compared to the reference category of 'up to £9,999') indicated a lesser likelihood of CAM use. This may suggest some consistency with previous research suggesting CAM use is related to higher levels of household income (Eisenberg et al., 1998), although in this study, higher levels of income did not influence CAM use in the regression model. Participants with 'A' levels or postgraduate qualifications were more likely to be CAM-users, also suggesting similarities with previous work that has suggested higher education levels are a factor influential in CAM use in the general population (Astin, 1998; Thomas et al., 2001) and in IBS (van Tilburg et al., 2008). In most cases, a certain level of disposable income would be necessary to undertake CAM treatment as most CAM treatment, especially in the UK, does not fall under the remit of the NHS. Educational attainment and CAM use may be related in some instances by increased knowledge of treatment options for IBS or having a feeling of wanting to question the effectiveness and use of conventional medical treatment (e.g. Astin, 1998).

Participants who were diagnosed over five years ago and 3-4 years ago were more likely to use CAM than those diagnosed in the last 12 months which again is consistent with other work into CAM use. It has been demonstrated that the chronicity of complaints is important in CAM use

(Eisenberg et al., 1998). Chronicity may also be associated with findings that CAM use is influenced if conventional care has offered no relief over time (Vincent & Furnham, 1996) or the individual has perceived 'failure' of conventional treatment (Smart et al., 1986). One further suggestion may be that time of diagnosis alone is not influential in CAM use and that other factors such as relief gained from conventional medication or perceptions of health care consultations are worthy avenues for future exploration.

Logistic regression analysis revealed a number of illness perceptions predicted CAM use. Stronger beliefs in illness identity (number of symptoms) meant participants were more likely to use CAM. Stronger beliefs in illness consequences were also shown to predict CAM use. These findings allow comparison with previous work. CAM-users in the general population have been shown to report a more severe illness experience (Bishop & Lewith, 2010; Testerman et al., 2004) and in those affected by IBS and other functional bowel disorders, detrimental health status will influence healthcare seeking including CAM use (Donker et al., 1999; Verhoef et al., 1990). One study that has used the IPQ-R, also found illness consequences have been shown to predict current CAM use in a general population of CAM-users (Bishop et al., 2006). Perceptions regarding more serious consequences of IBS being linked to CAM use is also consistent with previous work in both IBS and IBD populations (Scott, et al., 2003; Talley et al., 1997).

Health status in IBS has also been shown to influence conventional health care seeking (Koloski et al., 2001). The finding that those participants who reported stronger illness perceptions (e.g. consequences and emotional representations), appear more likely to use CAM. Indirectly, such perceptions may be indicating that conventional treatment has not helped alleviate IBS symptoms and this has encouraged these individuals to explore other treatments. The reporting of more symptoms (illness identity) may suggest some participants may be attributing additional, perhaps unrelated troublesome symptoms to

their IBS. The Rome criteria refer to a number of symptoms, some of which are not directly attributed to the bowel, such as fatigue. An 'accumulation' of such symptoms may also influence a decision to use CAM.

Higher scores on the cyclical timeline scale were also associated with a greater likelihood of CAM use. Although not demonstrated in previous research into IBS and CAM use, this finding is not unexpected as IBS is well documented as a condition with fluctuation of periods of intense symptom experience and periods of relief (e.g. Drossman, 1999). A stronger belief in risk factors (e.g. smoking or alcohol use) as a cause of IBS indicated a lesser likelihood of CAM use. The perceptions may relate to a belief in a degree of self infliction with risk factor as a causal influence on IBS. It may be that IBS symptoms would be perceived to subside or be relieved if smoking or alcohol use ceased or was reduced. Nahin et al. (2007) found that those that were less engaged in behaviours such as smoking and drinking alcohol were more likely to use CAM. As smoking and drinking habits were not explored in this study, it may be that people with IBS smoke fewer cigarettes and drink less alcohol than others in the population that are non-users of CAM. This represents an avenue to be explored in future study. Other studies have found evidence of psychological causal representations as being influential in CAM use in general populations (Bishop et al., 2006; Searle & Murphy, 2000). This may suggest the attribution of specific causal beliefs concerning risk factors such as smoking or drinking alcohol are particular to IBS or may be specific to this sample.

Stronger beliefs on the BMQ-harm scale also indicated a greater likelihood of participants using CAM. Previous studies have also suggested that beliefs about the potentially harmful effects of conventional medicine are influential in CAM use (Hilsden et al., 1998; Vincent & Furnham, 1996). This finding may also be related to previous work in IBS that has identified issues with conventional medicines such as 'failure of' (Smart et al., 1986) and being 'sceptical of' conventional

medicine (Verhoef et al., 1990). Although the lack of systematic investigation is evident in investigating beliefs about conventional medication in this area, the findings from this study are theoretically consistent with previous work and expectations.

Many of the IPQ-R scales did not predict CAM use. Emotional representations did not predict CAM use despite showing a difference in scores between CAM-user and non-user groups. Bishop et al. (2006) also found emotional representations did not predict current CAM use. It may be that emotional distress unrelated to IBS may be influential in CAM use. Other studies have suggested stressful life events (Verhoef et al., 1990), anxiety (van Tilburg et al., 1998) and impaired psychological health (Donker et al., 1999; Koloski et al., 2003) as factors related to using CAM in IBS. The illness coherence and two control scales were also not predictors of CAM use. In the case of illness coherence, as considered previously, it may be that participants in this study, recruited largely from a self-help network website may have a good understanding of their IBS. Similarly, the BMQ-overuse scale was not a significant predictor of CAM use. The regression model predicted 22.9% of the variance in outcome, less than reported by Bishop et al. (2006), although this study had a large number of participants that did not use CAM unlike the Bishop et al. study.

Previous work has emphasised positive beliefs about CAM as a prominent reason for CAM use in the general population (Bishop et al., 2006; Furnham & Kirkaldy, 1996; Testerman et al., 2004) and in FBD (Koloski et al., 2003). CAM-users had more positive beliefs about CAM, as illustrated by higher CAMBI scores, than non-users. However in this study, none of the CAMBI scales predicted CAM use when controlling for other variables in the logistic regression analysis.

This study addressed CAM as a single entity, although participants were shown to use many different types of CAM for their IBS. Chapter one outlined the differing dimensions and philosophies to CAM, not least the

distinction between 'complementary' and 'alternative' treatments (Zolman & Vickers, 1999). It is possible there may be differences in predictive factors for different philosophies and groups of CAM (Bishop et al., 2006). Vincent & Furnham (1996) for example, found that homeopathy patients had stronger beliefs in natural treatments and felt conventional treatment to be less effective for their health complaint than osteopathy and acupuncture users. Bishop et al. (2006) found some differences in the relationships between illness and treatment representations and different CAM philosophies. Severe consequences for example, predicted use of mind-body interventions and biologically based therapies. Stronger beliefs in harm (from the BMQ) resulted in a greater likelihood of use of alternative treatments. These relationships could be further explored in future studies in IBS populations, possibly with reference to CAM user profiles for each CAM philosophy (Kelner & Wellman, 1997).

#### ***4.4.2 Theoretical considerations***

This study illustrated the benefits of incorporating treatment representations into the CSM to enhance the predictive quality of this theoretical approach. Although previously the extended CSM has been typically used in relation to conventional medical treatment adherence studies, the literature on CAM use, IBS and existing studies that have explored CAM use in IBS suggested that exploring treatment beliefs would be a worthwhile endeavour. Two studies to date have explored CAM use by using an extended model based on the CSM with the addition of CAM beliefs (Bishop et al., 2006; 2008). This study added to previous work in that the incorporation of conventional medication beliefs (Horne & Weinman, 2002) into the CSM both enhanced the model and illustrated that a component of conventional treatment beliefs was an important predictor of CAM use in IBS. The inclusion of CAM beliefs in the theoretical approach met with limited success in predicting CAM use, as none of these dimensions was a predictor of CAM use. However, CAM-users did have stronger beliefs in favour of CAM than non-users. More positive CAM beliefs were also associated with use of a greater

number of CAM treatments. This may be an area that may benefit from further investigation, as such pro-CAM beliefs may precede or influence CAM treatment outcome or reported quality of life. The relationships between CAM beliefs and reported quality of life are explored in the following chapter.

Furthermore, exploration of CAM use in this context represents examination of the pathways between illness and treatment representations and a specific coping behaviour (Searle et al., 2007). Horne and Weinman (2002) illustrated that both illness and conventional treatment representations were predictors of adherence to asthma medication. Searle et al. (2007) however, found more consistent relationships with coping 'cognitions' (i.e. strategies or procedures, measured by checklist) than coping behaviours. The following chapter will explore the relationships between illness and treatment representations, and such coping 'cognitions' and strategies further.

#### ***4.4.3 Limitations of the study***

In predicting CAM use using a logistic regression model, the demographic factors and beliefs about illness and treatment accounted for a moderate amount of variance although some of the odds ratios of the IPQ-R and BMQ scales were smaller when compared to demographic factors. The moderate amount of variance explained in the outcome (CAM use) suggests that other factors not considered in this study may be relevant in CAM use in IBS such as perceptions concerning health care consultations. The diagnostics of the model in terms of such factors as multicollinearity and influential and residual values were all within normal parameters. The only apparent issue was the confidence intervals for 'no qualifications' which crossed over 1, meaning this particular confidence interval may be unreliable and should be interpreted with caution.

Similarly, a number of treatment beliefs were significantly associated with number of CAM treatments used but the Pearson's coefficients were

small to moderate. The significant differences between CAM-users and non-users on the IPQ-R, BMQ and CAMBI scales also showed small effect sizes. The study was also cross-sectional, making it more difficult to assume causation or direction of influences of illness and treatment perceptions on CAM use. However, the large sample size would suggest a degree of robustness in the findings and smaller effect sizes in group differences can be seen as a product of the large sample size.

Examination of participant demographics in this study suggests a degree of consensus with the 'CAM-user profile' (Thomas et al., 2001; Astin, 1998) in that the majority of participants were female and CAM use was influenced by higher income. The female predominance in IBS documented elsewhere (Andrews et al., 2005; Hungin et al., 2005; Thompson et al., 2000; Wilson, et al., 2004) was evident in this study, although it is still possible that there exists a 'hidden' male cohort with IBS that may be reluctant to seek health care. Furthermore, despite recruiting a large number of participants, the sample largely consisted of white, British participants who were either largely of Christian or no religious background. Such findings may be related to the type of individuals who use the internet for information or support with their IBS (e.g. Coulson, 2005) rather than being indicative of any sort of demographic indication of greater prevalence within these ethnic and religious groupings. Many western countries have similar prevalence rates of IBS (Wilson et al., 2004). Moreover, many will not seek care for their IBS (Saito et al., 2002; Thompson et al., 2000) which may suggest that such individuals may be less likely to seek out information and potentially less likely to participate in a research study. It may also be worthwhile to investigate other ethnic, spiritual or religious groups, who were not highly represented in this study, in future studies as this may be an important influence on CAM use. Testerman et al. (2004) found beliefs in spirituality as one factor influential on CAM use.

The diversity in geographical location of participants was not thought to have affected the findings given the apparent consistency and



robustness of CSM research over different western populations (e.g. Hagger & Orbell, 2003). However, it should also be noted that other studies showing high prevalence of CAM in IBS (Kong et al., 2005; van Tilburg et al., 2008) used a GI outpatient clinic sample and health maintenance organisation sample respectively. It is possible that such participants may experience a more severe illness experience than individuals who are not currently outpatients or receiving treatment. There may also be more subtle differences in the experience of IBS as a small number of participants in this study had not been diagnosed by a health care professional. However, table 4.1 illustrates that over half of those not diagnosed had still used CAM at some point. These aspects may be investigated further in future work.

The method of administering the survey may have had some effect on the findings. This sample was self-selecting and many participated from responding to an advertisement on a self-help network website. It may be assumed that in seeking 'self help' many were relatively well informed about IBS and this may have had some effect on their representations of IBS and treatment. Potential differences between those that take part in research on the internet as opposed to more traditional paper and pencil tests have been considered as a potential problem for research conducted online (e.g. Ahern, 2005; Duffy, 2002). However, there is a growing body of evidence, established using comparisons based on psychometrically sound measures, that any differences are either small or do not exist when paper and pencil and internet administration of tests are compared (Basnov et al., 2009; Gosling et al., 2004; Vallejo et al., 2007). Furthermore, the internal reliability of the scales of measures and the age range of participants suggest that the sample compares well with previous work using the same measures of illness perceptions and treatment beliefs (e.g. Bishop et al., 2006). It should also be noted that there were still significant differences and associations between scores and it would perhaps be unrealistic to expect every dimension of the IPQ-R, BMQ or CAMBI to predict CAM use.

Despite these limitations the systematic and theoretical approach to the study has yielded some new and important findings. Studies into CAM use in IBS are scarce, but the results here concur, to a degree, with what is known about CAM use in general populations. However, given the prevalence of IBS it is possible many CAM-users with unspecified health complaints from studies into general populations and CAM use may have had IBS. This study adds to the understanding in that a stronger perception of risk factors as causes of IBS, such as alcohol or smoking, is less likely to result in CAM use. This gives some insight into which factors are implicated in the use of CAM in a specific illness group. Also evident is that there are differences in many dimensions of illness perceptions and treatment beliefs between CAM-users and non-users.

The lack of previous work in this area and using a theoretical framework has been partly addressed by this study. This study has used the systematic and theoretical framework of the CSM and the findings support the view that an extended CSM (e.g. Bishop et al., 2006; 2008; Horne & Weinman, 2002) has utility in exploring CAM use in IBS. Several illness perceptions and treatment beliefs regarding harm caused by conventional medicines predicted CAM use in those with IBS. Future studies in this area may pay consideration to examining the relationships between different categories (based on philosophy and approach) of CAM. The results suggest many with IBS will turn to herbal treatments and often other forms of CAM to relieve their symptoms with the possibility that this may be to relieve underlying issues such as stress. As with conventional care, CAM may be taken to deal with a particular facet of IBS that is prominent such as constipation or diarrhoea. Additionally, potential distinctions should be made between 'off the shelf' CAM products and CAM provided by a practitioner. Most participants in this study seemed to indicate they purchased their own CAM treatment in contrast to other studies into CAM use in IBS populations (Donker et al., 1999; Koloski et al., 2003; Smart et al., 1986; Verhoef et al., 1990).

#### **4.4.4 Conclusions**

This cross-sectional analysis found that CAM use in participants with IBS was over fifty percent. The use of an extended CSM had the benefit of highlighting illness and treatment representations that were related to CAM use. Several dimensions of illness perceptions and beliefs about harm caused by conventional medicines predicted CAM use when controlling for demographic factors. There were also a number of differences on the IPQ-R, BMQ and CAMBI scales between CAM-users and non-users. Furthermore, there were also significant correlations between treatment beliefs and number of CAM treatments used. The findings illustrate the benefits in using an extended CSM to systematically investigate the cognitive and emotional aspects of IBS. The extended CSM enabled examination of components that are both associated with the number of CAM treatments used and that predicted CAM use in IBS. In terms of predicting CAM use, illness identity, stronger illness consequences, cyclical timeline and causal risk factors all predicted CAM use. Beliefs about harm caused by conventional medication also predicted CAM use in those with IBS. To develop these findings and to examine the possibility that beliefs may change due to using CAM, prospective longitudinal studies are needed.

These findings also indicate implications for conventional care, although such implications are tentative based on this single cross-sectional study. Firstly, perceptions about consequences of IBS could be addressed in initial health care consultations. Such an approach has been shown to be beneficial to the prognosis of those with IBS in terms of reduced use of health care services (e.g. Oerlemans et al., 2010; van Dulmen et al., 1996; 1997) and may help to reduce the need for CAM. Second, patients could be provided with information that IBS is a condition that is cyclical in nature and they may have periods where symptoms are more intense. As 'identity' with symptoms was a predictor of CAM use, attention could be paid to addressing those presenting with IBS about the variation and cyclical nature of symptoms so they are fully informed about their condition. Finally, as beliefs about harm of conventional

medicines predicted CAM use, time could be taken to reassure about the possibility of any harmful effects of continued use of medication. These scenarios show how conventional care may potentially target troublesome illness perceptions in those presenting with IBS. As many people with IBS will visit their GP before a CAM practitioner, and given the suggested role of illness perceptions in IBS, it is logical to consider that such perceptions could be routinely addressed by GPs during the first consultation alongside a positive diagnosis of IBS.

The differences observed in measures based on an extended CSM between CAM-users and non-users are both evident and expected from what expectations based on previous work. These findings have provided further basis for the exploration of interrelations between constructs of the CSM between CAM-users and non-users separately. These interrelations will be addressed by analyses presented in the following chapter.

## Chapter 5

### **An examination of components of the Common-Sense Model of illness between CAM-users and non-CAM users with IBS**

*This chapter presents further findings from the cross-sectional study and thus extends the analysis reported in chapter 4 in which CAM-users and non-users were found to differ on a number of illness perceptions and treatment beliefs. The chapter reports an examination of the pathways in an extended common-sense model (CSM) of illness representations in both CAM-users and non-users with IBS including testing the theorised mediating role of coping between illness perceptions (and treatment beliefs) and outcome.*

#### **5.1 Introduction**

As illustrated in chapter one, IBS is a prevalent functional illness with multiple symptoms and of unidentified aetiology. Consequently IBS is difficult to treat and can result in between 35% and 50% of those affected, using CAM for symptom relief (Kong et al., 2005; van Tilburg et al., 2008). Findings presented in the previous chapter also showed 57% of participants in this cross-sectional study used CAM to treat their IBS.

Evidence presented in chapter one shows illness perceptions are important in both IBS and in CAM use. Rutter & Rutter (2002, 2007) demonstrated individuals' perceptions about IBS are associated with impaired quality of life (e.g. Rutter & Rutter, 2002, 2007; Spiegel et al., 2004). The findings in chapter four illustrated such illness perceptions, as well as treatment beliefs, predicted CAM use in IBS, findings that are consistent with the general population (e.g. Bishop et al., 2006). Chapter four also demonstrated the value of utilising an extended CSM framework to investigate the influence of illness and treatment perceptions on a specific coping behaviour (i.e. CAM use) adopted by those affected by IBS.

Within the CSM, individuals process both cognitive and emotional responses to illness which influence coping strategies undertaken in an attempt to maintain a state free from illness or symptoms (Leventhal et al., 1998). Previous research utilising the CSM in IBS has however, largely ignored the emotional component of the model (Rutter & Rutter, 2002, 2007) and the influence on emotional outcomes (Leventhal et al., 2003). Those with IBS have been shown to 'catastrophise' their symptoms (Lackner et al., 2004) and such emotional distress has the potential to influence poorer emotional outcomes according to the CSM (Leventhal et al., 2003).

As outlined in chapter two, an extended CSM delineates pathways from illness or treatment representations to outcome. These pathways are said to be mediated by coping procedures (Hagger & Orbell, 2003). Evidence demonstrating mediation of coping however is mixed in many cross-sectional studies (Carlisle et al., 2005; Hagger & Orbell, 2003). Heijmans (1998), Kemp et al. (1999) and Scharloo et al. (1998) all failed to detect mediation effects using cross-sectional designs. However, other studies with a sample of rheumatoid arthritis patients (Carlisle et al., 2005) and relatives of people with schizophrenia found evidence of mediation of certain coping strategies (Fortune et al., 2005).

In IBS, Rutter and Rutter (2002) found mediation of coping in a cross-sectional study although any distinction between mediation and partial mediation was not clarified. However, in a longitudinal study of IBS patients from a number of general practices, no evidence of mediation of coping was detected (Rutter & Rutter, 2007). Several CSM studies have adopted the Baron and Kenny (1986) 'causal steps' approach to (simple) mediation testing (section 3.6.3) relying on the researchers' interpretation of the degree of mediation (e.g. Carlisle et al., 2005; Rutter & Rutter, 2002). The findings presented in this chapter are augmented with a formal test of significance for detected mediation effects (section 3.6.3, Preacher & Hayes, 2004).

Chapter one reported that quality of life is often more impaired in IBS compared with other, sometimes more serious conditions (e.g. Amouretti et al., 2006). CAM-users with unspecified health issues also report inferior quality of life (Astin, 1998) as they also do in IBS (van Tilburg et al., 2008). It may then be proposed that CAM-users with IBS will report lower quality of life than those not using CAM. Furthermore, taking into consideration findings presented in chapter four which show CAM-users differ from non-users on a number of illness and treatment perceptions, there was a cogent rationale to examine CSM pathways in CAM-users and non-users separately. It is also apparent that to date, no published studies have examined an extended CSM in IBS patients across two such groups.

The main aim of this chapter therefore is to consider the relationships between three main components of an extended CSM namely, interpretation (perceptions and beliefs), coping and outcome in the form of a self-report health related quality of life measure. In exploring these pathways and interrelations, CAM-users and non-users were considered comparatively. Within this main aim, four specific objectives were addressed:

5.1.1 To examine differences between CAM-users and non-users on subscale scores of the IBS-QOL

5.1.2 To examine differences between CAM-users and non-users on scale scores of the Brief-COPE

5.1.3 To explore relationships between measures of illness perceptions and treatment beliefs in CAM-users and non-users

5.1.4 To examine if coping acts as a mediator between illness perceptions, treatment beliefs and reported quality of life in CAM-users and non-users

## **5.2 Method**

This component of the research was conducted according to the methodology detailed in chapter three. As with the findings reported in chapter four, data collection took place online. A series of independent *t*-tests were conducted to examine for differences between CAM-users and non-users. Pearson's correlations were used to examine relationships between measures of illness and treatment representations. A combination of Pearson's correlations and regression analyses was used to test for simple mediation effects of coping (Baron & Kenny, 1986). Further bootstrapping tests (Preacher & Hayes, 2004) were able to give an estimation of the statistical significance and size of each mediation effect detected.

### **5.2.1 Design**

As detailed in the previous two chapters, this component of the research was a cross-sectional web-based survey. This method was selected as it offered the opportunity for substantial and diverse participant recruitment (section 3.1.2.1). To address the research objectives (section 5.1), participant data were taken from IPQ-R, BMQ and CAMBI. Coping was assessed by using the Brief-COPE and reported IBS-specific quality of life was assessed with the IBS-QOL. Participants were divided into two groups, either CAM-users or non-users according to whether they had used CAM to relieve their IBS or not.

### **5.2.2 Participants**

Six hundred and fifty three participants were recruited online from an IBS support network and IBS discussion forums. Over half (57%) had used CAM and approximately 84.7% were female. Most participants stated they had been diagnosed (93.7%) by a health care professional and 85% were from the UK (see section 4.3.1 for a full summary).

### **5.2.3 Measures**

The measures used to conduct this study are explained fully in section 3.3. For the purposes of this study, four measures were considered as



predictor or explanatory variables. The Illness Perception Questionnaire Revised version (IPQ-R; Moss-Morris et al., 2002) was used as a measure of illness perceptions. The Beliefs about Medicines Questionnaire general version (BMQ-general; Horne et al., 1999) was utilised to capture general beliefs about conventional medicines. The Complementary and Alternative Medicine Beliefs Inventory (CAMBI; Bishop et al., 2005) was used to ascertain beliefs about CAM. The Brief-COPE (Carver, 1997) was used to capture coping strategies.

The IBS-QOL (Patrick et al., 1998), an illness specific measure of quality of life, was used as an outcome measure. As was highlighted in chapter two, outcome in previous CSM research has often taken the form of a self-report quality of life measure (e.g. Rutter and Rutter, 2002). The total IBS-QOL score reflects a domain specific, multi-dimensional score of several wide ranging factors related to quality of life and was considered a suitable outcome measure (Drossman et al., 2000; Patrick et al., 1998). One of the subscales of the IBS-QOL, the Dysphoria subscale, was used as a measure of emotional quality of life (emotional outcome) enabling the pathway between the emotional representations and emotional outcome to be examined.

To address objectives three and four (section 5.1), the dichotomous outcome measure of CAM use (section 3.3.3.1) referred to in the previous two chapters was used to divide the data file into two groups according to whether participants were CAM-users or non-users.

#### **5.2.4 Procedure**

The procedure was carried out as detailed in section 3.4 using an online survey host. Participants were recruited online via advertisements on an IBS self-help network group webpage and other IBS related online discussion forums. Participants were presented with a direct 'one click' electronic link that routed to the study website. Full details of the procedure are provided in the section 3.4.

### **5.2.5 Statistical methods**

Scales were computed for the Brief-COPE and the IBS-QOL (section 3.3.2). As was considered in the previous chapter, data were screened for outlying values and distributions of scale variables assessed (Tabachnick & Fidell, 2007). Following this, inferential statistical testing was conducted in SPSS version 17 to assess differences between CAM-users and non-users using unrelated *t*-tests on the Brief-COPE and IBS-QOL. Relationships between the IPQ-R, BMQ and CAMBI scales (for both the CAM-users and non-users) were explored. Finally, in both CAM-users and non-users, tests of simple mediation were conducted according to Baron and Kenny's (1986) causal steps approach (see section 3.6.3). This was followed by testing for statistical significance of any mediation effect detected (Preacher & Hayes, 2004).

#### **5.2.5.1 Computing scales**

Prior to inferential statistical testing, the IPQ-R, BMQ, CAMBI scales and IBS-QOL scale and subscale were computed (as outlined in section 3.3.2) allowing for small numbers of missing values on each item. The Brief-COPE was computed without accounting for any missing data as each scale of the measure consists of two items only, so a total score was computed for participants that had two responses for items of each scale. For the purposes of addressing the third objective in this study (section 5.1), to test if coping mediated relationships between the IPQ-R, BMQ, CAMBI and the IBS-QOL, the data were split into two separate files according to CAM use or no-CAM use (subsequently referred to as the CAM-users and non-users).

#### **5.2.5.2 Data screening**

As considered in chapter 4 (section 4.2.5.2), data were checked for outlying values that may unduly influence inferential statistical tests (Tabachnick & Fidell, 2007, section 3.6). The IPQ-R, BMQ and CAMBI scales were screened prior to analysis in chapter four (section 4.2.5.2). The Brief-COPE scales and IBS-QOL subscales were therefore screened for outlying values prior to statistical testing. Box-plots were

used to visually identify outliers that were present in several Brief-COPE scales and IBS-QOL subscales. Detected outliers were checked for any pattern in responses (e.g. response set). However all values were found to be in the correct scoring range for each scale and demonstrated sufficient variation in scores. With identified outlying values, the 'winsorizing' strategy (Erceg-Hurn & Mirosevich, 2008) adopted in the previous chapter to reduce their influence was used by changing these values to less extreme figures (section 4.2.5.2). This involved changing the outlying value to the next non-outlying value to reduce the influence of these particular cases (e.g. Field, 2009). The Brief-COPE scale, 'substance use' was unresponsive to trimming of outliers in non-users, so this scale was not adjusted, however, the distribution of residual values in regression models containing this scale were assessed for normality.

The Brief-COPE scale and IBS-QOL scale and subscale distributions were assessed for normality visually by using histograms for both CAM-user and non-user responses. Examination of the histograms for the Brief-COPE scales and IBS-QOL subscales revealed several scales that suggested distributions deviated from normality. In examining Brief-COPE scales, there was noticeable non-normality of responses, more so in CAM-users where only the self distraction, instrumental support and emotional support scales were deemed normal. In non-users, active coping, self distraction, instrumental support, planning and acceptance were approximately normally distributed. Most other scales were deemed to show a positive skew apart from planning and active coping in CAM-users, which were negatively skewed. Many of the IBS-QOL subscales were normally distributed, although the Dysphoria subscale demonstrated a positive skew in CAM-users, as did food avoidance in non-users. In both groups the relationships and sexual subscales demonstrated a negative skew.

### **5.2.5.3 Statistical tests**

Parametric analysis was favoured as the measures used in this study were considered psychometrically stable enough to have elicited

parametric data (section 3.3.2). Statistical analysis was also conducted on a list-wise basis in SPSS to ensure greater accuracy, meaning any case with missing data on any of the measures included in a particular analysis was omitted from the analysis (see section 3.6.1). To address the first two study objectives (section 5.1) and taking into account the documented robustness of *t*-tests to non-normality (see sections 3.6.3 and 4.2.5), independent *t*-tests were conducted to examine for differences in CAM-users and non-users on the total score and subscales of the IBS-QOL and scale scores on the Brief-COPE.

To meet the third objective, Pearson's correlations were used to assess relationships between scales of the IPQ-R, BMQ and CAMBI for CAM-users and non-users. Parametric testing was favoured and Pearson's correlation is also regarded to be robust against any violation of non-normality with sample sizes greater than 40 (e.g. Field, 2009) and has typically been regarded as robust against violations of normality (Nefzger & Drasgow, 1957).

#### **5.2.5.3.1 Process to determine mediation**

Baron and Kenny (1986) specified a number of causal steps to determine 'simple' mediation, where a mediator variable explains the relationship between a predictor and outcome. Statistically, this may be illustrated by the mediator variable reducing the effect of a predictor variable on outcome to non-significance, or to reduced significance (referred to as 'partial' mediation, see section 3.6.3). Chapter three (section 3.6.3) outlined that the Baron and Kenny (1986) approach to mediation testing was judged to 'fit' well with the aims of the study and the proposed relationships between the CSM components and have a theoretical basis. To statistically determine if coping acted as a mediating variable (objective four, section 5.1), data were firstly split into two separate files representing CAM-users and non-users. This enabled testing of the relationships between components of the CSM according to the pathways identified by Baron and Kenny (1986) in each group. These pathways are assessed by firstly establishing a statistically significant

relationship between predictor and outcome. Second, a significant relationship between predictor and potential mediator was assessed. Finally, a significant relationship between mediator and outcome whilst controlling for the predictor was examined. As is consistent with previous research using the CSM, the process of establishing simple mediation (Baron and Kenny, 1986) was conducted by examination of a single predictor, a single mediator and an outcome. As chapters two and three have outlined, IPQ-R, BMQ and CAMBI scores were considered predictor variables. Scores from the various scales of the Brief-COPE were considered as possible mediating variables and the total score of the IBS-QOL was considered as the outcome with the only exception being use of the dysphoria subscale of the IBS-QOL as a measure of emotional outcome.

Within CAM-users and non-users, Pearson's correlations were firstly conducted to assess relationships between illness perceptions, treatment beliefs and IBS-QOL scores (tables 5.5 & 5.6) which constituted step one of Baron and Kenny's criteria. Secondly, using significant relationships identified from tables 5.5 and 5.6, Pearson's correlations were computed between illness perceptions, treatment beliefs and the Brief-COPE scales (effectively step two of the Baron and Kenny criteria, where the predictor must predict/correlate with the mediator tables 5.7 & 5.8). The findings from significant correlations then denoted which pathways were tested for mediation using multiple regression analyses. This was conducted in a consistent way. For example, within CAM-users, illness identity (predictor) was related to IBS-QOL (outcome). Significant relationships were then identified between illness identity (predictor) and scales of the Brief-COPE (potential mediators). Non-significant relationships between predictor and potential mediator variables were therefore discarded at this stage as further testing for mediation would not satisfy the requirements of the Baron and Kenny (1986) criteria (section 3.6.3).

Significant relationships from the preceding two steps were then tested via a number of multiple regression equations to test for 'simple mediation' in both CAM-users and non-users. Firstly, each predictor variable was regressed on outcome. Single mediator variables were then entered in block two of each regression model to observe the effect of the mediator on outcome whilst controlling for the effect of the predictor (effectively step three of Baron and Kenny's criteria). Furthermore, the presented outcome of the total regression model in each case illustrates where the mediator predicted outcome and the effect of the predictor coefficient was reduced from that observed in the first regression block. It may be observed that the inclusion of certain predictor variables in multiple places (in both groups) is purely to examine the intervening effect of Brief-COPE scales when added to each model.

Previous studies utilising the CSM which have tested for mediation have often omitted a formal test of significance in relation to mediation. To avoid possible effects of partial mediation being overlooked a test of the significance of any potential mediation effect was included (Sobel, 1982). Partial mediation may be overlooked where the effect of the predictor variable is reduced in the third regression equation but the amount of reduction in coefficient value of the predictor may be small in size (the difference between pathway  $c$  and  $c'$  should be significantly different from zero, see figure 3.2). The Sobel test considers the non-standardised regression coefficients (these values are in the original units of measurement) alongside their standard errors to estimate the size of the mediation effect in the form of a  $z$  score. The Sobel test however, assumes that the difference in pathway  $c$  and  $c'$  is normally distributed (figure 3.2) which may distort the significance of any mediation effect. To rectify this, Preacher and Hayes (2004) provide an SPSS macro (i.e. SPSS syntax commands) to estimate the statistical significance of mediation by using a procedure known as 'bootstrapping'.

Bootstrapping is a statistical procedure that produces a theoretical population distribution, by re-sampling the original data from this 'population' through simulation. In testing for significance of the mediation effect, the difference in pathways  $c$  and  $c'$  is tested in a number of distributions derived from the original sample and values stored. This process is conducted at least 1000 times (Hayes, 2009) and the final estimate of the size of the mediation effect is the mean of all the estimates. The Preacher and Hayes (2004) SPSS macro provides both 95% and 99% confidence intervals whereby the pathway values are sorted into order according to size and a significant mediation effect can be interpreted from confidence intervals that do not cross zero and are reported here as a  $z$  score (Preacher & Hayes, 2004). The  $z$  score may be interpreted in the normal way (e.g.  $\pm 1.96$  for 95% significance), but the probable non-normality of the difference between  $c$  and  $c'$  occasionally resulted in values less than 1.96 being statistically significant. To illustrate this, Sobel mean estimates are also presented in mediation analyses along with 95% or 99% confidence intervals to illustrate statistical significance of the mediation effect (tables 5.9 – 5.18).

Fairchild et al. (2009) also introduced SPSS procedures to determine the proportion of variance in the outcome explained by the mediation effect. This refers to the unique  $R^2$  attributable to the difference between pathway  $c$  and  $c'$  (which conversely should equal the product of pathways  $ab$ , figure 3.2), and the effect of this on outcome (effectively an estimate of effect size). This may be expressed as a percentage of the total variance explained in each equation (Fairchild et al., 2009). The Preacher and Hayes (2004) SPSS macro now incorporates this measure of  $R^2$  and is presented alongside the mediation analyses here<sup>5</sup>.

### 5.3 Results

There were four main objectives addressed by this study. Firstly, differences between CAM-users and non-users on the subscales of the

---

<sup>5</sup> This SPSS macro is available from Andrew Hayes' webpage at: <http://www.comm.ohio-state.edu/ahayes/>

IBS-QOL were considered (5.1.1). Secondly, differences between CAM-users and non-users were observed on scale scores of the Brief-COPE (5.1.2). Thirdly, for CAM-users and non-users relationships were explored between illness perceptions and treatment beliefs (5.1.3). Fourthly, the coping style in each group was assessed for mediation between illness perceptions, treatment beliefs and reported quality of life (5.1.4).

### **5.3.1 Differences between CAM-users and non-users: IBS-QOL scores**

Firstly, independent *t*-tests were conducted to examine for differences between the CAM-users and non-users on scales of the Brief-COPE and IBS-QOL scale and subscales (tables 5.1 and 5.2, and figures 5.1 to 5.4).

As table 5.1 illustrates, there were significant differences between the CAM-users and non-users on all the IBS-QOL subscales. CAM-users with IBS reported significantly lower total IBS-QOL scores ( $M=43.33$ ,  $SD=20.71$ ) than the non-users group ( $M=49.17$ ,  $SD=22.05$ ),  $t(643)= 3.44$ ,  $p<.01$ . CAM-users also rated their emotional quality of life (Dysphoria) as inferior ( $M=39.43$ ,  $SD=27.21$ ) than non-users ( $M=44.70$ ,  $SD=29.20$ ),  $t(643)= 2.36$ ,  $p<.05$ . The CAM-users also reported significantly more interference with activity ( $M=41.20$ ,  $SD=24.85$ ) than non-users ( $M=45.92$ ,  $SD=26.08$ ),  $t(643)= 2.34$ ,  $p<.05$ . CAM-users also reported a poorer body image ( $M=41.20$ ,  $SD=24.85$ ) than non-users ( $M=45.92$ ,  $SD=26.08$ ),  $t(643)= 3.44$ ,  $p<.01$ . More health worries were reported by CAM-users ( $M=51.66$ ,  $SD=23.55$ ) than non-users ( $M=55.55$ ,  $SD=23.66$ ),  $t(643)= 2.07$ ,  $p<.05$ . CAM-users also reported greater food avoidance ( $M=27.47$ ,  $SD=25.31$ ) than non-users ( $M=35.03$ ,  $SD=29.12$ ),  $t(541.36)= 3.45$ ,  $p<.01$  although the variances in each group were not equal according to Levene's test ( $F=10.69$ ,  $p<.01$ ), therefore the SPSS correction was reported.



CAM-users also had stronger perceptions regarding the reactions of others to their IBS on the 'social reaction' subscale ( $M=43.09$ ,  $SD=26.05$ ) than non-users ( $M=49.46$ ,  $SD=27.76$ ),  $t(643) = 2.99$ ,  $p<.01$ . Sexual issues were also rated as poorer in those that used CAM ( $M=56.96$ ,  $SD=33.93$ ) than non-users ( $M=66.59$ ,  $SD=33.01$ ),  $t(643)= 3.61$ ,  $p<.001$ . Similarly CAM-users also gave stronger ratings for the relationships scale ( $M=56.17$ ,  $SD=27.71$ ) than non-users ( $M=62.52$ ,  $SD=27.34$ ),  $t(643)= 2.89$ ,  $p<.01$ .

The general trend in the group differences is clear and is observable in figures 5.1 and 5.2. Those with IBS who use or have used CAM rate their quality of life as poorer compared to those that do not use CAM to relieve their IBS. The effect sizes offer an indication of the magnitude of difference between the group means with most of the effect sizes being small (see section 4.3.5 and table 4.4).

### **5.3.2 Differences between CAM-users and non-users: *Brief-COPE scores***

Table 5.2 illustrates that there were only two scales where CAM-users and non-users did not differ significantly. There were no differences between CAM-users ( $M=2.48$ ,  $SD=.84$ ) and non-users ( $M=2.42$ ,  $SD=.79$ ) on the substance use scale  $t(602.268)= -.847$ ,  $p>.05$  (equal variances not assumed,  $F=3.97$ ,  $p<.05$ ). There were also no differences between CAM-users ( $M=3.57$ ,  $SD=1.67$ ) and non-users ( $M=3.35$ ,  $SD=1.52$ ) on the behavioural disengagement scale  $t(639)= -1.732$ ,  $p>.05$ .

Generally, CAM-users seemed to be more likely to adopt the remaining coping strategies than non-users even in the case of potentially maladaptive coping strategies. CAM-users ( $M=4.66$ ,  $SD=1.65$ ) used self-distraction more often than non-users ( $M=4.11$ ,  $SD=1.67$ ),  $t(639)= -4.116$ ,  $p<.001$ . Similarly, CAM-users used 'denial' ( $M=2.87$ ,  $SD=.78$ ) more than non-users ( $M=2.50$ ,  $SD=1.31$ ),  $t(639)= -4.45$ ,  $p<.001$ . CAM-users ( $M=4.06$ ,  $SD=1.96$ ) were also more likely to 'self blame' themselves for having IBS than non-users ( $M=3.68$ ,  $SD=1.87$ ),  $t(639)= -$

2.50,  $p < .01$ . CAM-users also indicated a greater degree of self-distraction ( $M=4.66$ ,  $SD=1.65$ ) than non-users ( $M=4.11$ ,  $SD=1.67$ ),  $t(639) = -4.12$ ,  $p < .001$ . In terms of venting emotions, there were also significant differences with CAM-users expressing greater levels ( $M=4.10$ ,  $SD=1.56$ ) than non-users ( $M=3.64$ ,  $SD=1.54$ ),  $t(639) = -3.69$ ,  $p < .001$ .

**Table 5.1 Descriptive statistics illustrating differences between CAM-users and non-users on IBS-QOL scale and subscales**

<i>IBS-QOL dimension</i>	<i>CAM use for IBS (y/n)</i>	<i>Cronbach's alpha</i>	<i>Mean</i>	<i>SD</i>	<i>t-value (effect size 'r')</i>
Total Score	No (n=275)	.95	49.17	22.05	<b>3.44** (r=.14)</b>
	Yes (n=370)	.95	43.33	20.71	
Dysphoria	No	.93	44.70	29.20	<b>2.36* (r=.09)</b>
	Yes	.93	39.43	27.21	
Interference with activity	No	.86	45.92	26.08	<b>2.34* (r=.09)</b>
	Yes	.84	41.20	24.85	
Body Image	No	.68	50.71	24.15	<b>3.44** (r=.13)</b>
	Yes	.66	44.04	24.50	
Health worry	No	.49	55.55	23.66	<b>2.07* (r=.08)</b>
	Yes	.47	51.66	23.55	
Food avoidance	No	.80	35.03	29.12	<b>3.45** (r=.14)</b>
	Yes	.77	27.47	25.31	
Social reaction	No	.75	49.46	27.76	<b>2.99** (r=.12)</b>
	Yes	.76	43.09	26.05	
Sexual score	No	.84	66.59	33.01	<b>3.61*** (r=.14)</b>
	Yes	.82	56.96	33.93	
Relationships score	No	.68	62.52	27.34	<b>2.89** (r=.11)</b>
	Yes	.65	56.17	27.71	

\*  $p < .05$  \*\* $p < .01$  \*\*\*  $p < .001$

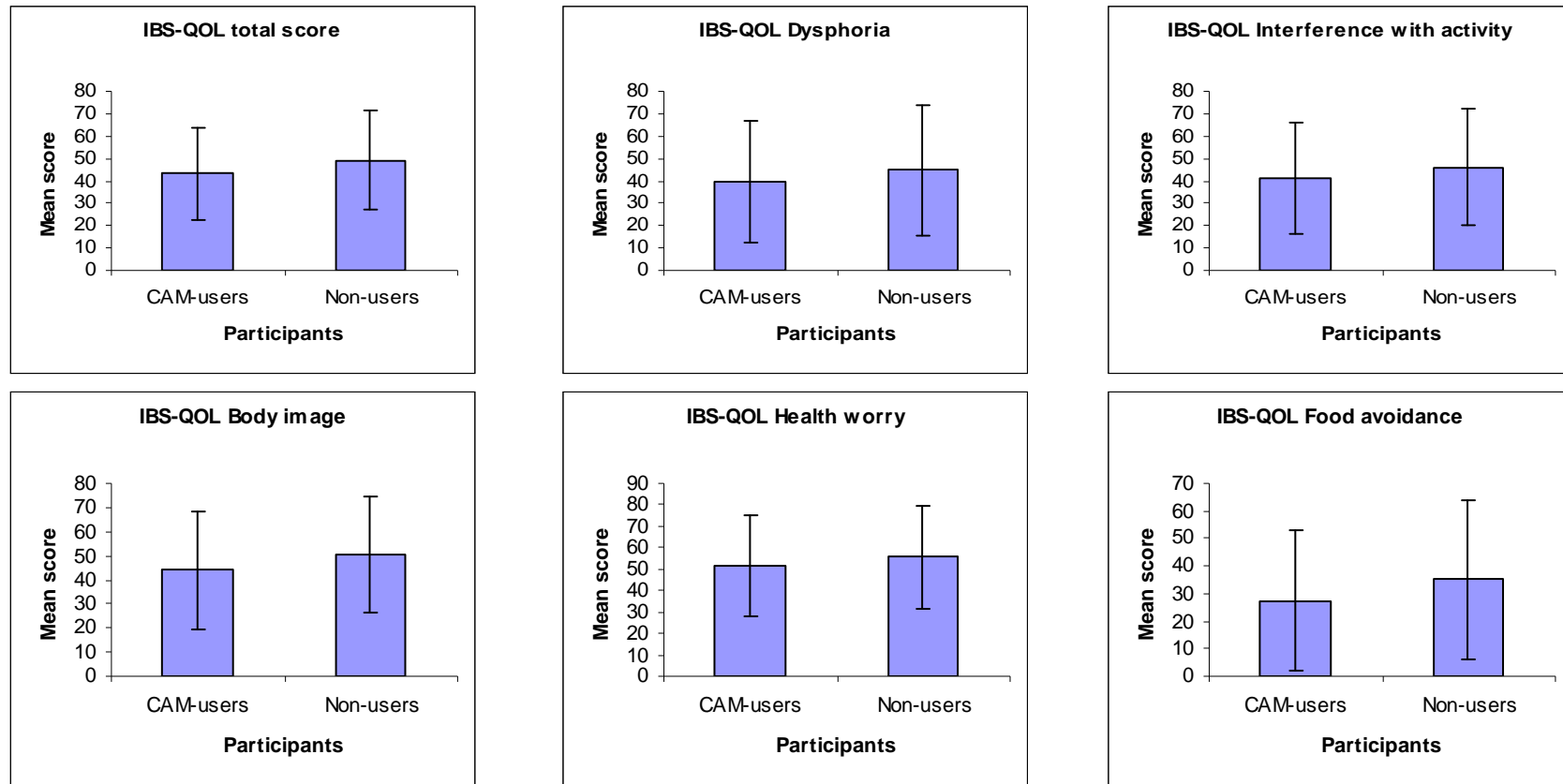
IBS-QOL scores have been transformed to a score out of 100. Lower scores are interpreted to mean poorer reported quality of life

CAM-users however seemed to be more adoptive of active coping ( $M=6.01$ ,  $SD=1.62$ ) than non-users ( $M=5.24$ ,  $SD=1.73$ ),  $t(639) = -5.74$ ,  $p < .001$ . Emotional support as a means of coping was also rated higher by CAM-users ( $M=4.78$ ,  $SD=1.80$ ) than non-users ( $M=4.26$ ,  $SD=1.82$ ),

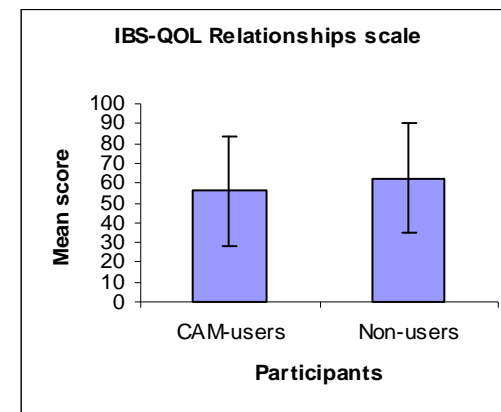
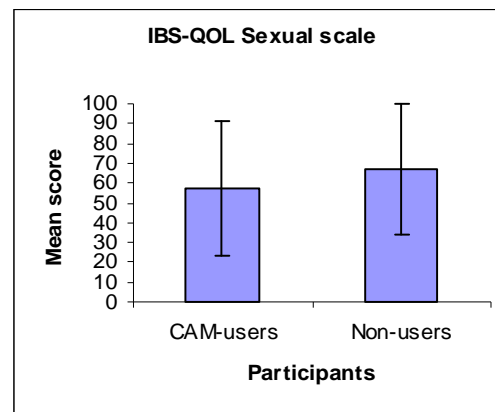
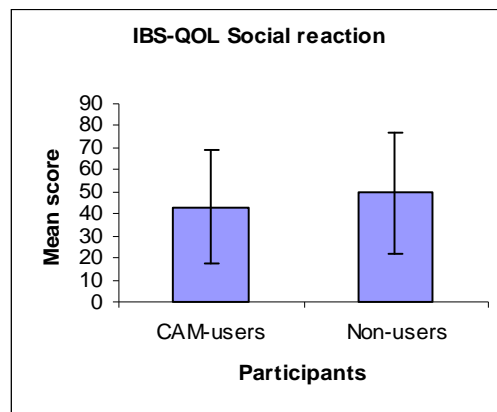
$t(639) = -3.57, p < .001$ . Instrumental support was more readily adopted by CAM-users ( $M = 5.40, SD = 1.77$ ) than non-users ( $M = 4.90, SD = 1.86$ ),  $t(639) = -3.44, p < .01$ . CAM-users also rated the use of humour to cope with their IBS more highly ( $M = 4.02, SD = 1.87$ ) than non-users ( $M = 3.72, SD = 1.90$ ),  $t(639) = -1.99, p < .05$ .

The remaining adaptive coping scales all violated the assumption of equal variances between the two groups. CAM-users were also more likely to positively reframe their situation ( $M = 3.86, SD = 1.73$ ) than non-users ( $M = 3.40, SD = 1.49$ ),  $t(623.14) = -3.63, p < .001$  where the assumption of equal variances was violated ( $F = 5.14, p < .05$ ). The 'planning' scale also violated the assumption of the equal variances between the two groups ( $F = 5.37, p < .05$ ) however CAM-users still rated planning more highly ( $M = 5.93, SD = 1.62$ ) than non-users ( $M = 5.28, SD = 1.76$ ),  $t(552.18) = -4.74, p < .001$ . Equal variances were not assumed on the acceptance scale ( $F = 4.78, p < .05$ ) where CAM-users rated their acceptance of having IBS more highly ( $M = 5.78, SD = 1.52$ ) than the non-users ( $M = 5.45, SD = 1.67$ ),  $t(548.66) = -2.59, p < .01$ . The use of religion seemed to be more prominent in CAM-users ( $M = 3.14, SD = 1.67$ ) than the non-users ( $M = 2.44, SD = .78$ ),  $t(554.61) = -7.06, p < .001$ , although the assumption of equal variances was again violated ( $F = 131.60, p < .001$ ), meaning the SPSS correction was reported. These trends may be observed visually in figures 5.3 to 5.4.

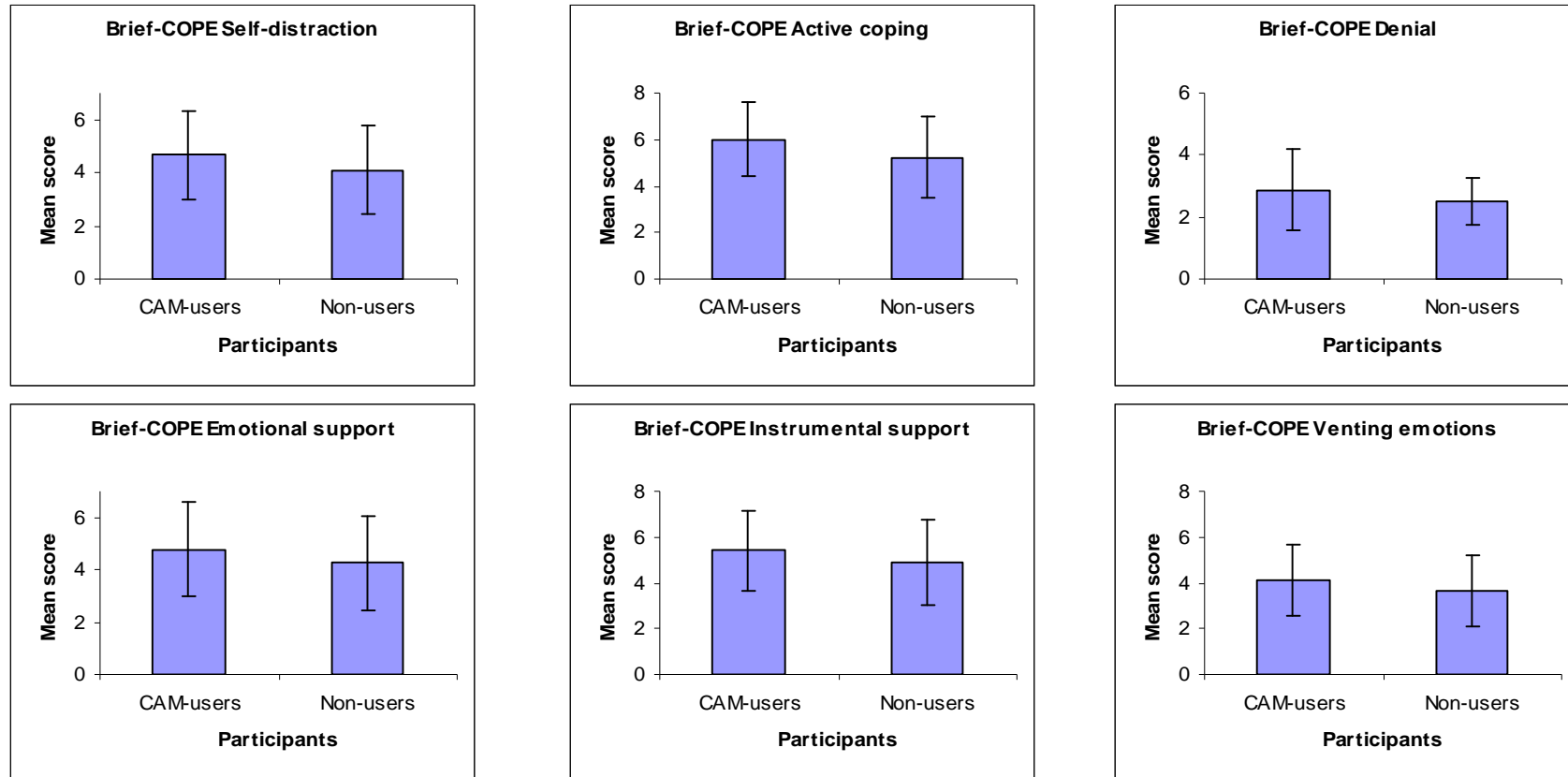
**Figure 5.1 Bar graphs illustrating significant differences between CAM-users and non-users on IBS-QOL subscales (total score, dysphoria, interference with activity, body image, health worry and food avoidance)**



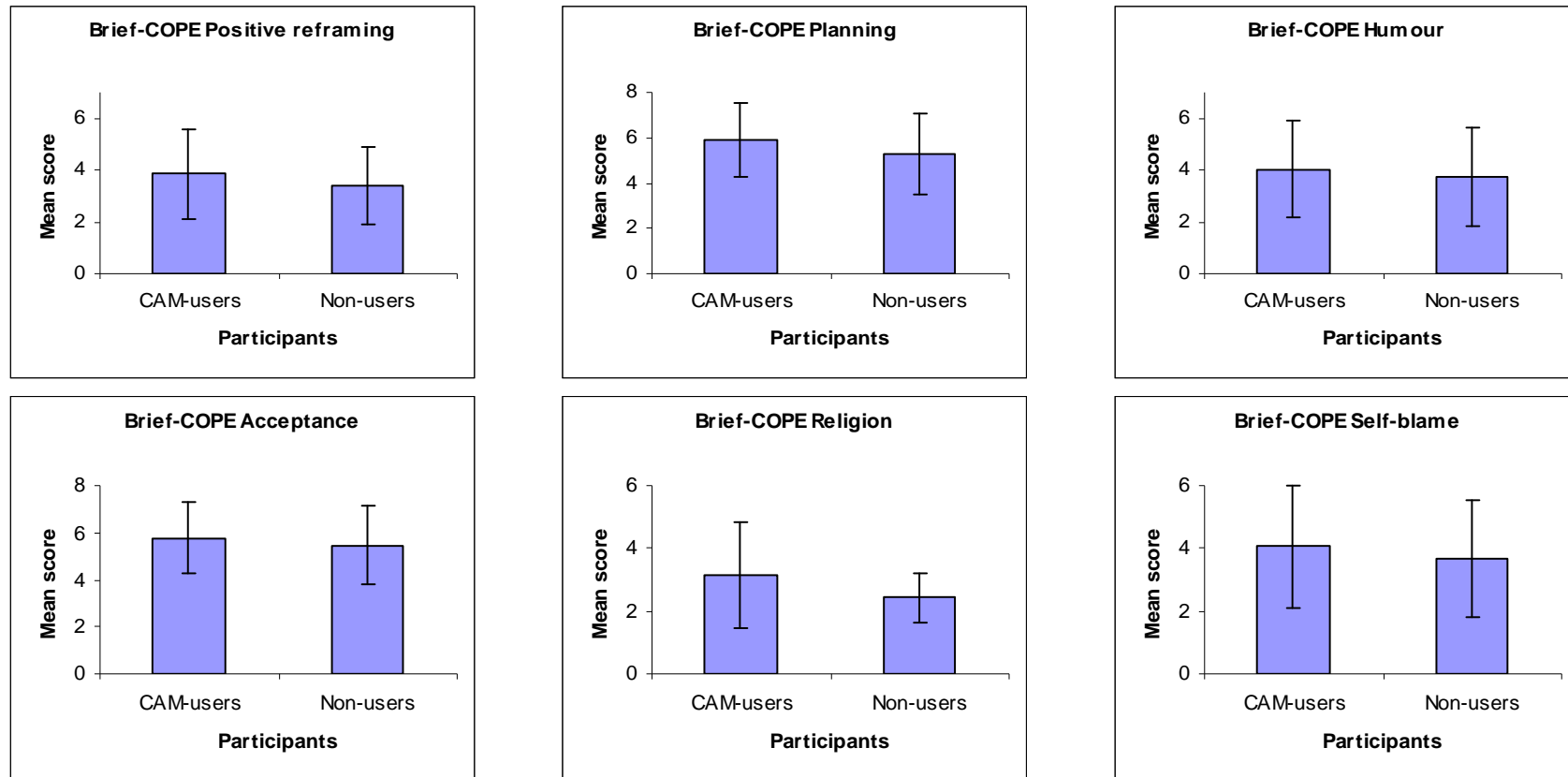
**Figure 5.2 Bar graphs illustrating significant differences between CAM-users and non-users on IBS-QOL subscales (Social reaction, sexual and relationships subscales)**



**Figure 5.3 Bar graphs illustrating significant differences between CAM-users and non-users on Brief-COPE scales (self-distraction, active coping, denial, emotional support, instrumental support and venting emotions)**



**Figure 5.4 Bar graphs illustrating significant differences between CAM-users and non-users on Brief-COPE scales (Positive reframing, planning, humour, acceptance, religion and self blame)**



**Table 5.2 Descriptive statistics and *t*-values for differences between CAM-users and non-users on Brief-COPE scales**

Brief-COPE scale	CAM use for IBS (y/n)	Cronbach's alpha	Mean	SD	<i>t</i> -value (effect size 'r')
Self distraction	No (n=271)	.55	4.11	1.67	<b>-4.12*** (r =.16)</b>
	Yes (n=370)	.51	4.66	1.65	
Active coping	No	.68	5.24	1.73	<b>-5.74*** (r =.22)</b>
	Yes	.75	6.01	1.62	
Denial	No	.54	2.50	.78	<b>-4.45*** (r =.16)</b>
	Yes	.64	2.87	1.31	
Substance use	No	.95	2.71	.79	-.60
	Yes	.93	2.78	.84	
Emotional support	No	.81	4.26	1.82	<b>-3.57*** (r =.14)</b>
	Yes	.81	4.78	1.80	
Instrumental support	No	.78	4.90	1.86	<b>-3.44** (r =.14)</b>
	Yes	.78	5.40	1.77	
Behavioural disengagement	No	.64	3.35	1.52	-1.73
	Yes	.67	3.57	1.67	
Venting emotions	No	.50	3.64	1.54	<b>-3.69*** (r =.14)</b>
	Yes	.55	4.10	1.56	
Positive reframing	No	.70	3.40	1.49	<b>-3.63*** (r =.14)</b>
	Yes	.72	3.86	1.73	
Planning	No	.76	5.28	1.76	<b>-4.74*** (r =.19)</b>
	Yes	.74	5.93	1.62	
Humour	No	.89	3.72	1.90	<b>-1.99* (r =.08)</b>
	Yes	.86	4.02	1.87	
Acceptance	No	.71	5.45	1.67	<b>-2.59** (r =.10)</b>
	Yes	.56	5.78	1.52	
Religion	No	.90	2.44	.78	<b>-7.06*** (r =.25)</b>
	Yes	.84	3.14	1.67	
Self blame	No	.76	3.68	1.87	<b>-2.50** (r =.10)</b>
	Yes	.79	4.06	1.96	

\* p<.05 \*\*p<.01 \*\*\* p<.001

The range of possible scores was 2 – 8, with higher scores meaning greater adoption of that particular coping style.

In sum, the observed trend in the differences between the two groups was that CAM-users seemed to score more highly on both adaptive and maladaptive coping strategies than non-users. The effect sizes were however mostly small (see section 4.3.5 and table 4.4) with only the



religion and active coping scale differences approaching a moderate effect size.

### **5.3.3 Relationships between illness perceptions and treatment beliefs**

As is common in CSM based research, to assess theoretical consistency (Moss-Morris et al., 2002; Rutter & Rutter, 2002) and to address the third objective in this study (section 5.1), relationships were explored between scales of the IPQ-R. As this study considered an 'extended' CSM, the scales of the BMQ-General and CAMBI for CAM-users and non-users were also considered (tables 5.3 and 5.4).

#### **5.3.3.1 Non-users**

In non-users (table 5.3), stronger illness identity (reporting more symptoms) was positively associated with reporting more consequences of IBS ( $r=.19, p<.01$ ) and having stronger emotional representations of illness ( $r=.14, p<.05$ ). Stronger illness identity was also related to stronger beliefs in natural treatments ( $r=.29, p<.001$ ), beliefs about participation in treatment ( $r=.17, p<.01$ ) and holistic health beliefs ( $r=.13, p<.05$ ). Stronger beliefs in a chronic timeline were associated with stronger consequences of IBS ( $r=.41, p<.001$ ) and stronger emotional representations ( $r=.32, p<.01$ ). Greater beliefs in a chronic timeline of IBS were also associated with lesser beliefs about both treatment ( $r=-.28, p<.001$ ) and personal control ( $r=-.42, p<.001$ ), weaker beliefs about risk factors as a cause of IBS ( $r=-.16, p<.01$ ) and weaker beliefs in medication harm ( $r=-.16, p<.05$ ) and overuse ( $r=-.17, p<.01$ ). Stronger beliefs in a cyclical timeline were associated with beliefs regarding an internal ( $r=.20, p<.01$ ) and external ( $r=.16, p<.01$ ) cause as well as being indicative of a lesser degree of coherence about IBS ( $r=-.15, p<.05$ ). Reporting of stronger consequences was associated with less personal control ( $r=-.27, p<.001$ ), less treatment control ( $r=-.28, p<.001$ ), less understanding (coherence) of IBS ( $r=-.17, p<.01$ ) and stronger emotional representations ( $r=.62, p<.001$ ). Stronger consequences also resulted in reporting of stronger beliefs in an external cause ( $r=.17, p<.01$ ). Having

greater personal control over IBS was strongly related to treatment control ( $r=.62, p<.001$ ) as well as being related to greater coherence ( $r=.28, p<.001$ ), beliefs in an internal cause ( $r=.21, p<.01$ ), beliefs in risk factors as a cause ( $r=.25, p<.001$ ), greater concern that medicines may cause harm ( $r=.21, p<.01$ ), stronger beliefs in participation in treatment ( $r=.17, p<.01$ ) and stronger beliefs in holistic health ( $r=.29, p<.001$ ). Greater personal control also resulted in reporting of greater emotional representations ( $r=-.27, p<.001$ ).

Similarly, stronger beliefs in treatment control resulted in stronger emotional representations being reported ( $r=-.30, p<.001$ ). Treatment control was however associated with stronger beliefs in illness coherence ( $r=.23, p<.001$ ), stronger beliefs in risk factors as a cause of IBS ( $r=.13, p<.05$ ) and stronger beliefs in medication harm ( $r=.15, p<.05$ ). Greater treatment control also resulted in more positive beliefs about CAM on the natural treatments scale ( $r=.16, p<.05$ ), the participation in treatment scale ( $r=.20, p<.01$ ) and beliefs about holistic health ( $r=.24, p<.001$ ). Stronger beliefs in illness coherence were negatively related to emotional representations ( $r=-.26, p<.001$ ) and beliefs in an external cause ( $r=-.28, p<.001$ ). Stronger emotional representations resulted in stronger beliefs about both internal ( $r=.23, p<.001$ ) and external causes ( $r=.17, p<.01$ ) of IBS.

The causal scales were all positively related. A stronger perception of an internal cause was positively related to perceptions of an external cause ( $r=.28, p<.001$ ) and more strongly to beliefs regarding risk factors ( $r=.44, p<.001$ ). External causal beliefs were also related to beliefs in risk factors causing IBS ( $r=.43, p<.001$ ). Stronger beliefs in an internal cause were also related to beliefs regarding the overuse of medication ( $r=.13, p<.05$ ) and holistic health ( $r=.25, p<.001$ ). Similarly, external causal beliefs were also related to beliefs in overuse of conventional medication ( $r=.20, p<.01$ ). Stronger beliefs in risk factors causing IBS were related to both beliefs about harm ( $r=.16, p<.01$ ) and more strongly

to overuse ( $r=.26$ ,  $p<.001$ ) of conventional medication as well as being more weakly related to beliefs in holistic health ( $r=.12$ ,  $p<.05$ ).

As with the causal beliefs, beliefs about conventional treatment were also related. Beliefs in harm were related to medication overuse ( $r=.65$ ,  $p<.001$ ) although this was to a greater degree than previous work (e.g. Horne et al.,1999). Beliefs in harm were also related to the three dimensions of the CAMBI, beliefs in natural treatment ( $r=.34$ ,  $p<.001$ ), beliefs regarding participation in treatment ( $r=.13$ ,  $p<.05$ ) and beliefs in treating the whole body (holistic health) ( $r=.27$ ,  $p<.001$ ). The BMQ overuse scale was related to natural treatment beliefs ( $r=.31$ ,  $p<.001$ ) and holistic health beliefs ( $r=.17$ ,  $p<.01$ ). The CAMBI scales were also related showing consistency with Bishop et al. (2005). Beliefs in natural treatments were related to participation in treatment beliefs ( $r=.28$ ,  $p<.001$ ) and more strongly to holistic health beliefs ( $r=.46$ ,  $p<.001$ ). Beliefs in treatment participation were also strongly related to holistic health beliefs ( $r=.51$ ,  $p<.001$ ).

### **5.3.3.2 CAM-users**

In exploring the relationships between illness perceptions and treatment beliefs in CAM-users there were both similar patterns of relationships detected as well as different associations when compared with non-users. Table 5.4 illustrates that CAM-users' ratings of illness identity were related to illness consequences ( $r=.29$ ,  $p<.001$ ) and emotional representations ( $r=.17$ ,  $p<.01$ ) which were both stronger associations than observed in non-users. CAM-users however showed relationships between illness identity and both the chronic ( $r=.16$ ,  $p<.01$ ) and cyclical ( $r=.11$ ,  $p<.05$ ) timeline scales and external causes ( $r=.21$ ,  $p<.001$ ). Greater illness identity was also associated with less personal ( $r=-.11$ ,  $p<.05$ ) and treatment ( $r=-.18$ ,  $p<.01$ ) control. As with non-users, CAM-user ratings of a chronic timeline were related to illness consequences ( $r=.31$ ,  $p<.001$ ), emotional representations ( $r=.19$ ,  $p<.001$ ) and negatively related to overuse of conventional medication ( $r=-.11$ ,  $p<.05$ ). Higher ratings on the chronic timeline scale also indicated less personal ( $r=-.25$ ,

$p < .001$ ) and treatment ( $r = -.43, p < .001$ ) control. Treatment control beliefs aside the trend of these relationships was generally slightly weaker than in non-users. Stronger beliefs in a chronic timeline also resulted in lower internal cause beliefs ( $r = -.15, p < .01$ ) and higher beliefs in participation in treatment ( $r = .13, p < .05$ ). CAM-users also differed in their perceptions of a cyclical timeline which was solely related to stronger beliefs in personal control ( $r = .18, p < .01$ ).

CAM-users showed an almost identical pattern to non-users when comparing the IPQ-R consequences scale with other scales although in CAM-users generally stronger relationships were observed than in non-users. Stronger consequences were related to higher emotional representations ( $r = .60, p < .001$ ) and beliefs in external causes of IBS ( $r = .27, p < .001$ ). Stronger consequences were also negatively related to both personal ( $r = -.34, p < .001$ ) and treatment ( $r = -.36, p < .001$ ) control as well as illness coherence ( $r = -.21, p < .001$ ). The relationships between personal control beliefs and other scales were similar to non-users and generally stronger relationships were observed. As with non-users, stronger personal control beliefs were associated with greater treatment control ( $r = .67, p < .001$ ), illness coherence ( $r = .30, p < .001$ ), beliefs in internal causes ( $r = .32, p < .001$ ), beliefs in risk factors as a cause of IBS ( $r = .18, p < .01$ ) and beliefs in holistic health ( $r = .19, p < .001$ ). Stronger beliefs in personal control were associated with lesser emotional representations of IBS ( $r = -.27, p < .001$ ) and to lesser beliefs about the overuse of medication ( $r = -.13, p < .05$ ) the latter finding being unique to CAM-users.

Treatment control ratings also showed similar relationships to non-users. Greater treatment control beliefs were related to greater illness coherence ( $r = .25, p < .001$ ) and stronger holistic health beliefs ( $r = .15, p < .01$ ) although this relationship was less strong than in the non-users. There was also a slightly stronger negative relationship found between treatment control and emotional representations ( $r = -.34, p < .001$ ) than in non-users. Unique to CAM-users, greater treatment control perceptions

were also found to relate to stronger beliefs in an internal cause ( $r=.25$ ,  $p<.001$ ) and risk factors ( $r=.15$ ,  $p<.01$ ) as causes of IBS.

Stronger illness coherence showed a negative relationship with both emotional representations ( $r=-.37$ ,  $p<.001$ ) and beliefs in an external cause ( $r=-.20$ ,  $p<.001$ ) although these relationships were stronger and weaker respectively when compared to non-users. In addition to the same pattern of relationships found in non-users, CAM-users were found to demonstrate lesser beliefs in medication overuse ( $r=-.13$ ,  $p<.05$ ) and natural treatment beliefs ( $r=-.13$ ,  $p<.05$ ) as illness coherence increased. Compared to non-users, there was a less strong relationship between emotional representations and external causal beliefs in CAM-users ( $r=.12$ ,  $p<.05$ ).

Again, in a similar pattern to non-users, beliefs about internal causes were consistently related to beliefs in external causes ( $r=.25$ ,  $p<.001$ ), risk factors ( $r=.43$ ,  $p<.001$ ) and beliefs in holistic health in CAM-users ( $r=.27$ ,  $p<.001$ ). These relationships all demonstrated a similar strength to those observed in non-users. CAM-users also demonstrated a relationship between internal causal beliefs and natural treatment beliefs ( $r=.14$ ,  $p<.01$ ). External causal beliefs were associated with risk factor beliefs ( $r=.36$ ,  $p<.001$ ) although to a slightly lesser extent than in non-users.

Beliefs about conventional treatment and CAM were related in similar ways to the non-users, although to a slightly lesser extent where there were similar patterns of relationship. Beliefs about harm were related to the overuse scale ( $r=.60$ ,  $p<.001$ ). Beliefs about harm were also related to natural treatment beliefs ( $r=.27$ ,  $p<.001$ ) and holistic health beliefs ( $r=.23$ ,  $p<.001$ ). Beliefs in medication overuse were related to natural treatment beliefs ( $r=.17$ ,  $p<.01$ ) but to a lesser extent than non-users and negatively related to participation in treatment ( $r=-.23$ ,  $p<.001$ ). The scales of the CAMBI were also related consistently, although less strong than in non-users. Beliefs in natural treatments were related to both

participation in treatment ( $r=.26, p<.001$ ) and holistic health beliefs ( $r=.37, p<.001$ ). Participation in treatment was also related to beliefs in natural treatments ( $r=.41, p<.001$ ).

#### **5.3.4 Testing the theorised mediating role of coping**

As outlined previously (section 5.2.5.3) mediation was tested in three steps according to criteria set out by Baron and Kenny (1986). Firstly, predictor variables were correlated on outcome. Secondly, predictor variables were correlated with potential mediating variables. Third, multiple regression analyses were used to determine if potential mediating variables predicted outcome whilst controlling for predictor variables. Then the Preacher and Hayes (2004) bootstrapping procedure was utilised to determine statistical significance of identified mediation effects detected in the three steps outlined.

**Table 5.3 Relationships between IPQ-R, BMQ and CAMBI scales (non-users): Pearson's *r* (n=266)**

	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Identity	.08	.11	<b>.19**</b>	.05	-.02	-.03	<b>.14*</b>	.18	.05	.06	.05	.03	<b>.25***</b>	<b>.19**</b>	<b>.18**</b>
2. Timeline chronic		.07	<b>.40***</b>	<b>-.28***</b>	<b>-.42***</b>	.01	<b>.32***</b>	-.05	-.08	<b>-.17**</b>	<b>-.16*</b>	<b>-.15*</b>	-.02	.01	-.10
3. Timeline cyclical			.06	.08	-.01	<b>-.17**</b>	.12	<b>.19**</b>	<b>.15*</b>	.06	-.02	.09	.003	.02	.03
4. Consequences				<b>-.25***</b>	<b>-.26***</b>	<b>-.15*</b>	<b>.62***</b>	.03	<b>.18**</b>	-.03	-.07	.01	.05	<b>.16**</b>	.07
5. Personal control					<b>.61***</b>	<b>.25**</b>	<b>-.26***</b>	<b>.22***</b>	-.07	<b>.26***</b>	<b>.17**</b>	.09	.09	.08	<b>.24***</b>
6. Treatment control						<b>.22***</b>	<b>-.30***</b>	.10	-.09	<b>.15*</b>	<b>.13*</b>	.10	<b>.14*</b>	.09	<b>.19**</b>
7. Illness coherence							<b>-.25***</b>	-.03	<b>-.26***</b>	-.11	.08	-.10	-.08	-.05	.02
8. Emotional representations								<b>.21***</b>	<b>.16*</b>	.05	.01	.07	.11	.06	.09
9. Internal cause									<b>.29***</b>	<b>.46***</b>	.10	<b>.15*</b>	.11	-.02	<b>.23***</b>
10. External cause										<b>.43***</b>	.02	<b>.19**</b>	.04	-.06	.02
11. Risk factors											<b>.17**</b>	<b>.28***</b>	.05	-.01	.09
12. BMQ Harm												<b>.65***</b>	<b>.30***</b>	.09	<b>.24***</b>
13. BMQ Overuse													<b>.30***</b>	-.02	<b>.18**</b>
14. CAMBI Natural														<b>.32***</b>	<b>.50***</b>
15. CAMBI Participation															<b>.52***</b>
16. CAMBI Holistic															

\* p<.05 \*\*p<.01 \*\*\* p<.001

**Table 5.4 Relationships between IPQ-R, BMQ and CAMBI scales (CAM-users): Pearson's *r* (n=359)**

	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Identity	<b>.16**</b>	<b>.11*</b>	<b>.29***</b>	<b>-.11*</b>	<b>-.18**</b>	-.03	<b>.18**</b>	.03	<b>.20***</b>	.08	.07	.06	.10	.01	-.02
2. Timeline chronic		-.02	<b>.31***</b>	<b>-.26***</b>	<b>-.43***</b>	.0	<b>.19***</b>	<b>-.15**</b>	-.06	-.04	-.09	<b>-.11*</b>	.04	<b>.13*</b>	-.02
3. Timeline cyclical			-.06	<b>.18**</b>	.05	-.06	.06	.05	-.10	.01	.09	-.01	.06	.01	-.01
4. Consequences				<b>-.34***</b>	<b>-.36***</b>	<b>-.21***</b>	<b>.60***</b>	-.03	<b>.28***</b>	.02	.02	.10	.10	-.04	.02
5. Personal control					<b>.67***</b>	<b>.30***</b>	<b>-.28***</b>	<b>.32***</b>	-.05	<b>.19***</b>	-.01	<b>-.12*</b>	.03	.09	<b>.19***</b>
6. Treatment control						<b>.25***</b>	<b>-.34***</b>	<b>.25***</b>	.01	<b>.15**</b>	-.01	-.10	.06	.07	<b>.15**</b>
7. Illness coherence							<b>-.37***</b>	.05	<b>-.20***</b>	-.01	-.06	<b>-.14**</b>	<b>-.13*</b>	.10	-.01
8. Emotional representations								.05	<b>.13*</b>	.01	.07	.09	.01	-.003	.07
9. Internal cause									<b>.26***</b>	<b>.44***</b>	.01	.03	.10	-.003	<b>.27***</b>
10. External cause										<b>.35***</b>	.04	<b>.10*</b>	.05	.01	.08
11. Risk factors											-.02	.09	.06	<b>-.13*</b>	<b>.11*</b>
12. BMQ Harm												<b>.60***</b>	<b>.36***</b>	.07	<b>.25***</b>
13. BMQ Overuse													<b>.27***</b>	<b>-.19***</b>	-.01
14. CAMBI Natural														<b>.17**</b>	<b>.37***</b>
15. CAMBI Participation															<b>.39***</b>
16. CAMBI Holistic															

\* p<.05 \*\*p<.01 \*\*\* p<.001



#### **5.3.4.1 Step one: Predictor–outcome relationship**

Baron and Kenny (1986) suggest the first stage of testing for mediation is to determine a significant relationship between predictor and outcome. Relationships between illness representations and treatment beliefs and total scores from the IBS-QOL were examined for both CAM-users and non-users. This process enabled non-significant relationships to be excluded from further testing of mediation as a non-significant correlation between predictor and outcome, would not yield a significant regression coefficient to be reduced (step three).

Table 5.5 illustrates the relationships between predictors and outcome. The general trend that emerged was that ‘negative’ predictors (e.g. identity, consequences) resulted in lower reported quality of life scores, whereas greater control and understanding resulted in participants reporting increased quality of life. Examination of table 5.5 showed that in both non-users and CAM-users illness identity was significantly negatively related to total IBS-QOL score ( $r=-.20$ ,  $p<.01$  and  $r=-.31$ ,  $p<.001$  respectively), suggesting that stronger illness identity is associated with impaired quality of life, something more evident in those that use CAM. Both CAM-users ( $r=-.30$ ,  $p<.001$ ) and non-users ( $r=-.29$ ,  $p<.001$ ) showed beliefs in a chronic timeline to be related to lower reported quality of life scores. Strong perceptions of illness consequences were strongly and negatively related to reported quality of life in both CAM-users ( $r=-.70$ ,  $p<.001$ ) and non-users ( $r=-.66$ ,  $p<.001$ ). Higher ratings of personal control resulted in higher reported quality of life in both CAM-users ( $r=.30$ ,  $p<.001$ ) and non-users ( $r=.25$ ,  $p<.001$ ). Similarly, greater control over treatment was positively related to reported quality of life in CAM-users ( $r=.35$ ,  $p<.001$ ) and non-users ( $r=.33$ ,  $p<.001$ ). Greater illness coherence also resulted in higher quality of life being reported in CAM-users ( $r=.26$ ,  $p<.001$ ) and non-users ( $r=.19$ ,  $p<.01$ ).

Stronger emotional representations resulted in lower reported quality of life in both CAM-users ( $r=-.65$ ,  $p<.001$ ) and non-users ( $r=-.70$ ,  $p<.001$ ).

However stronger beliefs in an internal cause were weakly negatively related to reported quality of life in non-users only ( $r=-.15$ ,  $p<.05$ ). Stronger beliefs in external causal factors were related to lower reported quality of life scores in both groups (non-users:  $r=-.17$ ,  $p<.01$ ; CAM-users:  $r=-.20$ ,  $p<.001$ ). Greater beliefs in harm caused by conventional medication were related to reduced reported quality of life in both groups, which yielded the same coefficient value ( $r=-.13$ ,  $p<.05$ ). Finally, in CAM-users only, more positive beliefs in natural treatments resulted in lower IBS-QOL scores ( $r=-.11$ ,  $p<.05$ ).

Table 5.6 presents the relationships between emotional representations and emotional outcome (the IBS-QOL Dysphoria subscale). In both groups the relationship between stronger emotional representations and poorer reported emotional quality of life was present in both groups (CAM-users:  $r=-.74$ ,  $p<.001$ ; non-users:  $r=-.78$ ,  $p<.001$ ).

The illness perceptions and treatment beliefs that were significantly related to IBS-QOL scores (including emotional representations and emotional outcome) were then examined for relationships with scales on the Brief-COPE (step two of the Baron and Kenny criteria).

#### **5.3.4.2 Step two: predictor–mediator relationship**

Predictor variables that showed significant relationships with outcome (tables 5.5 and 5.6) were then examined for significant relationships with coping strategies (non-significant relationships were therefore discarded at this stage). This was to establish the second step of the Baron and Kenny test for mediation in that each predictor should be significantly related to the potential mediator. Significant relationships were then explored further with regression equations to test for step three of the mediation criteria (section 5.2.5.3).

##### **5.3.4.2.1 Non-users**

In non-users (table 5.7), stronger illness identity was related to greater self blame ( $r=.16$ ,  $p<.01$ ). Those who had a stronger belief in a chronic timeline also had higher ratings of behavioural disengagement ( $r=.21$ ,

$p < .01$ ). Stronger perceptions of illness consequences were related to greater use of denial ( $r = .24, p < .001$ ), substance use ( $r = .13, p < .05$ ), behavioural disengagement ( $r = .25, p < .001$ ), venting emotions ( $r = .17, p < .01$ ) and self blame ( $r = .28, p < .001$ ). Greater personal control was related to more acceptance ( $r = .15, p < .05$ ) and related to less use of denial ( $r = -.15, p < .05$ ) and behavioural disengagement ( $r = -.25, p < .01$ ). Higher ratings of treatment control were also related to less use of denial ( $r = -.15, p < .05$ ), behavioural disengagement ( $r = -.38, p < .001$ ) and self blame ( $r = -.14, p < .05$ ). More illness coherence was related to greater acceptance ( $r = .17, p < .01$ ) but less use of self blame ( $r = -.13, p < .05$ ), behavioural disengagement ( $r = -.18, p < .01$ ) and denial ( $r = -.21, p < .01$ ). Stronger emotional representations were positively associated with more use of denial ( $r = .31, p < .001$ ), substance use ( $r = .14, p < .05$ ), behavioural disengagement ( $r = .34, p < .001$ ), venting emotions ( $r = .23, p < .001$ ) and self blame ( $r = .40, p < .001$ ).

**Table 5.5 Relationships between IPQ-R, BMQ, CAMBI scales, IBS-QOL total score: Pearson's  $r$**

<i>IPQ-R, BMQ &amp; CAMBI scales</i>	<i>Non-users: IBS-QOL (total) (n=266)</i>	<i>CAM-users: IBS-QOL (total) (n=359)</i>
Identity	-.20**	-.31***
Timeline chronic	-.30***	-.29***
Timeline cyclical	-.07	-.01
Consequences	-.66***	-.70***
Personal control	.25***	.30***
Treatment control	.33***	.35***
Illness coherence	.19**	.26***
Emotional representations	-.70***	-.65***
Internal cause	-.15*	-.07
External cause	-.17**	-.20***
Risk factors	-.07	-.05
BMQ Harm	-.07	-.07
BMQ Overuse	-.13*	-.13*
CAMBI Natural	-.11	-.11*
CAMBI Participation	-.06	.04
CAMBI Holistic	-.06	.01

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

In terms of causal factors, stronger beliefs in internal causes were related to more venting of emotions ( $r=.13, p<.05$ ), greater self blame ( $r=.31, p<.001$ ) but less acceptance of IBS ( $r=-.13, p<.05$ ). Greater belief in an external cause resulted in more use of denial ( $r=.19, p<.01$ ) and more self blame ( $r=.14, p<.05$ ). Stronger participant beliefs in overuse of conventional medication resulted in greater substance use ( $r=.14, p<.05$ ) less acceptance of having IBS ( $r=-.13, p<.05$ ) and greater self blame for having IBS ( $r=.16, p<.05$ ).

**Table 5.6 Relationships (Pearson's  $r$ ) between IPQ-R 'emotional representations' scale and IBS-QOL 'dysphoria' subscale (emotional outcome)**

	<i>Non-users: Dysphoria subscale (n=266)</i>	<i>CAM-users: Dysphoria subscale (n=359)</i>
Emotional Representations	<b>-.78***</b>	<b>-.74***</b>

\*\*\*  $p<.001$

#### **5.3.4.2.2 CAM-users**

CAM-users (table 5.8) showed similarities with non-users in use of certain coping strategies. Stronger illness identity was related to more denial ( $r=.19, p<.001$ ), greater behavioural disengagement ( $r=.20, p<.001$ ) and more self blame for having IBS ( $r=.18, p<.01$ ). Stronger perceptions of a chronic timeline were related to more behavioural disengagement ( $r=.14, p<.01$ ) and greater acceptance ( $r=.11, p<.05$ ). Stronger perceptions of consequences of IBS was related to more use of denial ( $r=.23, p<.001$ ), more behavioural disengagement ( $r=.30, p<.001$ ), greater venting of emotions ( $r=.11, p<.05$ ), more self blame ( $r=.26, p<.001$ ) but less acceptance ( $r=-.11, p<.05$ ).

Higher ratings of personal control resulted in less use of denial ( $r=-.16, p<.01$ ), less behavioural disengagement ( $r=-.43, p<.001$ ) but more use of instrumental support ( $r=.12, p<.05$ ). Similarly, stronger treatment control

resulted in less denial ( $r=-.12, p<.05$ ), less behavioural disengagement ( $r=-.36, p<.001$ ) but greater use of instrumental support ( $r=.12, p<.05$ ) and religion ( $r=.12, p<.05$ ). More coherence regarding IBS indicated less use of denial ( $r=-.18, p<.01$ ), behavioural disengagement ( $r=-.18, p<.01$ ), less self blame ( $r=-.13, p<.05$ ) but more acceptance of having IBS ( $r=.24, p<.01$ ). Stronger emotional representations resulted in more behavioural disengagement ( $r=.30, p<.001$ ) and more self blame ( $r=.30, p<.001$ ) but less use of humour ( $r=-.11, p<.05$ ).

Stronger participant beliefs in external causes resulted in more denial ( $r=.16, p<.01$ ) and less acceptance of having IBS ( $r=-.11, p<.05$ ). Stronger beliefs in natural treatments resulted in greater self distraction ( $r=.16, p<.01$ ), more active coping ( $r=.17, p<.01$ ), use of more emotional support ( $r=.19, p<.001$ ), more instrumental support ( $r=.18, p<.01$ ), more venting of emotions ( $r=.21, p<.001$ ), more positive reframing ( $r=.11, p<.05$ ) and planning ( $r=.22, p<.001$ ), more acceptance ( $r=.11, p<.05$ ) and greater use of religion ( $r=.20, p<.001$ ).

Significant relationships between illness perceptions, treatment beliefs and coping strategies identified from these correlation tests were used to guide which variables were entered into multiple regression analyses to test for step three of the mediation criteria.

#### ***5.3.4.3 Step three: mediator–outcome relationship, controlling for predictor variable***

From testing of the first two steps of the Baron and Kenny criteria for simple mediation, significant relationships found between predictors and outcome (tables 5.5 and 5.6) guided exploration of relationships between predictor and potential mediating variables (tables 5.7 and 5.8). The final stage of testing for mediation determined the scales of the Brief-COPE that predicted IBS-QOL scores whilst controlling for predictor variables. For a mediation effect to be present a reduction in the effect of the predictor variable on the outcome variable needed to be observed.

Pathways that satisfied the Baron and Kenny criteria for mediation are presented in tables 5.9 to 5.18 (non-significant findings for step three are therefore omitted). These tables illustrate the reduction of the Beta coefficient between predictor and outcome and the significant pathway between mediator and outcome whilst controlling for each predictor. This is illustrated by providing regression coefficients from pathways  $X \rightarrow Y$  and  $M \rightarrow Y(X)$  are presented for both CAM-users and non-users. The significance of any mediation effects was tested using the Sobel test and bootstrapping estimates (based on a theoretical sample of 1000 datasets) which are also presented in the following tables. *z* scores (and associated significance) are presented to indicate the statistical significance of the mediation effect along with the Sobel test estimate and associated confidence intervals from the bootstrapping procedure (Preacher & Hayes, 2004). To illustrate the unique portion of variance in each regression model accounted for by the mediation effect, an estimate of  $R^2$  mediation effect is presented (Fairchild et al., 2009).

#### ***5.3.4.3.1 Step three of mediation testing: IPQ-R symptom based scales (identity, timeline chronic and consequences) and IBS-QOL scores***

Step three of establishing mediation was considered for IPQ-R symptom based scales that were shown to be significantly related to IBS-QOL scores (outcome) and scales of the Brief-COPE (potential mediators). Tables 5.9 and 5.10 illustrate regression coefficient values for the mediator–outcome pathway, whilst controlling for the predictor (equation 2 in each table) for each group of participants. Coefficient values are provided for each predictor variable showing coefficient values for the direct path to outcome and to illustrate any reduction in effect due to inclusion of the mediator in each regression model.

#### ***Illness identity***

In non-users (table 5.9), self blame partially mediated ( $z=-2.48, p<.05$ ) the pathway between illness identity ( $Beta= -.13, p<.05$ ) and IBS-QOL. The mediation effect accounted for 2.30 (10.46%) of the total variance

explained by the model of 22%. CAM-users (table 5.10), demonstrated a similar pattern although a stronger mediation effect where self blame partially mediated ( $z=-3.28$ ,  $p<.01$ ) the pathway between illness identity ( $Beta= -.24$ ,  $p<.01$ ) and IBS-QOL scores. The variance explained by mediation was 4.10 (17.83%) of the total variance explained by the model of 23%. The  $R^2$  change for both groups showed that self blame was contributing over half of the variance explained.

Between the illness identity and IBS-QOL pathway there were two additional partial mediators in CAM-users. Denial partially mediated ( $z=-2.40$ ,  $p<.05$ ) the pathway between illness identity ( $Beta= -.28$ ,  $p<.001$ ) and IBS-QOL scores adding a small but significant 3% of variance to the regression model. The variance explained by mediation was 4 (19.17%) of the total variance explained by the model of 13%. Behavioural disengagement also partially mediated ( $z=-3.39$ ,  $p<.01$ ) the pathway between illness identity ( $Beta= -.25$ ,  $p<.001$ ) and IBS-QOL scores adding approximately half (10%) of the variance explained. The mediation effect accounted for 3.98 (21.61%), of the total variance explained of 20%.

### ***Chronic timeline***

In both groups, the coping style behavioural disengagement partially mediated the pathway between the IPQ-R chronic timeline scale and IBS-QOL scores. In CAM-users, behavioural disengagement ( $R^2$  change = .10) demonstrated a significant mediation effect ( $z=-2.53$ ,  $p<.05$ ) reducing the effect of timeline beliefs ( $Beta= -.23$ ,  $p<.001$ ) of which the mediation effect accounted for 2.47 (13.0%) of the total variance explained of 19%. A stronger partial mediation effect of behavioural disengagement ( $R^2$  change = .11) was detected in non-users ( $z=-3.12$ ,  $p<.01$ ) with the effect of timeline beliefs reduced ( $Beta= -.21$ ,  $p<.001$ ). The mediation effect accounted for 3.89 (21.61%) of the total explained variance of 18%.

**Table 5.7 Relationships between IPQ-R, BMQ and CAMBI scales and Coping strategies (non-users): Pearson's *r* (n=266)**

	<i>Identity</i>	<i>Timeline chronic</i>	<i>Consequences</i>	<i>Personal control</i>	<i>Treatment control</i>	<i>Illness coherence</i>	<i>Emotional representations</i>	<i>Internal cause</i>	<i>External cause</i>	<i>Medication overuse</i>
Self distraction	.12	-.05	<b>.14*</b>	-.02	-.03	-.07	.08	.04	-.02	-.02
Active Coping	.05	-.01	<b>.17**</b>	<b>.15*</b>	.10	.06	.01	<b>-.13*</b>	-.08	<b>-.13*</b>
Denial	.12	-.01	<b>.24***</b>	<b>-.15*</b>	<b>-.15*</b>	<b>-.21**</b>	<b>.31***</b>	.08	<b>.19**</b>	<b>.13*</b>
Substance use	.03	.01	<b>.13*</b>	-.05	-.03	-.10	.10	.11	.11	<b>.14*</b>
Emotional support	.03	-.03	.10	<b>.21**</b>	<b>.18**</b>	.06	.04	.01	-.09	<b>-.19**</b>
Instrumental support	.02	-.04	.10	<b>.12*</b>	<b>.16**</b>	-.01	-.01	-.04	.02	-.08
Behavioural disengagement	.05	<b>.21**</b>	<b>.25***</b>	<b>-.25**</b>	<b>-.38***</b>	<b>-.18**</b>	<b>.34***</b>	<b>.14*</b>	<b>.13*</b>	.09
Venting emotions	.10	.01	<b>.17**</b>	.06	-.04	-.04	<b>.23***</b>	<b>.13*</b>	-.01	-.01
Positive reframing	-.02	-.10	-.01	<b>.18**</b>	<b>.17**</b>	.12	<b>-.15*</b>	.03	-.01	.11
Planning	-.02	-.01	<b>.12*</b>	.10	<b>.14*</b>	-.01	.05	<b>-.13*</b>	-.02	<b>-.13*</b>
Humour	.01	.04	.01	.03	-.04	.00	.01	.01	.11	-.11
Acceptance	.03	.08	-.07	<b>.15*</b>	.10	<b>.17**</b>	<b>-.23***</b>	<b>-.13*</b>	-.09	<b>-.13*</b>
Religion	.05	-.10	.03	<b>.13*</b>	<b>.13*</b>	.08	-.05	.02	.03	-.02
Self blame	<b>.16**</b>	.08	<b>.28***</b>	.05	<b>-.14*</b>	<b>-.13*</b>	<b>.40***</b>	<b>.31***</b>	<b>.14*</b>	<b>.16*</b>

\* p<.05 \*\*p<.01 \*\*\* p<.001



**Table 5.8 Relationships between IPQ-R, BMQ and CAMBI scales and Coping strategies (CAM-users): Pearson's *r* (n=359)**

	<i>Identity</i>	<i>Timeline chronic</i>	<i>Consequences</i>	<i>Personal control</i>	<i>Treatment control</i>	<i>Illness coherence</i>	<i>Emotional representations</i>	<i>External cause</i>	<i>Medication overuse</i>	<i>Natural treatments</i>
Self distraction	.08	-.03	<b>.12*</b>	.05	.07	-.01	.04	.08	-.03	<b>.16**</b>
Active Coping	-.01	-.06	.10	<b>.20***</b>	<b>.22***</b>	<b>.11*</b>	-.08	.03	-.01	<b>.17**</b>
Denial	<b>.19***</b>	-.03	<b>.23***</b>	<b>-.16**</b>	<b>-.12*</b>	<b>-.18**</b>	.09	<b>.16**</b>	<b>.12*</b>	.05
Substance use	.07	.02	.10	-.04	-.03	-.04	.10	.04	.01	-.10
Emotional support	.06	.04	.03	<b>.15**</b>	<b>.16**</b>	.06	-.004	-.08	-.01	<b>.19***</b>
Instrumental support	.01	.06	.09	<b>.12*</b>	<b>.12*</b>	-.03	.05	.01	-.02	<b>.18**</b>
Behavioural disengagement	<b>.20***</b>	<b>.14**</b>	<b>.30***</b>	<b>-.43***</b>	<b>-.36***</b>	<b>-.18**</b>	<b>.30***</b>	.08	.10	.02
Venting emotions	.09	.03	.11*	.003	.05	.03	<b>.16**</b>	-.02	.06	<b>.21***</b>
Positive reframing	-.003	<b>-.11*</b>	.003	<b>.17**</b>	<b>.22***</b>	.05	-.05	.08	.08	<b>.11*</b>
Planning	-.06	-.08	.06	<b>.13*</b>	<b>.22***</b>	.03	-.03	.03	.03	<b>.22***</b>
Humour	<b>.12*</b>	.03	.02	.08	<b>.13*</b>	<b>.12*</b>	<b>-.11*</b>	.06	-.05	.09
Acceptance	-.02	<b>.11*</b>	<b>-.11*</b>	.07	.08	<b>.24**</b>	<b>-.18**</b>	<b>-.18**</b>	<b>-.11*</b>	<b>.11*</b>
Religion	.08	-.02	<b>.21***</b>	.05	<b>.12*</b>	-.06	<b>.16**</b>	.03	.08	<b>.20***</b>
Self blame	<b>.18**</b>	.03	<b>.26***</b>	-.06	-.08	<b>-.13*</b>	<b>.30***</b>	.07	.10	.04

\* p<.05 \*\*p<.01 \*\*\* p<.001

### ***Illness consequences***

There were a number of coping strategies that partially mediated the pathway between the IPQ-R illness consequences scale and IBS-QOL scores in both CAM-users and non-users. In non-users, denial ( $R^2$  change = .04) partially mediated the pathway between illness consequences and IBS-QOL scores ( $z=-3.09$ ,  $p<.01$ ) reducing the effect of illness consequences ( $Beta= -.62$ ,  $p<.001$ ). The mediation effect accounted for 9.2 (19.17%) of the overall variance of 48% in IBS-QOL scores. A smaller mediation effect of denial ( $R^2$  change = .01) was detected in CAM-users which partially mediated ( $z=-1.91$ ,  $p<.05$ ) reducing the effect of illness consequences ( $Beta= -.68$ ,  $p<.001$ ) and accounting for 4.91 (10.02%) of the overall variance of 49%.

Behavioural disengagement ( $R^2$  change = .03) partially mediated the illness consequences–IBS-QOL pathway in CAM-users ( $z=-3.78$ ,  $p<.01$ ) reducing the effect of illness consequences ( $Beta= -.64$ ,  $p<.001$ ) and accounting for 11.24 (21.62%) of the overall variance predicted of 52%. A similar mediation effect of behavioural disengagement ( $R^2$  change = .05) was detected in non-users ( $z=-3.33$ ,  $p<.01$ ) which explained 10.04 (20.08%) of the 50% variance predicted and reducing the effect of illness consequences ( $Beta= -.61$ ,  $p<.001$ ). Similar mediation effects were detected when the role of self blame was assessed. In CAM-users, self blame ( $R^2$  change = .06) partially mediated the illness consequences–IBS-QOL pathway ( $z=-4.20$ ,  $p<.01$ ) which explained 11.85 (21.55%) of the 55% variance predicted and reducing the effect of illness consequences ( $Beta= -.63$ ,  $p<.001$ ). The non-users also demonstrated a partial mediation effect of self blame ( $R^2$  change = .08) between illness consequences and IBS-QOL scores ( $z=-3.90$ ,  $p<.01$ ) which accounted for 13.11 (25.21%) of the total variance in the model of 52% and a reduction in the effect of illness consequences ( $Beta= -.58$ ,  $p<.001$ ).

**Table 5.9 Mediation tests for IPQ-R symptom based scales (identity, timeline chronic and consequences) for non-users (outcome variable = total IBS-QOL score)**

<i>1)Predictor variable (IPQ-R) 2)Potential mediator (Brief- COPE scale)</i>	<i>Adjusted R<sup>2</sup> (R<sup>2</sup> change)</i>	<i>Beta Coefficients (Predictor without mediator)</i>	<i>Mediation effect (z) (Sobel estimate and Confidence interval)</i>	<i>R<sup>2</sup> % for mediation effect (% of total R<sup>2</sup>)</i>
1) Illness Identity 2) Self blame <i>F(2, 270)= 39.09***</i>	.22 (.19)	-.13* (-.20**) -.44***	-2.48* (-.54, 95%CI= -.95, -.16)	2.30 (10.46)
1) Timeline chronic 2) Behavioural disengagement <i>F(2,272)= 32.05***</i>	.18 (.11)	-.21*** (-.29***) -.34***	-3.12** (-.43, 99%CI= -.78, -.08)	3.89 (21.61)
1) Illness consequences 2) Denial <i>F(2,271)= 126.32***</i>	.48 (.04)	-.62*** (-.67***) -.20***	-3.09** (-.25, 99%CI= -.49, -.09)	9.20 (19.17)
1) Illness consequences 2) Substance use <i>F(2,271)= 118.22***</i>	.46 (.02)	-.64*** (-.66***) -.13**	-1.79* (-.09, 95%CI= -.20, -.01)	3.40 (7.39)
1) Illness consequences 2) Behavioural disengagement <i>F(2,271)= 135.23***</i>	.50 (.05)	-.61*** (-.67***) -.24***	-3.33** (-.29, 99%CI= -.58, -.09)	10.04 (20.08)
1) Illness consequences 2) Venting emotions <i>F(2,269)= 132.03***</i>	.49 (.05)	-.62*** (-.67***) -.23***	-2.64** (-.20, 99%CI= -.44, -.04)	6.86 (14.0)
1) Illness consequences 2) Self blame <i>F(2,269)= 132.03***</i>	.52 (.08)	-.58*** (-.67***) -.30***	-3.90** (-.39, 99%CI= -.68, -.16)	13.11 (25.21)

\* p<.05 \*\*p<.01 \*\*\* p<.001

**Key for tables 5.9 to 5.18:**

Outcome variable = total IBS-QOL score.

- 1) Predictor variable (IPQ-R scale).
- 2) Mediator (Brief-COPE scale).

R<sup>2</sup> change is the change in variance with the addition of the mediator in block two of the regression model.

The z-scores represent the significance of the mediation effect and are supplemented by the Sobel mean estimate from bootstrapping and either a 95 or 99% confidence interval to illustrate how statistical significance of mediation was inferred.

The R<sup>2</sup> for the mediation effect is illustrative of how much of the outcome variance is explained by the mediation effect. This is also expressed as a percentage of the total variance explained by each regression model.

**Table 5.10 Mediation tests for IPQ-R symptom based scales (identity, timeline chronic and consequences) for CAM-users (outcome variable = total IBS-QOL score)**

1)Predictor variable (IPQ-R) 2)Potential mediator (Brief-COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel estimate and Confidence interval)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Illness Identity 2) Denial F(2,368)= 28.66***	.13 (.03)	-.28*** (-.31***) -.20***	-2.40** (-.22, 99%CI= -.49, -.03)	2.1 (16.15)
1) Illness Identity 2) Behavioural disengagement F(2,368)= 46.84***	.20 (.10)	-.25*** (-.31***) -.33***	-3.39** (-.49, 99%CI= -.94, -.17)	3.98 (19.90)
1) Illness Identity 2) Self Blame F(2, 367)= 57.27***	.23 (.13)	-.24** (-.31***) -.38***	-3.28** (-.51, 99%CI= -.99, -.13)	4.10 (17.83)
1) Timeline chronic 2) Behavioural disengagement F(2,367)= 44.71***	.19 (.12)	-.23*** (-.28***) -.35***	-2.53* (-.25, 95%CI= -.47, -.06)	2.47 (13.0)
1) Illness consequences 2) Denial F(2,368)= 179.72***	.49 (.01)	-.68*** (-.70***) -.10*	-1.91* (-.09, 95%CI= -.19, -.01)	4.91 (10.02)
1) Illness consequences 2) Behavioural disengagement F(2,367)= 197.88***	.52 (.03)	-.64*** (-.70***) -.19***	-3.78** (-.27, 99%CI= -.47, -.09)	11.24 (21.62)
1) Illness consequences 2) Venting emotions F(2,366)= 178.53***	.49 (.01)	-.68*** (-.70***) -.09*	-1.59ns (-.05, 95%CI= -.13, .001)	- -
1) Illness consequences 2) Acceptance F(2,366)= 179.57***	.49 (.01)	-.69*** (-.70***) -.10*	-1.60ns (-.05, 95%CI= -.13, .001)	- -
1) Illness consequences 2) Self blame F(2,367)= 223.17***	.55 (.06)	-.63*** (-.70***) -.26***	-4.20** (-.33, 99%CI= -.57, -.15)	11.85 (21.55)

\* p<.05 \*\*p<.01 \*\*\* p<.001

Outcome variable = total IBS-QOL score

1) Predictor variable (IPQ-R scales)

2) Mediator (Brief-COPE)

A partial mediation effect distinct to non-users was through the coping style of substance use ( $z=-1.79$ ,  $p<.05$ ;  $R^2$  change = .02) which explained 3.4 (7.39%) of the total variance of 46% and reduced the effect of illness consequences ( $Beta= -.64$ ,  $p<.001$ ). Similarly, the venting of emotions partially ( $R^2$  change = .05) mediated the consequences-IBS-QOL pathway in non-users ( $z=-2.64$ ,  $p<.01$ ) which explained 6.86 (14.0%) of the total variance of 49% and reduced the effect of illness consequences ( $Beta= -.62$ ,  $p<.001$ ). In CAM-users, the three Baron and Kenny

mediation criteria were established for venting emotions, however the Sobel test revealed no significant effect of mediation ( $z=-1.59$ ,  $p>.05ns$ ). One further coping strategy in CAM-users, acceptance, also satisfied the Baron and Kenny criteria but the effect failed to reach significance ( $z=-1.60ns$ ,  $p>.05ns$ ).

In sum, within the IPQ-R symptom scales, the pathways that demonstrated significant mediation effects may be interpreted as thus. Stronger symptom based scale scores were largely related to greater adoption of maladaptive coping strategies (e.g. self blame, denial). The coping strategies were also related to lower reported quality of life scores. These relationships partially explained the poorer reported quality of life in each model for both CAM-users and non-users. The one exception was CAM-users, where stronger illness consequences were related to lesser acceptance, which was related to lower reported quality of life scores.

#### ***5.3.4.3.2 Step three of mediation testing: for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) and IBS-QOL scores***

##### ***IPQ-R Personal control***

As with the symptom based IPQ-R scales, several coping strategies were shown to partially mediate the personal control–IBS-QOL pathway in both CAM-users and non-users. Denial ( $R^2$  change = .04) was found to partially mediate the pathway in CAM-users (table 5.12) ( $z=2.31$ ,  $p<.01$ ) reducing the effect of personal control ( $Beta= .28$ ,  $p<.001$ ) and accounting for 1.90 (14.62%) of the overall variance predicted of 13%. A similar but slightly stronger partial mediation effect of denial ( $R^2$  change = .11) was detected in non-users (table 5.11) ( $z=2.46$ ,  $p<.01$ ) which explained 2.70 (15.88%) of the 17% variance predicted and reduced the effect of personal control ( $Beta= .21$ ,  $p<.001$ ).

Behavioural disengagement was found to partially mediate the personal control–IBS-QOL pathway in both groups. In CAM-users, a significant partial mediation effect of behavioural disengagement ( $R^2$  change = .08) was detected ( $z=4.85$ ,  $p<.01$ ) which reduced the effect of personal control ( $Beta= .18$ ,  $p<.01$ ) which accounted for 6.84 (40.24%) of the overall variance of 17%. In non-users, behavioural disengagement ( $R^2$  change = .11) demonstrated a slightly less powerful partial mediation effect ( $z=3.56$ ,  $p<.01$ ) which reduced the effect of personal control ( $Beta= .18$ ,  $p<.01$ ) and accounted for 4.2 (24.71%) of the overall variance in the model of 17%. Acceptance ( $R^2$  change = .02) was also found to partially mediate the personal control–IBS-QOL pathway but this was distinct to non-users. Acceptance showed a small but significant partial mediation effect ( $z=1.78$ ,  $p<.05$ ) which reduced the effect of personal consequences ( $Beta= .24$ ,  $p<.001$ ) and which accounted for 2.69 (33.63%) of the overall small amount of variance predicted of 8%.

### ***IPQ-R Treatment control***

In both CAM-users and non-users, denial satisfied the Baron and Kenny criteria. However, observation of the 95% confidence intervals (tables 5.11 & 5.12) shows in both cases the confidence intervals cross zero. Therefore no significant effect of mediation for denial was detected in CAM-users ( $z=1.38$ ,  $p>.05ns$ ) and the non-users ( $z=1.76$ ,  $p>.05ns$ ).

Behavioural disengagement however, was found to partially mediate the treatment control–IBS-QOL pathway in both groups. In CAM-users, a significant partial mediation effect of behavioural disengagement ( $R^2$  change = .08) was detected ( $z=4.56$ ,  $p<.01$ ) which reduced the effect of treatment control ( $Beta= .23$ ,  $p<.001$ ) which accounted for 6.50 (34.21%) of the overall variance of 19%. In non-users, a significant but slightly less strong, partial mediation effect of behavioural disengagement ( $R^2$  change = .08) was detected ( $z=3.71$ ,  $p<.01$ ) which reduced the effect of treatment control ( $Beta= .21$ ,  $p<.001$ ) which accounted for 5.20 (30.59%) of the overall variance of 17%. Unique to non-users, self blame ( $R^2$  change = .17) was shown to partially mediate the treatment control–IBS-

QOL pathway ( $z=2.30$ ,  $p<.05$ ), which reduced the effect of treatment control ( $Beta= .26$ ,  $p<.001$ ) and accounted for 3.70 (13.70%) of the total variance of 27%.

### ***IPQ-R Illness coherence***

The illness coherence–IBS-QOL pathway was partially mediated by a number of coping strategies in both CAM-users and non-users. In CAM-users a significant partial mediation effect of behavioural disengagement ( $R^2$  change = .08) was detected ( $z=2.64$ ,  $p<.01$ ) which reduced the effect of illness coherence ( $Beta= .23$ ,  $p<.001$ ) and which accounted for 1.99 (18.09%) of the overall variance of 11%. The effect was slightly stronger in CAM-users ( $z=3.03$ ,  $p<.01$ ), where denial ( $R^2$  change = .10) reduced the effect of illness coherence ( $Beta= .14$ ,  $p<.05$ ) and accounted for 2.62 (18.71%) of the total variance of 14%.

Behavioural disengagement was found to partially mediate the illness coherence–IBS-QOL pathway in both groups. In CAM-users, behavioural disengagement ( $R^2$  change = .12) was found to be a partial mediator ( $z=3.16$ ,  $p<.01$ ) which reduced the effect of illness coherence ( $Beta= .20$ ,  $p<.001$ ) and accounted for 3.03 (16.83%) of the total variance in IBS-QOL scores of 18%. A lesser partial mediation effect of behavioural disengagement ( $R^2$  change = .13) was detected in non-users ( $z=2.72$ ,  $p<.01$ ) where the effect of illness coherence was reduced ( $Beta= .15$ ,  $p<.01$ ) and the mediation effect accounted for 2.46 (14.47%) of the total variance of 17%.

Acceptance was also found to partially mediate the illness coherence–IBS-QOL pathway in both groups. In CAM-users, the effect of illness coherence was significantly reduced ( $Beta= .23$ ,  $p<.001$ ) on the addition of acceptance ( $R^2$  change = .02) to the regression model ( $z=2.07$ ,  $p<.05$ ). The mediation effect accounted for 1.73 (21.63%) of the overall variance of 8%. A similar trend was detected in the non-users where acceptance ( $R^2$  change = .02) partially mediated ( $z=1.95$ ,  $p<.05$ ) the illness coherence–IBS-QOL pathway and reduced the effect of illness

coherence ( $Beta = .19$ ,  $p < .01$ ) accounting for 1.31 (21.83%) of the overall variance of 6%.

Self blame also demonstrated a similar pattern across both groups. In CAM-users, self blame ( $R^2$  change = .15) partially mediated the illness coherence–IBS-QOL pathway ( $z = 2.28$ ,  $p < .05$ ) reducing the effect of illness coherence ( $Beta = .21$ ,  $p < .001$ ) and accounting for 2.38 (10.82%) in the total variance in IBS-QOL scores of 22%. In non-users, a significant partial mediation effect of self blame ( $R^2$  change = .19) was also detected ( $z = 2.14$ ,  $p < .05$ ) where the influence of illness coherence was reduced ( $Beta = .15$ ,  $p < .01$ ) and the mediation effect accounted for 2.23 (9.70%) of the total variance predicted by the model of 23%.

Observation of tables 5.11 and 5.12 shows that overall, variance predicted by each of the models was generally less than with regression models constructed from the symptom based scales (tables 5.9 & 5.10). These analyses show that greater treatment and personal control and better understanding of IBS (coherence) resulted in better quality of life ratings. In both groups IPQ-R control and coherence scales were associated with lesser likelihood of adoption of maladaptive coping strategies. Control and coherence scales led to greater acceptance of IBS which influenced stronger quality of life ratings. The lower variance predicted by these regression models may suggest symptom based representations are more influential than control and coherence representations on reported quality of life.



**Table 5.11 Mediation tests for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) for the non-users**

1)Predictor variable (IPQ-R) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel estimate and Confidence interval)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Personal control 2) Denial F(2,271) = 29.29***	.17 (.11)	.21*** (.27***) -.33***	2.46** (.27, 99%CI= .01, .59)	2.70 (15.88)
1) Personal control 2) Behavioural disengagement F(2,271)= 29.75***	.17 (.11)	.18** (.27***) -.34***	3.56** (.44, 99%CI= .13, .85)	4.20 (24.71)
1) Personal control 2) Acceptance F(2,268)= 13.41***	.08 (.02)	.24*** (.27***) .14***	1.78* (.12, 95%CI= .01, .29)	2.69 (33.63)
1) Treatment control 2) Denial F(2,275)= 33.40***	.19 (.10)	.27*** (.30***) -.32***	1.76ns (.19, 95%CI= -.03, .43)	- -
1) Treatment control 2) Behavioural disengagement F(2,275)= 28.47***	.17 (.08)	.21*** (.30***) -.30***	3.71** (.50, 99%CI= .15, .96)	5.20 (30.59)
1) Treatment control 2) Self blame F(2,271)= 51.81***	.27 (.17)	.26*** (.32***) -.42***	2.30* (.34, 95%CI= .02, .66)	3.70 (13.70)
1) Illness coherence 2) Denial F(2, 269)= 23.25***	.14 (.10)	.14* (.21***) -.33	3.03** (.33, 99%CI= .11, .65)	2.62 (18.71)
1) Illness coherence 2) Behavioural disengagement F(2,269)= 28.32***	.17 (.13)	.15** (.21***) -.36***	2.72** (.30, 99%CI= .05, .66)	2.46 (14.47)
1) Illness coherence 2) Acceptance F(2,268)= 9.96***	.06 (.02)	.19** (.22***) .16*	1.95* (.14, 95%CI= .02, .31)	1.31 (21.83)
1) Illness coherence 2) Self blame F(2,269)= 41.31***	.23 (.19)	.15** (.21***) -.44***	2.14* (.28, 95%CI= .02, .56)	2.23 (9.70)

\* p<.05 \*\*p<.01 \*\*\* p<.001

#### **5.3.4.3.3 Step three of mediation testing: for IPQ-R emotional representations and causal scales (and IBS-QOL scores)**

Differences between CAM-users and non-users were most noticeable when testing for mediation between emotional representations and causal scales of the IPQ-R and quality of life scores. The non-users demonstrated a greater number of mediation effects.

**Table 5.12 Mediation tests for IPQ-R control and coherence based scales (personal control, treatment control and illness coherence) for CAM-users**

1)Predictor variable (IPQ-R) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel estimate and Confidence interval)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Personal control 2) Denial F(2,368)= 27.76***	.13 (.04)	.28*** (.31***) -.19***	2.31** (.14, 99%CI= .003, .32)	1.90 (14.62)
1) Personal control 2) Behavioural disengagement F(2,367)= 37.51***	.17 (.08)	.18** (.31***) -.30***	4.85** (.58, 99%CI= .26, .92)	6.84 (40.24)
1) Treatment control 2) Denial F(2,369)= 35.05***	.16 (.05)	.32*** (.34***) -.22***	1.38ns (.09, 95%CI= -.05, .24)	- -
1) Treatment control 2) Behavioural disengagement F(2,368)= 44.47***	.19 (.08)	.23*** (.34***) -.30***	4.56** (.54, 99%CI= .27, .92)	6.50 (34.21)
1) Illness coherence 2) Denial F(2,362)= 22.40***	.11 (.04)	.22*** (.26***) -.21***	2.64** (.15, 99%CI= .02, .33)	1.99 (18.09)
1) Illness coherence 2) Behavioural disengagement F(2,362)= 41.11***	.18 (.12)	.20*** (.26***) -.35***	3.16** (.25, 99%CI= .03, .49)	3.03 (16.83)
1) Illness coherence 2) Acceptance F(2,361)= 15.70***	.08 (.02)	.23*** (.26***) .12*	2.07* (.11, 95%CI= .01, .23)	1.73 (21.63)
1) Illness coherence 2) Self blame F(2,362)= 51.71***	.22 (.15)	.21*** (.26***) -.40***	2.28* (.18, 95%CI= .02, .35)	2.38 (10.82)

\* p<.05 \*\*p<.01 \*\*\* p<.001

### **Emotional representations**

There were a number of partial mediation effects specific to non-users (table 5.13). Denial ( $R^2$  change = .02) partially mediated the emotional representations-IBS-QOL pathway ( $z=-2.98$ ,  $p<.01$ ) reducing the effect of emotional representations ( $Beta= -.66$ ,  $p<.001$ ) and accounting for 11.20 (21.54%) of the total variance in IBS-QOL scores of 52%. Venting emotions ( $R^2$  change = .03) also acted as a partial mediator ( $z=-2.92$ ,  $p<.01$ ) which reduced the effect of emotional representations on IBS-QOL scores ( $Beta= -.67$ ,  $p<.001$ ) and accounted for 8.65 (16.32%) of the total variance explained of 53%.

Both behavioural disengagement and self blame partially mediated the emotional representations–IBS-QOL pathway in both CAM-users and non-users. In the CAM group behavioural disengagement ( $R^2$  change = .04) acted as a significant partial mediator ( $z=-3.81$ ,  $p<.01$ ) which reduced the effect of emotional representations ( $Beta= -.59$ ,  $p<.001$ ) and accounted for 10.57 (22.98%) of the total variance in the model of 46%. In non-users, a similar effect was evident where behavioural disengagement ( $R^2$  change = .02) acted as a partial mediator ( $z=-3.08$ ,  $p<.01$ ) which reduced the effect of emotional representations on IBS-QOL scores ( $Beta= -.66$ ,  $p<.001$ ). The mediation effect accounted for 12.32 (23.69%) of the total variance in the model of 52%. Similar size mediation effects were also detected when examining self blame as a mediating variable. In CAM-users, self blame ( $R^2$  change = .06) partially mediated the emotional representations–IBS-QOL pathway ( $z=-4.33$ ,  $p<.01$ ) reducing the effect of emotional representations ( $Beta= -.58$ ,  $p<.001$ ) and accounted for 12.16 (25.33%) of the total variance explained of 48%. Similarly, in non-users, self blame ( $R^2$  change = .04) acted as a partial mediator ( $z=-3.86$ ,  $p<.01$ ) and reduced the effect of emotional representations ( $Beta= -.63$ ,  $p<.001$ ). The mediation effect accounted for 17.67 (32.72%) of the total variance of 54%.

### ***IPQ-R causal scales***

At the third step of mediation testing, only the non-users demonstrated evidence of mediation in the IPQ-R internal causes–IBS-QOL pathway, although one of the Brief-COPE scales pathway was found to be not significant in terms of mediation. Acceptance was found to reduce the effect of internal causes on IBS-QOL ( $Beta= -.14$ ,  $p<.05$ ) but this effect was found to be not significant ( $z=-1.65$ ,  $p>.05ns$ ). Venting emotions ( $R^2$  change = .10) however was found to mediate the internal causes–IBS-QOL pathway ( $z=-2.08$ ,  $p<.01$ ) as the effect of internal causes was reduced to non-significance ( $Beta= -.11$ ,  $p>.05ns$ ). The mediation effect accounted for 1.23 (10.25%) of the total variance of 12%. Self blame ( $R^2$  change = .19) also fully mediated the internal cause–IBS-QOL pathway ( $z=-4.54$ ,  $p<.01$ ) reducing the effect of internal cause to non-significance

( $Beta = -.01$ ,  $p > .05ns$ ). This mediation effect accounted for 2.44 (11.62%) of the total variance explained of 21%.

In considering the external cause–IBS-QOL pathway, the third stage of mediation testing detected that denial was a significant mediator in both groups. In CAM-users, denial ( $R^2$  change = .04) partially mediated the external cause–IBS-QOL pathway ( $z = -2.72$ ,  $p < .01$ ) reducing the effect of external cause ( $Beta = -.16$ ,  $p < .01$ ) and accounted for 1.51 (18.88%) of the variance explained in the model of 8%. In non-users, denial ( $R^2$  change = .12) fully mediated the same pathway ( $z = -2.63$ ,  $p < .01$ ) reducing the effect of external cause to non-significance ( $Beta = -.09$ ,  $p > .05ns$ ) and accounting for 1.47 (10.50%) of the total variance of 14%.

There were two remaining mediation effects detected that were specific to each group. In CAM-users, acceptance ( $R^2$  change = .02) was found to partially mediate the external cause–IBS-QOL pathway ( $z = -2.09$ ,  $p < .01$ ) reducing the effect of external cause ( $Beta = -.18$ ,  $p < .01$ ) and accounting for 1.06 (17.67%) of the variance explained in the model of 6%. In non-users, self blame ( $R^2$  change = .20) was found to fully mediate the external cause–IBS-QOL pathway ( $z = -2.12$ ,  $p < .05$ ) reducing the effect of external cause to non-significance ( $Beta = -.10$ ,  $p > .05ns$ ) and accounting for 1.63 (7.41%) of the total variance of 22%.

The mediation effects presented follow a similar pattern to the IPQ-R symptom based scales. The majority of scales are negatively associated with maladaptive coping strategies, which themselves are related to poorer reported quality of life. In CAM-users, acceptance was the one adaptive coping style that was negatively associated with external cause and positively associated with reported quality of life.

**Table 5.13 Mediation tests for IPQ-R emotional representations and causal scales for non-users**

1) Predictor variable (IPQ-R) 2) Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Emotional representations 2) Denial F(2,271)= 151.03***	.52 (.02)	-.66*** (-.71***) -.16***	-2.98** (-.21, 99%CI= -.44, -.05)	11.20 (21.54)
1) Emotional representations 2) Behavioural disengagement F(2,271)= 151.32***	.52 (.02)	-.66*** (-.71***) -.16***	-3.08** (-.23, 99%CI= -.46, -.05)	12.32 (23.69)
1) Emotional representations 2) Venting emotions F(2,269)= 155.63***	.53 (.03)	-.67*** (-.71***) -.18***	-2.92** (-.18, 99%CI= -.36, -.05)	8.65 (16.32)
1) Emotional representations 2) Self blame F(2,270)= 159.57***	.54 (.04)	-.63*** (-.71***) -.21***	-3.86** (-.34, 99%CI= -.64, -.15)	17.67 (32.72)
1) Internal cause 2) Venting emotions F(2,269)= 20.27***	.12 (.10)	-.11ns (-.16*) -.33***	-2.08** (-.17, 99%CI= -.40, -.05)	1.23 (10.25)
1) Internal cause 2) Acceptance F(2,268)= 7.03**	.04 (.02)	-.14* (-.16*) .16**	-1.65ns (-.08, 95%CI= -.19, .01)	- -
1) Internal cause 2) Self blame F(2,269)= 37.13***	.21 (.19)	-.01ns (-.16*) -.46***	-4.54** (-.55, 99%CI= -.87, -.30)	2.44 (11.62)
1) External cause 2) Denial Denial F(2,270)= 22.51***	.14 (.12)	-.09ns (-.15*) -.35***	-2.63** (-.33, 99%CI= -.76, -.01)	1.47 (10.50)
1) External cause 2) Self blame F(2,269)= 39.48***	.22 (.20)	-.10ns (-.16**) -.45***	-2.12* (-.33, 95%CI= -.66, -.02)	1.63 (7.41)

\* p<.05 \*\*p<.01 \*\*\* p<.001

**Table 5.14 Mediation tests for IPQ-R emotional representations and causal scales for CAM-users**

1)Predictor variable (IPQ-R) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Emotional representations 2) Behavioural disengagement F(2,366)= 157.36***	.46 (.04)	-.59*** (-.65***) -.20***	-3.81** (-.25, 99%CI= -.46, -.07)	10.57 (22.98)
1) Emotional representations 2) Self blame F(2,366)= 170.35***	.48 (.06)	-.58*** (-.65***) -.25***	-4.33** (-.31, 99%CI= -.54, -.14)	12.16 (25.33)
1) External cause 2) Denial F(2,367)= 16.96***	.08 (.04)	-.16** (-.20***) -.22***	-2.72** (-.22, 99%CI= -.44, -.05)	1.51 (18.88)
1) External cause 2) Acceptance F(2, 366)= 11.65***	.06 (.02)	-.18** (-.20***) -.14**	-2.09** (-.13, 99%CI= -.32, -.01)	1.06 (17.67)

\* p<.05 \*\*p<.01 \*\*\* p<.001

**5.3.4.3.4 Step three of mediation testing: for BMQ and CAMBI scales (and IBS-QOL scores)**

Of all the scales of the BMQ and CAMBI, only the BMQ overuse and CAMBI natural treatment scales were implicated in being directly related to IBS-QOL scores (table 5.5). Further testing for mediation revealed that in both groups, acceptance satisfied the Baron and Kenny requirements for mediation in the BMQ overuse–IBS-QOL pathway. In CAM-users however (table 5.15), although the effect of BMQ overuse was reduced (*Beta*= -.12, *p*<.05) the mediation effect was not significant (*z*=-1.55, *p*>.05ns). In non-users, there was evidence of full mediation effect of acceptance (*R*<sup>2</sup> change = .03; *z*=-1.78, *p*<.05) as the effect of BMQ overuse on IBS-QOL scores was reduced to non-significance (*Beta*= -.10, *p*>.05ns). This mediation effect accounted for a small .05 (14.75%) of the total variance of 4%. In non-users, there was evidence of a full mediation effect of both self blame and substance use on the BMQ overuse–IBS-QOL pathway. Self blame (*R*<sup>2</sup> change = .20) was found to demonstrate a significant mediation effect (*z*=-2.05, *p*<.05) and reduced the effect of BMQ overuse to non-significance (*Beta*= -.07, *p*>.05ns). This mediation effect accounted for 1.1 (5.24%) of the total

variance of 21%. Substance use ( $R^2$  change = .04) demonstrated a full mediation effect ( $z=-1.81$ ,  $p<.05$ ) with a reduction in the effect of BMQ overuse on IBS-QOL scores ( $Beta=-.11$ ,  $p>.05ns$ ). The mediation effect accounted for .07 (11.67%) of the total variance explained of 6%. In the only other evidence of mediation in this pathway in CAM-users, there was a full mediation effect of denial on the BMQ overuse–IBS-QOL pathway. The mediating effect of denial ( $R^2$  change = .05) was significant ( $z=-2.33$ ,  $p<.01$ ) also reducing the effect of BMQ overuse to non-significance ( $Beta= -.10$ ,  $p>.05ns$ ). The variance in outcome predicted by the model was a small 6% of which the mediation effect accounted for .06 (14.75%) of this effect.

The only CAMBI scale implicated in mediation analyses was the CAMBI natural treatment scale in non-users. Initial testing for predictor–outcome relationship (table 5.5) revealed no significant relationship between natural treatments and IBS-QOL score. However, as the correlation coefficient value was identified as being the same value as the correlation coefficient for CAM-users but was not significant (the value was significant in CAM-users) the natural treatments scale was still considered in mediation analyses. Self blame ( $R^2$  change = .20) was found to fully mediate ( $z=-2.68$ ,  $p<.05$ ) the CAMBI natural treatment–IBS-QOL pathway and reduced the effect of CAMBI natural treatment ( $Beta= -.05$ ,  $p>.05ns$ ). The mediation effect accounted for 1.4 (6.67%) of the total variance of 21%.

**Table 5.15 Mediation tests for BMQ overuse scale for CAM-users**

1)Predictor variable (BMQ) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z)  (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) BMQ Overuse 2) Denial F(2,369)= 13.19***	.06 (.05)	-.09ns (-.13*) -.23***	-2.33**  (-.23, 99%CI= -.51, -.05)	.07  (12.33)
1) BMQ Overuse 2) Acceptance F(2,367)= 8.31***	.04 (.03)	-.12* (-.13*) .16**	-1.55ns  (-.11, 95%CI= -.28, .02)	-  -

\*  $p<.05$  \*\* $p<.01$  \*\*\*  $p<.001$

**Table 5.16 Mediation tests for BMQ overuse and CAMBI natural treatments scales for non-users**

1)Predictor variable (BMQ) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) BMQ Overuse 2) Acceptance F(2,270)= 6.58**	.04 (.03)	-.10ns (-.13*) .18**	-1.78* (-.19, 95%CI= -.47, -.01)	.06 (14.75)
1) BMQ Overuse 2) Substance use F(2,267)= 8.83***	.06 (.04)	-.11ns (-.14*) -.21***	-1.81* (-.21, 95%CI= -.48, -.01)	.07 (11.67)
1) BMQ Overuse 2) Self blame F(2,271)= 37.18***	.21 (.20)	-.07ns (-.12*) -.45***	-2.05* (-.44, 95%CI= -.89, -.01)	1.10 (5.24)
1) CAMBI Natural treatments 2) Self blame F(2,271)= 36.85***	.21 (.20)	-.05ns (-.13*) -.45***	-2.68* (-.49, 95%CI= -.88, -.14)	1.40 (6.67)

\* p<.05 \*\*p<.01 \*\*\* p<.001

The directions of relationships in testing for mediation were consistent with observations thus far. Higher BMQ and CAMBI scores resulted in greater use of maladaptive coping strategies (namely denial, substance use and self blame) and lesser use of acceptance. The inverse was true for each of the coping strategies' relationship with reported quality of life. Adoption of maladaptive coping led to lower reported quality of life, whilst increased acceptance resulted in higher quality of life ratings. The amount of variance predicted in quality of life scores in CAM-users was small with most being accounted for by the addition of each coping scale to the regression model. In non-users, the predicted variance was noticeably larger in two of the models however this can be attributed to the greater effect of self blame on the BMQ overuse-IBS-QOL and CAMBI natural treatment-IBS-QOL pathways (table 5.16).

**5.3.4.3.5 Step three of mediation testing: for IPQ-R emotional representation scale and emotional outcome**

A lack of research exploring emotional representations in IBS led to a key objective of this study being to examine for evidence of mediation between emotional representations of IBS and reported emotional quality of life (represented by utilising the IBS-QOL Dysphoria subscale). On



testing for mediation (step three of Baron and Kenny's criteria) emotional representations were generally found to account for a large amount of variance in outcome and mediation effects detected were noticeably larger than the majority of effects associated between cognitive representations and quality of life. This component of the research was also primarily exploratory to examine if emotional representations guide different coping strategies to cognitive representations.

In CAM-users (table 5.17), behavioural disengagement ( $R^2$  change = .05) was found to partially mediate the emotional representation–Dysphoria pathway ( $z=-4.51$ ,  $p<.01$ ) and reduced the effect of emotional representation ( $Beta= -.67$ ,  $p<.001$ ). The mediation effect accounted for 14.10 (23.50%) of the total variance explained of 60%. A similar effect was found in non-users (table 5.18) where behavioural disengagement ( $R^2$  change = .02) was found to partially mediate ( $z=-3.01$ ,  $p<.01$ ) the emotional representation–Dysphoria pathway, reducing the effect of emotional representation ( $Beta= -.74$ ,  $p<.001$ ) and this mediation effect accounted for 13.23 (21.0%) of the total variance in dysphoria of 63%. A similar pattern was noted in both groups in the case of self blame. In CAM-users, self blame ( $R^2$  change = .05) was found to show a partial mediation effect ( $z=-4.49$ ,  $p<.01$ ) reducing the effect of emotional representation ( $Beta= -.67$ ,  $p<.001$ ) and accounting for 14 (23.33%) of the total variance in the model of 60%. In non-users, self blame ( $R^2$  change = .01) also demonstrated a partial mediating effect ( $z=-2.92$ ,  $p<.01$ ) and reduced the effect of emotional representation on Dysphoria scores ( $Beta= -.73$ ,  $p<.001$ ). The mediation effect accounted for 16.80 (26.67%) of the total variance of 63%.

The remaining analyses revealed significant mediation effects that were isolated to non-users. Denial ( $R^2$  change = .01) was found to partially mediate the emotional representation–Dysphoria pathway ( $z=-2.42$ ,  $p<.01$ ) where the effect of emotional representation was reduced ( $Beta= -.75$ ,  $p<.001$ ) and the mediation effect accounted for 10.70 (17.26%) of the total variance of 62%. Venting emotions ( $R^2$  change = .02) was also

found to partially mediate the emotional representation–Dysphoria pathway in non-users ( $z=-2.75$ ,  $p<.01$ ) and reduced the effect of emotional representation ( $Beta= -.75$ ,  $p<.001$ ). The mediation effect accounted for 8.60 (13.65%) of the total variance in dysphoria scores of 63%.

**Table 5.17 Mediation tests for IPQ-R emotional representation scale and emotional outcome for CAM-users**

1)Predictor variable (BMQ) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Emotional representations 2) Behavioural disengagement $F(2,366)= 276.74^{***}$	.60 (.05)	-.67*** (-.71***) -.24***	-4.51** (-.39, 99%CI= -.65, -.20)	14.10 (23.50)
1) Emotional representations 2) Self blame $F(2,366)= 274.96^{***}$	.60 (.05)	-.67*** (-.74***) -.24***	-4.49** (-.39, 99%CI= -.66, -.19)	14.0 (23.33)

\*  $p<.05$  \*\* $p<.01$  \*\*\*  $p<.001$

**Table 5.18 Mediation tests for IPQ-R emotional representation scale and emotional outcome for the non-users**

1)Predictor variable (BMQ) 2)Potential mediator (Brief- COPE scale)	Adjusted R <sup>2</sup> (R <sup>2</sup> change)	Beta Coefficients (Predictor without mediator)	Mediation effect (z) (Sobel mean estimate and CI)	R <sup>2</sup> % for mediation effect (% of total R <sup>2</sup> )
1) Emotional representations 2) Denial $F(2,271)= 223.41^{***}$	.62 (.01)	-.75*** (-.78***) -.11**	-2.42** (-.19, 99%CI= -.43, -.03)	10.70 (17.26)
1) Emotional representations 2) Behavioural disengagement $F(2,271)= 229.95^{***}$	.63 (.02)	-.74*** (-.78***) -.14***	-3.01** (-.26, 99%CI= -.52, -.06)	13.23 (21.0)
1) Emotional representations 2) Venting emotions $F(2,269)= 231.33^{***}$	.63 (.02)	-.75*** (-.78***) -.15***	-2.75** (-.19, 99%CI= -.42, -.05)	8.60 (13.65)
1) Emotional representations 2) Self blame $F(2,270)= 227.50^{***}$	.63 (.01)	-.73*** (-.78***) -.13**	-2.92** (-.29, 99%CI= -.59, -.07)	16.80 (26.67)

\*  $p<.05$  \*\* $p<.01$  \*\*\*  $p<.001$

Between emotional representations and emotional outcome pathways, the variance explained by coping strategies was also minimal but statistically significant. The variance in Dysphoria scores predicted by

emotional representations was large. The subsequent pattern of relationships between the variables was also consistent with previous observations. Stronger emotional representations were related to poorer emotional quality of life via greater adoption of maladaptive coping strategies which included denial and self blame.

## **5.4 Discussion**

This study addressed four objectives. First, differences were assessed between CAM-users and non-users on subscales of the IBS-QOL and the total IBS-QOL score. Second, CAM-user and non-user differences were examined on scales of the Brief-COPE. Third, associations were examined between scales of the IPQ-R, BMQ and CAMBI for each of the two groups. Finally, tests of simple mediation were performed on scales of the IPQ-R, BMQ, CAMBI (predictor variables), Brief-COPE (potential mediator variables) and IBS-QOL scores (the outcome variable). Pathways were examined for similarities and differences between CAM-users and non-users. Additionally, this final objective also provisionally examined the role of emotional representations and emotional outcome as a separate (but parallel) branch of the CSM.

### ***5.4.1 CAM-user and non-user differences on IBS-QOL and Brief-COPE scales***

There were observable differences between CAM-users and non-users on scales of the Brief-COPE and IBS-QOL. Scores on the IBS-QOL were found to be lower than reported in previous studies (Bushnell et al.,2006; Drossman et al.,2000, van Tilburg et al.,2008) suggesting that those with IBS in this study reported lower quality of life scores. It was also detected that CAM-users, as expected, reported lower quality of life on all domains of the IBS-QOL. Similar to findings reported in chapter four, effect sizes based on mean differences on IPQ-R, BMQ and CAMBI scales were predominantly small. The results are consistent with previous work and expectations in that both CAM-users and those with IBS report impaired quality of life as opposed to non-users (Amouretti et

al., 2006; Astin, 1998; van Tilburg et al., 2008) and those seeking care report a more severe illness experience (Koloski et al., 2001; van der Horst et al., 1997). These findings are also consistent with differences between CAM-users and non-users on measures of illness perceptions and treatment beliefs detected in the previous chapter. CAM-users were shown to report greater experience of symptoms and stronger emotional representations related to their IBS.

Similarly, scores on the Brief-COPE were found to differ across the two groups on all but two of the scales (behavioural disengagement and substance use). On scales where there were observed differences, it was observed that CAM-users reported higher scores. The higher scores on the Brief-COPE suggest that CAM-users appear more readily willing to adopt certain coping procedures to deal with the symptoms of IBS, which may be due to these individuals perceiving a more intense symptom experience. This may be viewed as a consistent finding to results presented in chapter four, where several illness and treatment perceptions predicted CAM use, a specific coping behaviour in the context of the CSM.

#### ***5.4.2 Relationships between illness representations and treatment beliefs***

In both groups, reporting of greater illness consequences was related to stronger illness identity and more severe emotional representations. Greater illness consequences were also related to low reported personal and treatment control and less understanding (coherence) of their IBS. There were however, differences in the interrelations among illness and treatment representations between the two groups.

In non-users, beliefs in a chronic timeline of IBS were related to reporting of greater consequences and stronger emotional representations, and beliefs about less personal control, less control over treatment and a lesser belief in causal risk factors. These associations were similar in CAM-users although reporting of a chronic timeline was not related to

less illness coherence, but was related to a lesser belief in an internal cause. This finding may suggest CAM-users who have had IBS for a number of years may be less inclined to believe their IBS is caused by psychological factors. In both CAM-users and non-users, relationships between these IPQ-R dimensions demonstrated a degree of consistency with previous work with the IPQ-R (Hagger & Orbell, 2005; Moss-Morris et al., 2002) and the IPQ (Rutter & Rutter, 2002).

In CAM-users, more reported symptoms (illness identity) were associated with stronger emotional representations, stronger timeline beliefs (cyclical and chronic), lower personal and treatment control and stronger beliefs in an external cause. This was in contrast to non-users who only demonstrated a relationship between identity and emotional representations. This seems to emphasise the link between experienced symptoms and emotional distress caused by IBS, with a greater number of significant relationships found between these IPQ-R dimensions in CAM-users. Furthermore, within CAM-users, cyclical timeline perceptions were not related to any other scales. In non-users, the cyclical timeline scale was related to both greater beliefs in both internal and external causal beliefs and lesser understanding of IBS. In both groups, personal control, treatment control and illness coherence were all positively related; each of these scales was also associated with reporting of lower emotional representations which is consistent with previous studies in chronic illness groups (Hagger & Orbell, 2005; Moss-Morris et al., 2002). In both groups, higher personal control was associated with greater beliefs in both internal and risk factors as causes of IBS. This trend was similar for reported treatment control, although in non-users there was no association between treatment control and belief in internal cause. Both groups also reported greater understanding to be related to a lesser belief in an external cause.

The comparison of causal factors is generally more difficult to compare across different studies as responses and subsequent principal component analysis (section 4.2.5.3) are based on individual, often

illness specific, samples (Hagger & Orbell, 2003). Similar patterns were evident for both groups in terms of causal perceptions relating to IBS. Greater internal causal beliefs were related to stronger emotional representations, stronger beliefs in external causes and risk factors. Both groups also indicated associations between external causes and greater belief in risk factors as a cause of IBS. As previously considered, these relationships are more difficult to compare across studies. Only one study to date (Rutter & Rutter, 2002) has explored relationships between causal perceptions in IBS and found no correlation between causal dimensions in contrast to the findings in this study of a positive association between internal and external causes. These relationships may be accounted for, in part, by the increase in causal items in the IPQ-R (Moss-Morris et al., 2002) as opposed to the IPQ.

In both groups, the BMQ scales (harm and overuse) were also positively associated with each other as demonstrated in previous work (Horne et al., 1999). This trend was similar for the scales of the CAMBI which were all related thus demonstrating consistency with previous work (Bishop et al., 2005). There were also several logical associations between the BMQ and CAMBI scales. In both groups, greater beliefs in medication harm were associated with stronger beliefs in natural treatments and holistic health beliefs. In non-users, an identical pattern was observed between stronger beliefs in medication overuse, natural treatments and holistic health beliefs. In CAM-users, the relationship between overuse and natural treatments was still evident, but an association between stronger beliefs in medication overuse and lower beliefs in patient participation in treatment was observed.

Scales of the BMQ and CAMBI were also related to components of the IPQ-R. In non-users, greater BMQ harm scale scores were associated with stronger beliefs in risk factors as a cause of IBS, greater personal and treatment control and weaker beliefs in a chronic timeline. In CAM-users there were no significant associations between BMQ harm and other scales. Non-users had positive associations between the BMQ

overuse scale and all causal scales as well as a negative association with chronic timeline perceptions. CAM-users also showed an association between stronger beliefs in medication overuse, weaker beliefs in a chronic timeline and were also associated with greater external causal beliefs. Medication overuse was also related to weaker personal control and illness coherence. The negative relationship between the overuse scale and chronic timeline perceptions may suggest that in IBS, medication concerns become less important over time. This has been shown in other illnesses. In those with Asthma for example, stronger chronic timeline perceptions were associated with greater beliefs in necessity of medication (Horne & Weinman, 2002).

In non-users, stronger illness identity was related to higher CAMBI scores. This trend however, was not detected in CAM-users. In non-users stronger beliefs in natural treatments were related to greater perceived treatment control. In CAM-users stronger natural treatment beliefs were related to lower coherence and greater belief in patient participation in treatment was related to stronger illness consequences. Furthermore, CAM-users' stronger beliefs in treatment participation were related to greater beliefs in a chronic timeline. In both CAM-users and non-users, stronger internal cause beliefs were related to stronger beliefs in holistic health. Stronger holistic health beliefs were also related to stronger treatment and personal control in both groups. This may imply holistic health beliefs influence or are influenced by feelings of control over IBS, treatment or certainty in knowing the origin of one's IBS. Many of the relationships between components of illness perceptions and treatment beliefs appear logically consistent with previous work as well as illustrating some of the unique differences between CAM-users and non-users.

#### ***5.4.3 Illness and treatment perceptions, coping and quality of life***

The relationships between most illness and treatment perceptions (where observed) for the most part resulted in lower IBS-QOL scores across both groups. The exception to this trend being the IPQ-R control and

coherence scales, where positive associations were observed. Where the pathway from illness or treatment perceptions to quality of life was negative, the relationships between these perceptions and largely maladaptive (or avoidant) coping strategies were positive. The subsequent relationships between these coping strategies and quality of life were negative. In terms of mediation, coping strategies therefore in most cases partially explained the pathway observed between illness and treatment perceptions and quality of life. In the case of control and coherence perceptions, the observed relationships between these dimensions of illness perceptions and maladaptive (or avoidant) coping scales were negative. The subsequent relationships between these coping strategies and quality of life, was again negative. In the case of these pathways, it appears that stronger control and coherence beliefs resulted in less use of maladaptive coping strategies and resulted in improved IBS-QOL scores. In this context, these pathways may be seen to have an adaptive outcome. These patterns, although some differences were present, were largely consistent across both groups.

In assessing the influence of illness perceptions on IBS-QOL scores, illness identity, timeline (chronic), illness consequences and emotional representations were all consistently negatively associated with lower IBS-QOL scores in both groups. These findings appear consistent with previous work that has found influences of symptom severity and other psychological factors on reported quality of life in those with IBS (Hahn et al., 1997; Naliboff et al., 1998; Spiegel et al., 2008; Whitehead et al., 1996). There were also slight differences observed in the strength of the relationships between participant groups which may reflect differences in CAM-users and non-users reported in other studies (Astin, 1998; van Tilburg et al., 2008). In non-users, both internal and external causal perceptions were negatively related to lower IBS-QOL scores, however in CAM-users, this was isolated to external cause perceptions. Previous work has suggested individuals with IBS may tend to attribute internal causal attributions to the onset or as triggering their IBS which may include anxiety, depression and stress (Casiday et al., 2008; Hungin et



al., 2005; Lacy et al., 2007). This appears not to be the case in CAM-users in this sample. The dimensions of personal and treatment control and illness coherence were positively correlated with higher IBS-QOL scores. There appeared to be less influence of treatment beliefs on quality of life. Stronger beliefs in medication overuse were negatively associated with lower quality of life scores in both groups. In CAM-users, stronger beliefs in natural treatments were negatively related to quality of life scores. Generally, the relationships between treatment perceptions and quality of life were weaker than the associations observed between illness perceptions and quality of life.

Exploratory analyses of the effect of emotional representations of IBS on emotional outcome (the dysphoria subscale of the IBS-QOL) found stronger emotional representations were associated with reduced emotional quality of life. These findings add credence to the idea that those with IBS 'catastrophise' or have 'abnormal' beliefs about their illness which may lead to emotional distress (Drossman et al., 1999; Gomborone et al., 1995; Lackner et al., 2004). This evidence represents a new finding in terms of research utilising the CSM in IBS and represents an opportunity for further investigation over different time points or with other measures of emotional outcome. The influence of emotional representations on emotional outcome is consistent with the CSM (e.g. Leventhal et al., 2003) and the proposition that psychological processes related to the illness are influential on reported quality of life (Lea & Whorwell, 2001; 2004; Leventhal & Colman, 1997).

Mediation testing was guided by associations found between illness perceptions, treatment beliefs, coping and quality of life within CAM-users and non-users. To test 'simple' mediation, a single predictor, coping scale and total IBS-QOL score were entered into a series of multiple regression models at the final stage of testing (see section 5.2.5.3).

There was consistent partial mediation by several (avoidant or maladaptive) scales of the Brief-COPE on the pathway between illness and treatment perceptions and IBS-QOL scores in both groups. The majority of coping procedures that were found to mediate the predictor–outcome pathway, were found to be largely maladaptive or avoidant and were largely partial mediators. Self blame, behavioural disengagement, denial and venting emotions were all consistently implicated as partial mediating variables. The only adaptive Brief-COPE scale found to mediate this pathway was acceptance. In assessing the illness identity and chronic timeline in both groups, self blame and behavioural disengagement added more variance to each model than each of these illness perceptions, which seems to contradict previous findings that argue the pathway of illness perceptions to outcome is stronger than coping to outcome (Hagger & Orbell, 2003). Illness consequences predicted most of the variance in both groups, with many regression models predicting upwards of 45% in the variance in IBS-QOL scores. Illness consequences have also been reported as strong individual influences on reported quality of life in IBS (Rutter & Rutter, 2002) and rheumatoid arthritis (Carlisle et al., 2005). Symptom based perceptions such as illness consequences, have been identified as strong predictors of outcome in a meta-analysis of CSM studies (Hagger & Orbell, 2003).

Despite the small variances added by Brief-COPE scales in CAM-users, denial, behavioural disengagement and self blame partially mediated the illness consequences–IBS-QOL pathway, with the latter model predicting most variance and having the strongest mediation effect. In non-users venting emotions and substance use also acted as partial mediators in the same pathway. The variances predicted by each regression model were similar to those of CAM-users, although the strongest mediation effect was observable when assessing self blame in non-users. Even conducting ‘simple’ mediation analyses the variances predicted were higher in this study than in Rutter and Rutter (2002), who included multiple illness perceptions in path analyses to detect mediation of coping in IBS. A similar procedure was adopted in a study in young

people with chronic fatigue syndrome, which also reported less variance from multiple illness perceptions than is reported here (Gray & Rutter, 2007). These findings suggest that these dimensions, especially illness consequences are important factors in those with IBS, with a suggestion that these are slightly more important issues in non-users. Carlisle et al. (2005) found avoidant and resigned coping partially mediated the pathway between illness identity and disability as well as between illness identity and psychiatric morbidity in women with rheumatoid arthritis. However, the variances in outcome explained in these findings exceed those reported by Carlisle et al. (2005).

In testing the control and coherence scales, several coping scales partially mediated the predictor–outcome pathway in both groups. It was notable that the variances in outcome predicted by illness perceptions from these variables, was notably lower than with the illness identity, timeline and consequences scales. The variance added by each coping scale was also larger in many cases. Again, the maladaptive and avoidant coping strategies of denial, behavioural disengagement and self blame were the dominant partial mediators in both groups. Behavioural disengagement provided the largest mediation effects, with similar values across the two groups. One adaptive scale, acceptance, was found to partially mediate the illness coherence–IBS-QOL pathway in CAM-users and non-users, although the variance predicted in each model in these cases was small. In these scales, the relationships of these perceptions with IBS-QOL scores were positive and were partly mediated by largely negative relationships with coping strategies. Similarly, Rutter and Rutter (2002) found a direct relationship between the cure/control dimension of the IPQ and reported quality of life, but found no evidence of mediation of any coping strategies. In chronic fatigue syndrome, Gray and Rutter (2007) found focusing on symptoms mediated between illness coherence, treatment control and quality of life. The positive links between these illness representations and quality of life, suggest areas where possible future intervention may be targeted. Previous studies have shown that increased coherence or understanding in IBS can result

in less use of health care services (e.g. Ringström et al., 2009; Robinson et al., 2006).

Regression models with emotional representations and Brief-COPE scales predicted larger amounts of variance in IBS-QOL scores, more so in non-users which reached over 50% of variance. Behavioural disengagement and self blame were partial mediators in this pathway, and this effect was slightly more evident in non-users than CAM-users. In explaining over 32% of the total variance of 54%, self blame accounted for the largest mediation effect in all analyses conducted in non-users. In contrast to CAM-users, non-users also demonstrated partial mediation of denial and venting emotions. This underlines the importance of emotional representations in influencing quality of life and underlines the likelihood of significant emotional illness related distress in those with IBS. Interestingly, it appears that non-users' emotional representations had greater influence on IBS-QOL scores than CAM-users. Similarly, Gray and Rutter (2007) found focusing on symptoms mediated the relationship between greater emotional representations with poorer reported quality of life in chronic fatigue syndrome which predicted (with other variables in the model) 42% of the variance in reported quality of life. The documented emotional distress in those with IBS may be grounded, to an extent, in symptom 'catastrophising' (Lackner et al., 2004). The fact that this effect appeared to be more pronounced in non-users is difficult to explain as it may be expected greater illness related emotional distress may be one reason for using CAM. Given the types of CAM used for IBS (figure 4.3) it may be that CAM-users are receiving formal (or informal) explanations of their symptoms from CAM practitioners or retailers which are addressing their emotional concerns.

In non-users, acceptance acted as a partial mediator between the internal cause-IBS-QOL pathway, whilst venting emotions and self blame fully mediated the effects of the internal cause scale on quality of life. The variances in these models however were low. In examining the

external cause–IBS-QOL pathway, denial and self blame fully mediated this pathway in non-users and partially mediated the same pathway in CAM-users. In CAM-users, acceptance partially mediated the pathway between external cause and quality of life. Again, the variance predicted in quality of life scores was generally low in these cases and most of which was accounted for by coping suggesting that causal beliefs have less influence than other illness perceptions on reported quality of life in both groups. Rutter and Rutter (2002) found no evidence of mediation between causal beliefs and outcome. Gray and Rutter (2007) found maintaining activity mediated the pathway between risk factors and physical functioning, although it is likely that the items making up the risk factors scale in this case, were different to those reported in this study. These illustrations of detected mediation effects are in contrast to other cross-sectional studies that found no mediation of coping between the direct links connecting illness perceptions and outcome in Addisons disease (Heijmans, 1998), epilepsy (Kemp et al., 1999) and Huntington’s disease (Kaptein et al., 2006).

In examining the BMQ overuse and CAMBI natural treatments scales for both CAM-users and non-users, both scales were negatively associated with quality of life and associated positively with the maladaptive coping strategies that mediated the pathways. Acceptance mediated the BMQ overuse–IBS-QOL pathway in both groups, however in CAM-users this effect was one of partial mediation. Denial however, fully mediated this pathway in CAM-users. In non-users, self blame demonstrated a full mediation effect. In non-users, the only significant pathway involving the CAMBI was the natural treatment–IBS-QOL pathway. This pathway was fully mediated by self blame. These analyses predicted small amounts of variance in outcome with the exception of self blame and treatment beliefs in non-users, although the majority of the variance was explained by the coping scale of self blame. Other studies (Heijmans, 1998; Moss-Morris et al., 1996; Scharloo et al., 1998) have found that coping added little variance to regression equations in contrast to some of the findings

here, however this may be due to the lack of influence of treatment beliefs on outcome in both groups.

Exploratory analyses of the effect of emotional representations of IBS on emotional outcome (the Dysphoria subscale of the IBS-QOL) were also conducted. The trends in relationships with emotional outcome and maladaptive coping strategies were consistent with earlier findings. Stronger emotional representations were associated with reduced emotional quality of life and greater adoption of maladaptive coping strategies (denial, self blame, behavioural disengagement and venting emotions). Across both CAM-users and non-users, behavioural disengagement and self blame both partially mediated the emotional representation–Dysphoria subscale pathway. Specific to non-users, denial and venting emotions also partially mediated the same pathway. Observation of each of the regression models revealed that emotional representations accounted for the majority of the variance with each of the coping strategies contributing small but significant amounts of variance to each model. These findings augment the earlier points (Drossman et al., 1999; Lackner et al., 2004) that emotional representations are important factors in IBS and have connotations for emotional well being, seemingly more so in non-users.

#### ***5.4.4 Limitations of the study***

In considering the group differences on the Brief-COPE and IBS-QOL subscales, significant differences existed although the effect sizes were small which is consistent with the examination of the illness perception and treatment belief measures presented in chapter four. It should also be noted that the sample used in this study consisted largely of participants recruited via an IBS self-help website and that were computer literate enough to undertake the research. Although there is evidence that samples recruited via the internet demonstrate little or no difference on psychological and other measures (Ahern, 2005; Basnov et al., 2009; Vallejo et al., 2007), it may still be recommended that the relationships between CSM components be examined in samples of

those with IBS recruited from other arenas to add support to the findings here.

One further limitation with the study findings is that the study was cross-sectional. This factor makes causal interpretation more difficult as there is little certainty that illness and treatment perceptions are directly influencing coping strategies to deal with IBS. Previous studies utilising the CSM have often used cross-sectional designs. These have produced mixed results albeit with some evidence of mediation of coping (Carlisle et al., 2005; Hagger et al., 2005; Rutter & Rutter, 2002). Other research has found no evidence of mediation (Heijmans, 1998; Kaptein et al., 2006; Scharloo et al., 1998). The limitations of using cross-sectional designs are evident therefore in seeking to establish causal pathways and potentially to have more success in determining greater mediation effects, prospective longitudinal research may prove more rewarding.

There may also be issues with the amount of mediation detected in the present study. It is apparent a small number of regression models constructed predicted small portions of variance in outcome and could be therefore be discounted as less important findings. Carlisle et al. (2005) imposed criteria of each regression model having to predict at least nine percent of the outcome variance to be considered satisfactory. However, to impose such criteria would have resulted in the majority of results in this study being retained which would include the strongest statistical effects. Therefore, this would have little impact on the findings of the study. It can be argued that in several cases, the unique variance added ( $R^2$  change) by Brief-COPE scales to regression models was small. However, the Beta coefficients for these values were still of moderate size suggesting a greater proportion of variance in IBS-QOL scores is shared with each illness or treatment representation component. Preacher and Hayes (2004) argue that the significance of any mediation effect is sufficient to suggest there is an indirect relationship between predictor and outcome through the mediating variable.

Although there was substantial partial mediation demonstrated in this study, there were many pathways between illness perceptions, treatment beliefs and reported quality of life where there was no evidence of mediation. Where mediation was present, this was largely classed as 'partial' mediation of which the effect sizes appeared small to moderate. This, in part, may be due to many of the regression equations that demonstrated mediation where higher variances in outcome were predicted by illness representations, the influence of coping on these equations appeared to be small. There is further concern that use of a generic coping checklist, as in this study, may not be the best way to measure coping strategies to capture responses to cognitive and emotional representations of IBS (Hagger & Orbell, 2003; Leventhal et al., 1997; 1998). This may also have influenced the degree of mediation detected in each group. Although the Brief-COPE actually delineates fourteen distinct coping strategies, there is suggestion that such measures may still lack specificity in terms of the CSM. Leventhal et al. (1997; 1998) have previously argued that coping should be thought of in terms of procedures where the individual makes direct attempt to address illness related concerns (Leventhal et al., 1998). However there is no current consensus on how coping should be measured in CSM studies. Researchers may provide suggestions on how coping should be measured in such studies in the future. Given the complexity of measuring how individuals cope with specific illness threats, it may be beneficial to develop or utilise existing coping instruments for specific illnesses (e.g. Carlisle et al., 2005).

The predominance of maladaptive or dysfunctional coping strategies demonstrating mediation suggests the Brief-COPE could be more suited to measuring these particular coping strategies. Alternatively, in those with IBS, coping strategies may be guided towards trying to effectively 'block out' the symptoms and emotions associated with having IBS. It is also possible that there is some artefact in the measurement of coping in this, and possibly other studies. Moreover, in outlining steps for mediation Baron and Kenny (1986) recommend that there is little or no



measurement error in the mediator variable. It is recommended that to rectify such shortcomings more specific, behavioural measures of coping could be assessed in future study (Hagger & Orbell, 2003). This may take the form of examining medication adherence through both self report measures (e.g. Horne, 2001) and examining adherence to certain CAM treatments or visits to a practitioner (e.g. Bishop et al., 2008).

Observation of some of the regression analyses presented demonstrates that in some cases there are several coping strategies that partially mediated the relationship between predictor and outcome. There is therefore a possibility that these mediators may interact with each other in explaining the predictor–outcome pathway, effectively becoming multiple mediators (Preacher & Hayes, 2008). This may be an avenue for future research although it should be noted that in this study, where higher variances in outcome were predicted, the additional variance explained by each of the mediators was small when added to each regression model. This again, reiterates the stronger relationships between illness perceptions and outcome (e.g. Hagger & Orbell, 2003).

#### ***5.4.5 Conclusions and implications***

This study adds further new and important findings in relation to the CSM and the pathways therein as no published study to date, using an IBS population, has examined simple mediation effects with a diverse range of coping strategies between CAM-users and non-users. The fact that this study tested for significance of mediation effects was a further beneficial aspect of this study, as many previous CSM adopting the Baron and Kenny (1986) approach do not report significance testing for mediation. The study also suggests that extending the CSM to incorporate treatment beliefs is worthwhile. Further investigation is recommended to assess the influence of treatment beliefs on reported quality of life in further IBS and other chronic illness samples.

The findings presented in this chapter give rise to a number of theoretical and practical implications. This research has added support to the CSM

and shown that, in many cases coping does mediate the link between illness perceptions and outcome, albeit partially. There is also tentative support for extending the CSM to incorporate treatment beliefs into the model. The most noticeable influences on impaired reported quality of life, in both groups, appear to be illness identity, consequences and emotional representations, and several of these pathways are mediated by largely maladaptive or avoidant coping strategies. It is also perhaps interesting to note that substance use was a partial mediator in non-users only (between illness consequences and IBS-QOL scores). This might suggest non-users are more likely than CAM-users to use alcohol for example to try to reduce their IBS symptoms. This is seemingly in contrast to previous work in numerous illness populations which has indicated that illness identity has the strongest relationship with illness outcome (e.g. Hagger & Orbell, 2003), although this may be partly due to the lack of exploration into the emotional representations of the IPQ-R. The control and coherence scales are implicated in the association of better reported quality of life, but when examining variance predicted by regression models across the two groups, it is to a lesser extent than with the symptom based IPQ-R scales.

As the previous chapter found with the IPQ-R, BMQ and CAMBI, there were differences between CAM-users and non-users on several scales of the IBS-QOL and the Brief-COPE. CAM-users with IBS reported lower quality of life than non-users. The coping strategies related to illness perceptions and treatment beliefs across both of these participant groups were largely maladaptive or dysfunctional. However where higher (or lower) quality of life scores are reported there is opportunity for potential intervention and further study. The study also offers a degree of support for an extended CSM in that several coping strategies were shown to (partially) mediate the relationship between illness perceptions, and, to a lesser degree, some facets of treatment beliefs and reported quality of life. In addition, emotional representations in IBS are important factors. Much research into the CSM neglects the emotional component. However, this study has shown the importance of emotional influences

related to IBS on reported quality of life and emotional quality of life. Further study could examine coping strategies that are particular to emotional representations. In this respect, this study represented an exploration of relationships with an existing measure of coping perhaps more readily associated with cognitive representations of illness. There is further, perhaps more tentative evidence for utilisation of an extended CSM that accounts for treatment beliefs and the relationships uncovered in this study warrant further investigation.

The findings suggest that those with IBS may report high levels of illness consequences, illness identity and stronger emotional representations. These representations all had a detrimental influence on reported quality of life, through the effect of adopting largely maladaptive or avoidant coping strategies. These effects appear to be slightly stronger in non-users. Taking into account the positive relationships between control and coherence representations and quality of life, it may be suggested that one way to potentially improve quality of life in IBS would be to enhance these components. Relationships between illness perceptions in both groups suggest this could be achieved by challenging for example, perceptions of consequences and emotional representations, especially in those with IBS that have not used CAM. This may enhance the use of more adaptive coping strategies.

In terms of the emotional representation–emotional outcome pathway, denial and venting of emotions were unique partial mediators to non-users. Examining the relationship between emotional representations and emotional quality of life was an important aspect of this study. It is clear that those with IBS report emotional distress related to their condition and this appears to have a greater influence on quality of life in non-users. It is possible that some form of intervention to lessen the emotional distress caused by IBS could be implemented by self-help networks. Disclosure by writing has been found to help those cope with stressful situations brought on by dealing with illness (Cameron & Jago, 2008; Pennebaker, 1997).

To address one of the main limitations of this cross-sectional study, the following chapter will examine the stability of illness representations over time and if the representations and beliefs measured in this study, will predict coping and reported quality of life at a subsequent time point.

## Chapter 6

### **A prospective examination of pathways in the Common-Sense Model of illness representations between CAM-users and non-users with IBS**

*This chapter reports a follow-up study to examine longitudinal changes in illness perceptions and treatment beliefs in people with IBS. The web-based methodology was used to follow-up participants of the cross-sectional study and thus enables the research to incorporate a prospective examination of pathways in the 'extended' Common-sense model. This chapter specifically examines the role of coping as a mediator in the pathways between illness and treatment perceptions and quality of life.*

#### **6.1 Introduction**

The previous chapter reported a cross-sectional study that suggested a degree of empirical support for an extended common-sense model of illness representations (Leventhal et al., 1992; 1998). The study also found evidence of mainly partial mediation by largely maladaptive or dysfunctional coping procedures between illness and treatment beliefs and quality of life. There were also direct links between illness representations and reported quality of life. The strongest effects on outcome, in both CAM-users and non-users, came from regression models containing symptom based IPQ-R scales, namely, illness identity, consequences and emotional representations. The variances in IBS-QOL scores explained by coping procedures in these cases were smaller, although these were higher in other cases, namely when assessing the effect of treatment beliefs on outcome.

To complement the findings of the previous chapter a prospective study was conducted to examine for possible influence of illness and treatment perceptions over time.

As highlighted in chapter two, illness and treatment perceptions may be updated depending on the effectiveness of coping procedures (Leventhal et al., 1992; 1998). This will, in part, come from the appraisal of coping procedures. If it is evident a certain procedure has not worked, then information is fed back to the representation stage where illness perceptions may influence another form of coping procedure (Leventhal et al., 1998). One of the studies utilising a CSM approach in IBS, found illness perceptions as measured by the IPQ, did not significantly change over the study duration of 12 months (Rutter & Rutter, 2007). However, research conducted over both six months (e.g. Lee et al., 2010) and six years (e.g. Kaptein et al., 2010), found variation in illness perceptions over time. Furthermore, Rutter and Rutter (2007) also found no evidence that coping acted as a mediator over time.

To address some of the potential shortcomings of the cross-sectional study in chapter five and to investigate if illness and treatment perceptions indicated any change over time, a prospective web-based study was conducted. This design was employed to explore evidence for directional pathways between components of the CSM (detailed in chapter two) and to continue with the examination of differences between the two participant groups of CAM-users and non-users. This included consideration of if CAM use over time appeared to improve reported quality of life when compared with those not using CAM. There were three specific aims addressed by this research:

6.1.1 To assess any change in CSM variables over time in CAM-users and non-users in IBS.

6.1.2 To examine if illness perceptions and treatment beliefs influence reported quality of life after a minimum of six months in CAM-users and non-users with IBS.

6.1.3 To test for evidence of coping mediating pathways between illness and treatment perceptions (at time one) and reported quality of life (at time two) across CAM-users and non-users.

## **6.2 Method**

This component of the research was largely conducted according to the methodology considered and described in chapter three. As this was a prospective follow-up study, participants were recruited via the email address that was provided during participation of the previously considered cross-sectional study. Analysis of data firstly considered any differences between those taking part in the follow-up and those that opted not to, using unrelated *t*-tests. As was considered in previous chapters, parametric tests (sections 3.6.3, 4.2.5.4 and 5.2.5.3) were favoured to perform statistical analyses. Related *t*-tests were used to assess participant differences between time one and time two ratings on scores of illness and treatment perceptions, coping and quality of life. In terms of mediation testing, Pearson's correlations were used to assess relationships between time one illness and treatment perceptions and time two IBS-QOL scores. Time one perceptions were also correlated with time two Brief-COPE scores. Finally, linear regression models and Sobel tests (Preacher & Hayes, 2004) were used in the final stage of mediation testing (section 3.6.3).

### **6.2.1 Design**

This study was a prospective web-based survey. To address the specific objectives (section 6.1), participant responses about illness perceptions, treatment beliefs and beliefs about complementary treatments were taken from the IPQ-R, BMQ and CAMBI respectively. Coping was assessed by using the Brief-COPE and reported IBS-specific quality of

life was assessed with the IBS-QOL. Participant demographics were also obtained.

### **6.2.2 Participants**

Recruited from the previous cross-sectional study, 197 participants took part in this study. In the previous study (chapters four and five) 404 participants stated their interest in taking part in a follow-up study, from a total of 653 that took part in the study reported in the previous two chapters. Data from the survey website showed that there were 372 visits to the follow-up study website. 86 participants dropped out after commencing the study and 283 opted to start but not complete the study. From the 283 that commenced the study 197 responses represented a 69.11% completion rate.

Data show however, that a substantial number of participants that visited the study website chose not to take part in the follow-up study. Furthermore approximately 40 email addresses from the list of 404, returned unsent messages (see section 6.2.4). Both of these factors offer possible reasons for the attrition rate in this study. It is also possible between the two time points of data collection, several participants changed email addresses, or incorrect email addresses were provided by mistake. Ultimately, this meant these participants could not be contacted and the number of visits to the study website given above (372) probably included some duplicate visits from participants. As the attrition rate was a concern, between groups analysis was conducted across responders and non-responders for the follow-up study. Key statistical analysis consisted of examining participants that had participated in both the cross-sectional and follow-up studies. As with previous analyses, this was conducted by group according to CAM-use or no-CAM use (non-users).

### **6.2.3 Measures**

The measures used in this study are detailed in chapter three (section 3.3). As with previous chapters, measures of illness perceptions,



treatment beliefs and coping were considered either predictor or explanatory variables. The Illness Perception Questionnaire Revised version (IPQ-R; Moss-Morris et al., 2002) which was used as a measure of illness perceptions and the Beliefs about Medicines Questionnaire general version (BMQ-general; Horne et al., 1999) was utilised to capture general beliefs about conventional medicines. The Complementary and Alternative Medicine Beliefs Inventory (CAMBI; Bishop et al., 2005) was used to ascertain beliefs about CAM. The Brief-COPE (Carver, 1997) was used to capture coping styles.

The IBS-QOL (Patrick et al., 1998), as in the previous chapter, was used as an outcome measure. The IBS-QOL total score reflects several factors related to QOL in IBS. Again, in concordance with the previous chapter, one of the subscales of the IBS-QOL, the Dysphoria subscale, was used as a measure of emotional quality of life so pathways leading to emotional 'outcome' could be examined.

To address the research aims and to allow comparison with findings in the previous chapter, participant data was again divided into two groups: CAM-users (i.e. have used CAM to relieve their IBS) and non-users (i.e. have not used CAM to relieve their IBS) according to their responses to CAM use at time one.

#### **6.2.4 Procedure**

The procedure was carried out as detailed in section 3.4 using an online survey host. Participants were contacted via their email addresses that were provided when interest in a follow-up study was registered. Email 'invitations' were sent to participants to take part in the follow-up study, as well as thanking them for their time and taking part in the original study. This was done a minimum of six months after the cross-sectional study had taken place. Within the email, participants were presented with a direct electronic link to the study website, where participants were presented with detailed information about the follow-up study and a consent 'page' that they had to acknowledge they had read before they

could proceed. As with the cross-sectional study, participants were directed through web pages on the study website with the use of 'next' icons at the foot of each page of responses (section 3.4). All data were captured over a period of approximately six weeks from April 2009. Reminders were sent out approximately two weeks later in case any participants had missed the original email. A final reminder email was sent a further two weeks later (appendices XII to XIV).

### **6.2.5 Statistical analyses**

Scale scores were computed for the IPQ-R, BMQ, CAMBI, Brief-COPE and in addition to subscale scores for the IBS-QOL (see section 3.3.2). Scales and subscales were then screened for outlying values and data distribution in these variables was assessed (Tabachnick & Fidell, 2007). With the IPQ-R causal items, scales were computed as per the findings of the Principal Components Analysis presented in chapter four. This was to allow direct comparison between participants' causal attributions (as measured by the IPQ-R) over time, as well as the alpha values on each causal scale reaching acceptable levels (provided in tables 6.5 to 6.7, see also section 4.2.5.3).

As considered in chapter four, outlying values and distributions of scale variables were considered (Tabachnick & Fidell, 2007). Following this, inferential statistical testing was conducted in SPSS version 17 to assess differences between responders and non-responders for the follow-up study. This was conducted across CAM-users and non-users using unrelated *t*-tests. Differences between measure scales (for both CAM-users and non-users) at time one (the cross-sectional study) and time two (this study), were explored using related *t*-tests. In addition, unrelated *t*-tests were used to examine differences in IBS-QOL scores between CAM-users and non-users at time two, to give a unique indication of whether CAM-use influenced IBS-QOL scores over time, with indications from this analysis at the cross-sectional stage indicating CAM-users reported worse quality of life. Finally, tests of simple mediation were conducted according to Baron and Kenny's (1986)

causal steps approach in CAM-users and non-users (see section 3.6.3). The grouping of CAM-users and non-users was conducted according to participant responses to their use of CAM (yes or no, section 3.3.3.1).

#### **6.2.5.1 Computing scales**

The IPQ-R, BMQ, CAMBI scales and the IBS-QOL total score and subscales were computed from the follow-up data allowing for small numbers of missing values on each item (see section 3.3.2). As stated in chapter five, the Brief-COPE was computed without accounting for any missing data as each scale of the measure consists of two items only. Therefore a total score was computed for participants that had two responses for items of each scale. Data were again split according to CAM use for IBS (CAM-users) or no CAM use for IBS (non-users).

#### **6.2.5.2 Data screening**

To ensure accuracy in data analysis and consistency with the cross-sectional study, data were examined for outlying values (Tabachnick & Fidell, 2007, see section 3.6). Prior to statistical testing IPQ-R, BMQ, CAMBI, Brief-COPE scales and IBS-QOL scale and subscales were all screened for bivariate outliers (CAM-users and non-users).

Box-plots were used to visually identify outliers that were present in several Brief-COPE scales and IBS-QOL subscales. Detected outliers were examined to ensure all values were in the correct scoring range for each scale and subscale. Any outlying values were again modified to reduce the influence of these values (Field, 2009; Tabachnick & Fidell, 2007; see section 4.2.5.2). Outlying cases were changed to the lowest (or highest) next non-outlying value to reduce the influence of these particular cases (Field, 2009). The Brief-COPE scales denial and substance use were found to be unresponsive to modification. This meant that the distribution of residual values for influence of outlying values was checked in regression models that contained these scales.

The distributions for measure scales were then assessed. This was again conducted visually by observation of histograms for both the CAM-users and non-users. There was little deviation from normality in the IPQ-R, BMQ and CAMBI with most scales being normally distributed. In non-users, the timeline chronic and the illness coherence scales showed a positive skew, where 'risk factors' deviated negatively. In CAM-users, only the timeline chronic scale was found to be positively skewed.

Several Brief-COPE scales were found to deviate from normality. In both groups behavioural disengagement, venting emotions, positive reframing, humour, self blame and religion were all found to be positively skewed. The denial and substance use scales were also positively skewed in both groups to the extent that scores suggested these coping styles appeared to be little utilised by participants. In CAM-users, the emotional support scale was positively skewed, while in non-users, active coping was negatively skewed. All other scales had normally distributed scores.

Most of the eight IBS-QOL subscales were normally distributed in addition to the total IBS-QOL score, however in both CAM-users and non-users the sexual and food avoidance subscales were negatively and positively skewed respectively. In the non-users, the relationships subscale was also negatively skewed.

In using related *t*-tests the distributions of the differences between pairs of scores should be assessed for normality (e.g. Field, 2009). For the purposes of exploring differences between time one and time two measures in both groups, differences between time one and time two scores were computed. These distributions were examined in all CSM variables in addition to age and were all found to be normally distributed showing little evidence of skewness.

### **6.2.5.3 Statistical tests**

Parametric analysis was favoured as the measures used in this study were considered psychometrically stable enough to have elicited parametric data (see section 3.3.2). As with the previous two chapters, statistical analysis was conducted on a list-wise basis in SPSS to ensure greater accuracy, excluding any case with missing data on any of the measures (see section 3.6.1). As previous chapters have illustrated, *t*-tests are considered robust to violations of non-normality (see sections 3.6.2 and 4.2.5). This extends to situations with unequal group sizes where the sample is large (i.e. over 30) where in such situations equality of variance tests should be examined (Sawilowsky & Clifford Blair, 1992). Therefore, independent *t*-tests were conducted to examine for differences in responders and non-responders for this study. Related *t*-tests were used to examine for differences in measures over the study time points on the IPQ-R, BMQ, CAMBI, Brief-COPE and IBS-QOL. All analyses were conducted separately for CAM-users and non-users.

To address the final aims of the study, the approach taken in the previous chapter (section 5.2.5.3, see also section 3.6.3) to test for 'simple' mediation was adopted in both CAM-users and non-users. In assessing the Baron and Kenny (1986) steps for simple mediation, as this study was a follow-up, firstly simple linear regression models were used to assess relationships between scales of the IPQ-R, BMQ and CAMBI at time one (predictors) and IBS-QOL scores at time two (outcome). Significant relationships were then used as a guide as to which IPQ-R, BMQ and CAMBI scales should be correlated with the Brief-COPE (time two). Finally, a series of linear regression models were computed where each predictor variable was regressed on outcome. Brief-COPE scales (that were related to predictors) were entered into a second block of each regression model. This was to observe any effect of the mediator on outcome whilst controlling for the effect of the predictor (step three of Baron and Kenny's criteria). Only scenarios where the mediator successfully predicted outcome while reducing the effect of predictor coefficients are reported. Significance testing of the

mediation effect was conducted using the SPSS macro utilised in the previous chapter (Preacher & Hayes, 2004; chapter three, section 3.6.3).

### **6.3 Results**

This study sought to address three objectives. Firstly, differences between the CAM-users and non-users at time one and time two on IPQ-R, BMQ, CAMBI, Brief-COPE and IBS-QOL scores were considered. Secondly, the influence of time one IPQ-R, BMQ and CAMBI scores on IBS-QOL (time two) was assessed. Thirdly, mediation testing was conducted (between CAM-users and non-users) for predictor variables scores at time one and mediator and outcome scores at time two. In addition to the main aims, the rate of attrition was considered to be one potential limitation. Therefore participant data at study time one was examined for differences between responders and non-responders according to CAM-use or no-CAM use (section 6.3.2.). Key participant demographic information for responders is also presented from responses provided at study time one (6.3.1).

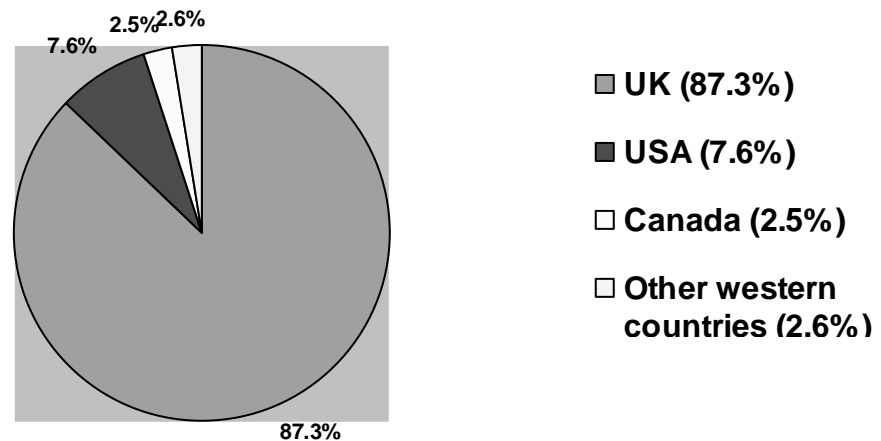
#### **6.3.1 Participant demographics**

The age range of participants for this study was 18-76, with 81.2% ( $n=160$ ) being female with one missing case in this category. The mean age overall was 38.56 years ( $SD=12.96$ ), which was slightly higher than the mean age recorded in the cross-sectional study. As was found at time one, there were slight differences in mean ages by gender. The mean age for males was 40.42 ( $SD=13.13$ ) years, which was slightly higher than females at 38.13 years ( $SD=12.93$ ).

Key categorical demographics are illustrated in table 6.1. Participants were asked if they had been diagnosed with IBS by a health care professional, with most participants (94.9%,  $n=187$ ) stating they had been diagnosed with IBS. Ninety four (50.3% approximately) participants had been diagnosed over 5 years ago, with approximately 20.3% ( $n=38$ ) being diagnosed one to two years ago. A majority of participants (73.1%,

*n*=144) of participants stated that they had been living with IBS symptoms for over 5 years (Table 6.1). When asked if they were taking prescribed medication for their IBS, approximately 48.7% (*n*=96) stated 'yes' with 101 stating 'no'. Table 6.1 also illustrates that approximately 73.7% (*n*=143) were employed with the largest percentage of approximately 23.9% (*n*=45) of participants indicating they had £20,000-£29,000 (or equivalent) household income, which is similar to figures reported in table 4.3. Approximately 76% of participants had educational qualifications ranging from GCSEs or 'O' levels to first degree. There were more participants that reported suffering from other conditions (co-morbidity) (62.4%, *n*=123) than reported no co-morbidity (37.6%, *n*=74).

**Figure 6.1 Pie chart illustrating geographical location of participants for follow-up study (percentage of the whole sample)**



In terms of geographical location, participant data for this study showed similarities to data presented in chapter four (section 4.3.1). Most participants were from the UK (87.3%), 7.6% were from the US and 2.5% from Canada (figure 6.1). Participants located in other countries accounted for approximately 2.5%. In terms of ethnic groupings, approximately 83% were white British, white Irish or other white background. Religious groupings were either mainly 'Christian' (53.1%)

or 'none' (38.6%) with other religious groups represented by small numbers of participants. The large proportion of Christian and no-religion in the sample perhaps reflect that the majority of participants were of a white ethnic background, many of whom were British or Irish.

Approximately 63.5% of participants ( $n=125$ ) reported that they had used CAM to relieve the symptoms of IBS either presently or in the past, the remaining 36.5% ( $n=72$ ) not using CAM. Table 6.1 also offers a demographic breakdown of CAM use by frequency. Table 6.1 also offers a demographic breakdown of CAM use by frequency. Notably, selected categories in income and time of diagnosis suggested higher CAM use.

Approximately 29% of CAM-users, who were responders at time two, reported (at time one) that they had visited a CAM practitioner at least once in the last 12 months compared with 23.6% of all CAM-users (i.e. including those who only responded at time one). Seventy three per-cent of CAM-users responding at study time two reported (at time one) that they had purchased their own CAM 'off the shelf', compared to 75% of all CAM-users. Many CAM-user responders had also been directed to take CAM (40%) compared with 34.9% of all CAM-users (section 4.3.2).

The use of specific types of CAM treatments by responders (reported at time one), again showed similarities across all CAM-users (section 4.3.2). Again the most popular treatments in responders were herbal treatments (42%), massage (31%) and aromatherapy (28%). There were slight increases in the reported use of talk therapies (25%), yoga (26%), relaxation techniques (23%) and homeopathy (21%). The use of bach flower remedies was consistently used in responders compared with all CAM-users at time one (23%). As reported with all CAM-users, other popular treatments that responders reported at time one were; acupuncture (18%), hypnosis (15%) and nutritional treatments (15%).



**Table 6.1 Key participant demographic (time one) data by frequency and frequency of CAM use in responders (n=197)**

<i>Variable</i>	<i>Category</i>	<i>Number (%*)</i>	<i>CAM use at time 1 %*</i>	
			<i>Y</i>	<i>N</i>
<b>Gender</b>	Male	36 (18.3)	56.6	44.4
	Female	160 (81.2)	65.6	34.4
<b>Diagnosis</b>	Yes	187 (94.9)	63.1	36.9
	No	10 (5.1)	70	30
<b>Time diagnosed</b>	Less than 12 months	3 (1.6)	33.3	66.7
	1-2 years	38 (20.3)	50	50
	2-3 years	23 (12.3)	65.2	34.8
	3-4 years	13 (7.0)	84.6	15.4
	4-5 years	16 (8.1)	68.7	31.3
	Over 5 years	94 (50.3)	64.9	35.1
	<b>Time with symptoms</b>	Less than 12 months	- (-)	-
1-2 years		11 (5.6)	36.4	63.6
2-3 years		15 (7.6)	66.7	33.3
3-4 years		16 (8.1)	75	25
4-5 years		11 (5.6)	72.7	27.3
Over 5 years		144 (73.1)	63.2	36.8
<b>Currently taking prescribed medication</b>		yes	96 (48.7)	54.2
	no	101 (51.3)	72.3	27.7
<b>Employed</b>	yes	143 (73.7)	67.8	32.2
	no	51 (26.3)	67.8	32.2
<b>Income</b>	up to £9999	16 (8.5)	52.9	47.1
	£10,000 - 14,999	14 (7.4)	50	50
	£15,000 - £19,999	17 (9.0)	64.7	35.3
	£20,000 - £29,000	45 (23.9)	64.4	35.6
	£30,000 - £39,999	33 (17.6)	72.7	27.3
	£40,000 - £49,999	24 (12.8)	58.3	41.7
	£50,000 and above	39 (20.7)	64.1	35.9
	<b>Education</b>	GCSEs, 'O' levels or equivalent	42 (21.5)	42.9
A Levels or equivalent		47 (24.1)	70.2	29.8
First Degree (BA, BSc)		62 (31.8)	69.4	30.6
Postgraduate qualification		34 (17.4)	70.6	29.4
No qualifications		10 (5.1)	60	40
<b>Co-morbidity reported</b>	Yes	123 (62.4)	65.9	34.1
	No	74 (37.6)	59.5	40.5

\* Percentages are corrected for missing values

### **6.3.2 Differences between responders and non-responders on CSM scale variables and age**

Tables 6.2 to 6.4 show comparisons between CSM variables (and age) between those who participated in this follow-up study (responders) and those that opted not to (non-responders) according to whether participants had reported CAM use in the cross-sectional study (time one). Illness and treatment perception scores showed limited differences across both time points (table 6.2), as did Brief-COPE (table 6.3) and IBS-QOL scores (table 6.4).

Table 6.2 shows that responders that were non-users showed significantly higher scores on illness identity ( $M=6.20$ ,  $SD=2.60$ ) than non-responders at time two ( $M=5.40$ ,  $SD=2.81$ ),  $t(255)= 2.07$ ,  $p<.05$ . Equal variances were assumed in each of the two groups (responders and non-responders)  $F=.36$ ,  $p>.05$ . The reverse was found in CAM-users, where non-responders had reported stronger illness identity ( $M=6.65$ ,  $SD=2.90$ ) than responders ( $M=5.98$ ,  $SD=2.46$ ), however, equal variances were not assumed ( $F=6.73$ ,  $p<.05$ ), and the resulting SPSS adjustment for the violation of equal variances resulted in:  $t(282.81)= -2.16$ ,  $p<.05$ . A similar trend was observed where CAM-users who were non-responders had significantly stronger external causal beliefs ( $M=15.27$ ,  $SD=3.76$ ) than responders at time two ( $M=14.11$ ,  $SD=3.91$ ),  $t(343)= -2.69$ ,  $p<.01$  and equal variances were observed between responders and non-responders ( $F=.26$ ,  $p>.05$ ). Non-responders also reported stronger beliefs regarding medication overuse ( $M=10.41$ ,  $SD=2.90$ ) than responders ( $M=9.67$ ,  $SD=2.74$ ),  $t(343)= -2.31$ ,  $p<.05$  with equal variances assumed ( $F=.43$ ,  $p>.05$ ). Both CAM-users and non-users reported greater beliefs in patient participation in treatment. In CAM-users, responders had higher mean participation in treatment scores ( $M=20.03$ ,  $SD=2.58$ ) than non-responders at time two ( $M=19.44$ ,  $SD=2.68$ ),  $t(343)= 1.99$ ,  $p<.05$ , with equal variances being assumed ( $F=.39$ ,  $p>.05$ ). In non-users, responders also reported higher participation scores ( $M=19.63$ ,  $SD=2.71$ ) than non-responders ( $M=18.77$ ,  $SD=2.72$ ),  $t(255)= 2.26$ ,  $p<.05$ , where equal variances between the

groups were observed ( $F=.01, p>.05$ ). Significant differences are also illustrated in figure 6.2 wherein the error bars represent plus or minus one standard deviation relative to each mean. There were no other significant differences between responders and non-responders on illness and treatment perception scales.

Table 6.3 illustrates Brief-COPE scores for both responders and non-responders. Only CAM-users showed a difference, with non-responders scoring more highly on three scales. Non-responders ( $M=3.0, SD=1.43$ ) scored significantly higher than responders ( $M=2.62, SD=1.02$ ) on the denial scale  $t(317.94)= -2.92, p<.01$ , where the assumption of equal variances was violated ( $F=15.37, p<.001$ ). Non-responders also scored more highly on the 'venting' of emotions scale ( $M=4.24, SD=1.56$ ) when compared to responders ( $M=3.84, SD=1.43$ ),  $t(343)= -2.30, p<.05$ , where equal variances between the two groups were assumed ( $F=1.14, p>.05$ ). In examining the humour scale, non-responders were also found to score more highly ( $M=4.23, SD=1.93$ ) than responders ( $M=3.70, SD=1.75$ ),  $t(343)= -2.49, p<.05$ , where equal variances were assumed ( $F=1.84, p>.05$ ). Significant differences are also illustrated visually in figure 6.3.

Table 6.4 shows that on IBS-QOL scores, only two subscales showed differences between responders and non-responders (figure 6.3). These differences were limited to CAM-users only. Responders scored significantly higher ( $M=62.81, SD=31.64$ ) on the sexual subscale of the IBS-QOL when compared to non-responders ( $M=52.96, SD=34.68$ ),  $t(265.99)= 2.67, p<.01$ , where the assumption of equal variances between the groups was broken as Levene's test was significant ( $F=5.63, p<.05$ ) so the SPSS correction was employed for this scenario. When assessing total IBS-QOL scores, responders using CAM scored significantly higher ( $M=46.18, SD=19.85$ ) than non-responders ( $M=41.39, SD=20.66$ ),  $t(343)= 2.08, p<.05$ , assuming equal variances between the two groups ( $F=.40, p>.05$ ). These two findings suggest that responders were reporting better quality of life than non-responders.

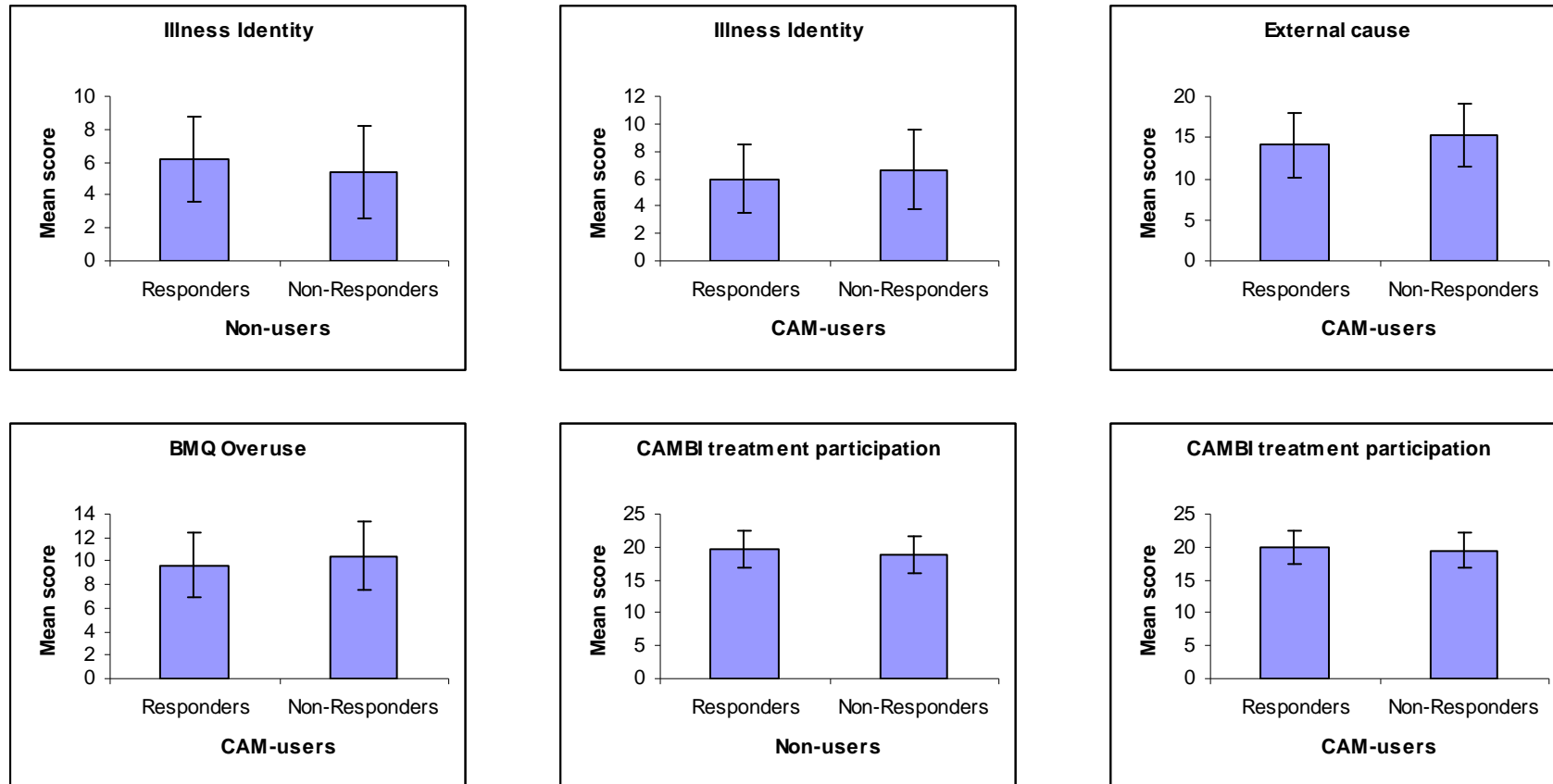
Tables 6.2 to 6.4 suggest that differences between the two sets of responses at time one were minimal. The most notable difference was that of the difference between responders and non-responders on IBS-QOL scores in CAM-users. This suggests that those taking part in the follow-up study, reported slightly better IBS-QOL scores than those not taking part at time two, although the effect sizes calculated show the magnitude of these differences to be small (i.e.  $r < .2$ ). There were no other differences between responders and non-responders on the Brief-COPE and IBS-QOL.

**Table 6.2 Descriptive statistics and unrelated t-tests for responder /non-responder differences on illness and treatment perception scales (and age) between CAM-users and non-users with IBS**

Variable	CAM use y/n	Mean (SD) Responders (non- users n=70; CAM- users n=121 )		Mean (SD) Non- Responders (non- users n=187; CAM- users n=224)		t-value (effect size 'r')
Age	No (n=257)	37.86	(12.48)	37.11	(13.95)	.40
	Yes (n=345)	36.90	(13.45)	37.21	(12.18)	-.21
Identity	No	6.20	(2.60)	5.40	(2.81)	<b>2.07* (.13)</b>
	Yes	5.98	(2.46)	6.65	(2.90)	<b>-2.16* (.13)</b>
Timeline Chronic	No	24.98	(3.98)	24.49	(3.66)	.92
	Yes	25.28	(3.93)	24.80	(3.75)	1.11
Timeline Cyclical	No	14.64	(2.97)	14.80	(2.88)	-.39
	Yes	15.04	(2.69)	15.48	(2.70)	1.44
Consequences	No	21.33	(4.22)	20.67	(4.75)	1.03
	Yes	21.82	(4.32)	22.69	(4.25)	-1.81
Personal control	No	18.86	(4.38)	19.64	(4.33)	-1.27
	Yes	20.19	(4.51)	19.36	(4.75)	1.58
Treatment control	No	13.83	(3.81)	14.41	(3.77)	-1.09
	Yes	14.55	(3.88)	14.29	(3.98)	.57
Illness coherence	No	14.06	(5.05)	13.88	(4.68)	.27
	Yes	14.23	(5.56)	14.16	(5.36)	.12
Emotional representations	No	21.86	(5.15)	21.40	(5.37)	.62
	Yes	22.47	(4.65)	23.08	(5.08)	-1.09
Internal cause	No	21.67	(5.59)	20.95	(5.89)	.89
	Yes	21.77	(6.22)	21.86	(6.43)	-.13
External cause	No	14.82	(4.65)	14.83	(3.79)	-.02
	Yes	14.11	(3.91)	15.27	(3.76)	<b>-2.69** (.14)</b>
Cause – risk factors	No	9.24	(2.73)	9.96	(3.21)	-1.66
	Yes	9.28	(2.81)	9.57	(3.28)	-.87
BMQ Harm	No	11.68	(3.09)	12.01	(3.16)	-.75
	Yes	12.71	(2.93)	13.17	(3.27)	1.29
BMQ Overuse	No	9.55	(2.86)	9.90	(2.87)	-.88
	Yes	9.67	(2.74)	10.41	(2.90)	<b>-2.31* (.12)</b>
CAMBI Natural treatments	No	21.63	(3.34)	21.29	(3.25)	.74
	Yes	21.79	(3.39)	22.26	(3.47)	-1.20
CAMBI treatment participation	No	19.63	(2.71)	18.77	(2.72)	<b>2.26* (.14)</b>
	Yes	20.03	(2.58)	19.44	(2.68)	<b>1.99* (.11)</b>
CAMBI holistic health	No	21.65	(3.87)	21.06	(3.54)	1.15
	Yes	22.41	(3.36)	21.92	(3.55)	1.24

\* $p < .05$  \*\* $p < .01$  (Effect sizes  $r = .1$  weak,  $r = .3$  moderate,  $r = .5$  strong)

**Figure 6.2 Bar graphs to illustrate significant differences between responders and non-responders on IPQ-R, BMQ and CAMBI scales for both CAM-users and non-users**



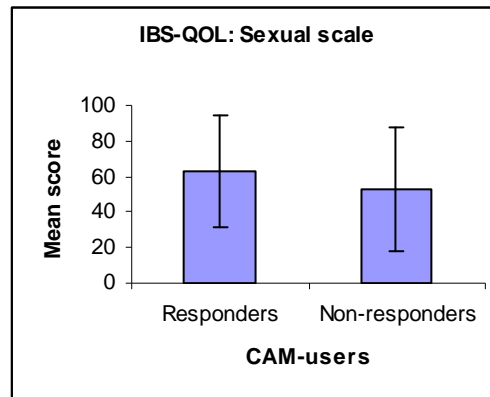
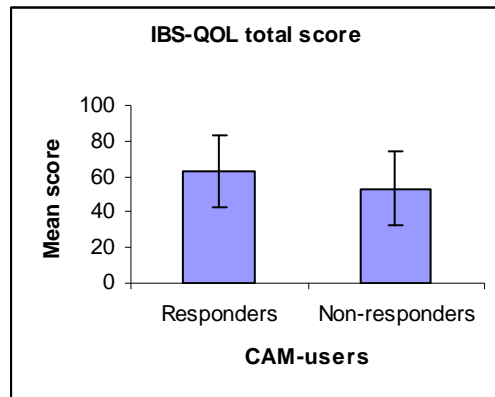
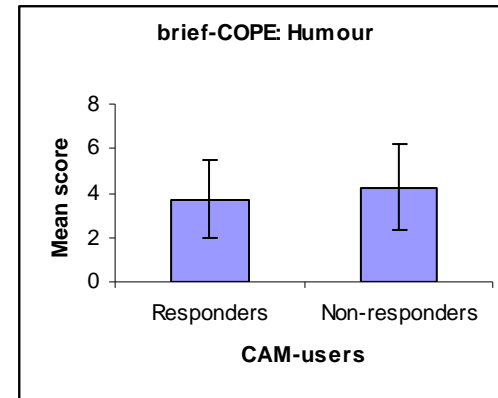
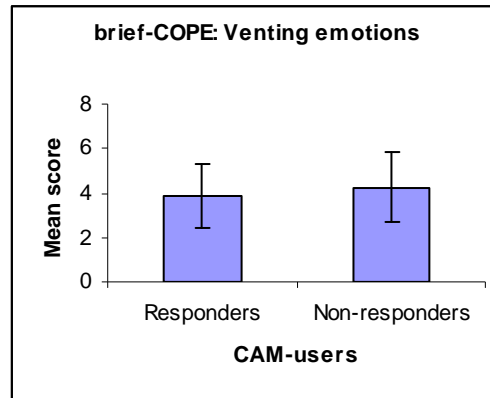
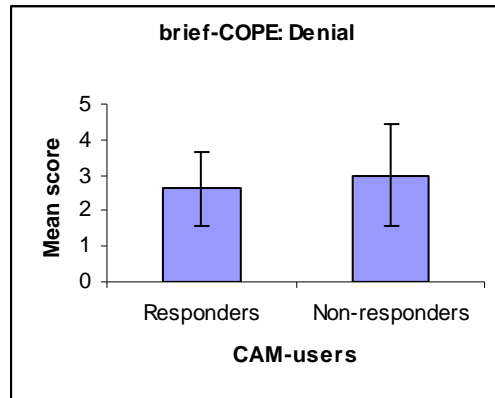
**Table 6.3 Descriptive statistics and unrelated t-tests for responder /non-responder differences on Brief-COPE scales between CAM-users and non-users with IBS**

Brief-COPE scale	CAM use y/n	Mean (SD) Responders (non-users n=70; CAM-users n=121)	Mean (SD) Non-Responders (non-users n=187; CAM-users n=224)	t-value (effect size 'r')
Self distraction	No (n=257)	4.06 (1.66)	4.10 (1.65)	-.17
	Yes (n=345)	4.60 (1.60)	4.67 (1.67)	-.38
Active coping	No	5.33 (1.73)	5.19 (1.72)	.56
	Yes	6.02 (1.61)	6.03 (1.58)	-.08
Denial	No	2.36 (.68)	2.54 (.81)	-1.82
	Yes	2.62 (1.02)	3.00 (1.43)	<b>-2.92** (.16)</b>
Substance use	No	2.50 (1.25)	2.78 (1.59)	-1.46
	Yes	2.69 (1.46)	2.86 (1.59)	-.98
Emotional support	No	4.20 (1.95)	4.24 (1.75)	-.14
	Yes	4.71 (1.79)	4.77 (1.79)	-.31
Instrumental support	No	4.86 (1.88)	4.86 (1.82)	.01
	Yes	5.33 (1.83)	5.44 (1.72)	-.54
Behavioural disengagement	No	3.20 (1.41)	3.37 (1.52)	-.83
	Yes	3.37 (1.51)	3.72 (1.74)	-1.88
Venting emotions	No	3.33 (1.44)	3.73 (1.55)	-1.87
	Yes	3.84 (1.43)	4.24 (1.56)	<b>-2.30* (.12)</b>
Positive reframing	No	3.39 (1.52)	3.35 (1.46)	.16
	Yes	3.57 (1.65)	3.94 (1.71)	-1.92
Planning	No	5.13 (1.91)	5.28 (1.72)	-.62
	Yes	5.85 (1.67)	6.02 (1.53)	-.93
Humour	No	3.84 (1.88)	3.58 (1.83)	1.03
	Yes	3.70 (1.75)	4.23 (1.93)	<b>-2.49* (.13)</b>
Acceptance	No	5.40 (1.56)	5.40 (1.69)	.02
	Yes	5.83 (1.48)	5.78 (1.55)	.29
Religion	No	2.47 (.82)	2.42 (.76)	.55
	Yes	3.12 (1.67)	3.13 (1.67)	-.10
Self blame	No	3.50 (1.79)	3.74 (1.89)	-.93
	Yes	3.97 (1.90)	4.10 (1.98)	-.62

\*p<.05 \*\*p<.01 (Effect sizes  $r=.1$  weak,  $r=.3$  moderate,  $r=.5$  strong)

The range of possible scores was 2 – 8, with higher scores meaning greater adoption of a particular coping strategy.

**Figure 6.3 Bar graphs to illustrate significant differences between responders and non-responders on Brief-COPE scales and IBS-QOL subscales in CAM-users**





**Table 6.4 Descriptive statistics and unrelated t-tests for responder /non-responder differences on IBS-QOL scale and subscales between CAM-users and non-users with IBS**

IBS-QOL scale/subscale	CAM use y/n	Mean (SD) Responders (non-users n=70; CAM-users n=121)		Mean (SD) Non-Responders (non-users n=187; CAM-users n=224)		t-value (effect size 'r')
Total IBS-QOL Score	No (n=257)	49.74	(21.65)	49.69	(22.22)	.01
	Yes (n=345)	46.18	(19.85)	41.39	(20.66)	<b>2.08* (.11)</b>
Dysphoria	No	45.64	(30.01)	44.95	(28.54)	.17
	Yes	42.66	(26.40)	37.33	(26.94)	1.76
Interference with activity	No	46.49	(26.97)	46.95	(25.71)	-.13
	Yes	43.80	(23.69)	39.23	(25.17)	1.64
Body Image	No	49.91	(23.03)	51.57	(24.77)	-.49
	Yes	46.30	(24.99)	42.25	(24.45)	1.46
Health worry	No	57.80	(22.12)	54.79	(23.41)	.93
	Yes	53.48	(22.51)	50.56	(24.06)	1.10
Food avoidance	No	37.02	(28.75)	34.80	(29.16)	.55
	Yes	30.81	(27.03)	25.37	(24.19)	1.85
Social reaction	No	50.66	(25.43)	50.12	(28.19)	.14
	Yes	45.64	(25.59)	41.05	(25.73)	1.59
Sexual score	No	63.21	(36.48)	68.12	(31.49)	-.99
	Yes	62.81	(31.64)	52.96	(34.68)	<b>2.67* (.16)</b>
Relationships score	No	61.79	(27.71)	63.46	(27.18)	-.44
	Yes	58.13	(26.65)	55.17	(27.85)	.96

\*p<.05 (Effect sizes  $r=.1$  weak,  $r=.3$  moderate,  $r=.5$  strong)

IBS-QOL scores have been transformed to a score out of 100. Lower scores mean poorer reported quality of life.

### 6.3.3 Differences in CSM variable scores at time one and time two

To assess the proposition of the CSM that illness (and treatment) perceptions change over time, scales of the IPQ-R, BMQ and CAMBI were assessed for differences across the two study time-points. This was conducted by the use of related *t*-tests and results are shown for

CAM-users and non-users (table 6.5). Furthermore, changes in scores of the Brief-COPE and any change in IBS-QOL scores over time were also tested (tables 6.6 & 6.7). Significant differences are illustrated in figures 6.4 to 6.8, where the error bars indicate plus or minus one standard deviation.

### **6.3.3.1 Illness and treatment perceptions**

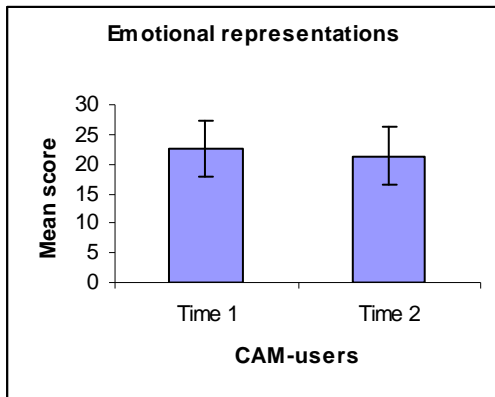
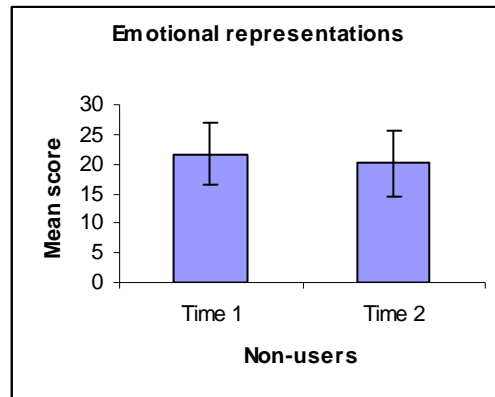
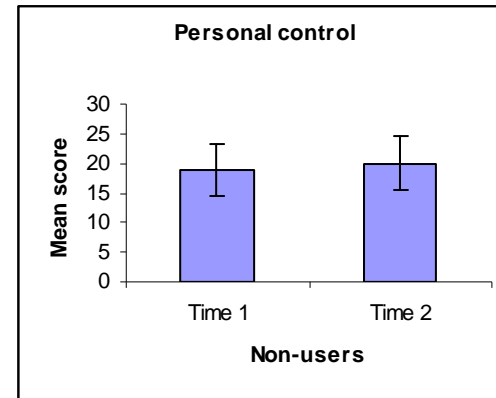
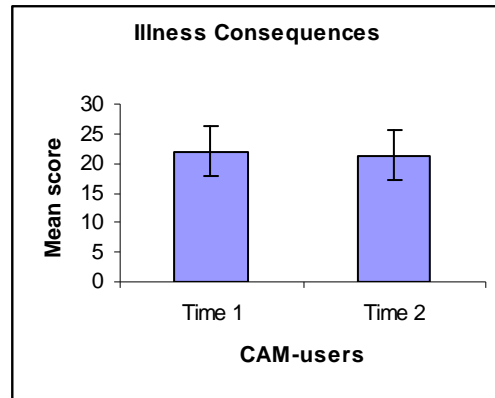
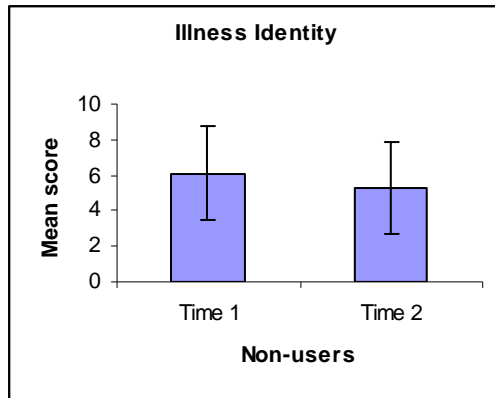
Table 6.5 shows descriptives and related *t*-test results for differences between time one and time two scores on IPQ-R, BMQ and CAMBI scales. Alpha values for all scales are also shown which suggest all scales reached acceptable levels of internal reliability (Bryman, 2008; see also section 4.2.5.3). In non-users, time two identity scores were significantly lower ( $M=6.09$ ,  $SD=2.62$ ) than time one ( $M=6.09$ ,  $SD=2.62$ ),  $t(68)= 2.11$ ,  $p<.05$ . A similar trend was observed for the illness consequences scale in CAM-users. Time two consequences scores were significantly lower ( $M=21.37$ ,  $SD=4.33$ ) than time one scores ( $M=22.04$ ,  $SD=4.16$ ) in responders,  $t(117)= 2.10$ ,  $p<.05$ . The reverse was true for personal control scores in non-users. Time two scores for personal control were significantly higher ( $M=19.92$ ,  $SD=4.52$ ) than at time one ( $M=18.79$ ,  $SD=4.43$ ),  $t(68)= -2.19$ ,  $p<.05$ . The only other change noted in illness and treatment perceptions was in emotional representations. Here, scores in both groups were lower at time two. In non-users, time two emotional representations were significantly lower ( $M=20.12$ ,  $SD=5.65$ ) than at time one ( $M=21.59$ ,  $SD=5.23$ ) in responders  $t(68)= 2.60$ ,  $p<.05$ . In CAM-users, time one emotional representations were significantly higher ( $M=22.56$ ,  $SD=4.63$ ) than at time two ( $M=21.30$ ,  $SD=4.85$ ),  $t(117)= 3.33$ ,  $p<.01$ . There were no other significant differences in IPQ-R, BMQ or CAMBI scores between the two time-points suggesting there was limited change in many of these dimensions between the two points of data capture. Many of the observed effect sizes demonstrated small to moderate differences over time which can be observed visually in figure 6.4.

**Table 6.5 Illness and treatment perception differences over the two study time-points in CAM-users and non-users**

Variable	CAM use y/n	Cronbach's alpha (time 2)	Mean (SD) time 1	Mean (SD) time 2	t-value (effect size <i>r</i> <sup>2</sup> )
Identity	No (n=69)	N/A	6.09 (2.62)	5.28 (2.57)	<b>2.11* (.25)</b>
	Yes (n=118)	N/A	6.00 (2.41)	5.56 (2.41)	1.64
Timeline Chronic	No	.81	24.96 (4.02)	24.48 (4.29)	1.03
	Yes	.87	25.31 (3.89)	24.77 (3.98)	1.49
Timeline Cyclical	No	.75	14.49 (2.99)	14.87 (3.14)	-1.01
	Yes	.73	15.04 (2.72)	15.09 (2.95)	-.18
Consequences	No	.83	21.25 (4.19)	20.57 (5.15)	1.47
	Yes	.84	22.04 (4.16)	21.37 (4.33)	<b>2.10* (.19)</b>
Personal control	No	.85	18.79 (4.43)	19.92 (4.52)	<b>-2.19* (.20)</b>
	Yes	.87	20.19 (4.48)	20.68 (4.56)	-1.27
Treatment control	No	.80	13.81 (3.85)	14.30 (3.57)	-1.03
	Yes	.82	14.59 (3.86)	15.06 (4.41)	-1.26
Illness coherence	No	.91	14.15 (5.06)	15.17 (5.07)	-1.81
	Yes	.94	14.16 (5.59)	14.75 (5.38)	-1.23
Emotional representations	No	.86	21.59 (5.23)	20.12 (5.65)	<b>2.60* (.23)</b>
	Yes	.88	22.56 (4.63)	21.30 (4.85)	<b>3.33** (.29)</b>
Internal cause	No	.84	21.54 (5.85)	21.47 (5.79)	.12
	Yes	.84	21.79 (6.26)	22.18 (6.33)	-.84
External cause	No	.64	14.76 (4.66)	14.63 (3.87)	.26
	Yes	.61	14.14 (3.90)	14.04 (3.86)	.29
Cause - risk factors	No	.75	9.20 (2.75)	9.94 (2.82)	-1.70
	Yes	.61	9.11 (2.79)	9.40 (3.09)	-1.13
BMQ Harm	No	.67	11.69 (3.04)	12.08 (2.85)	-1.26
	Yes	.61	12.71 (2.88)	12.63 (3.14)	.34
BMQ Overuse	No	.63	9.51 (2.85)	9.79 (2.49)	-.81
	Yes	.69	9.54 (2.72)	9.74 (2.69)	-1.00
CAMBI Natural treatments	No	.78	21.51 (3.26)	21.86 (3.13)	-.94
	Yes	.79	21.85 (3.38)	21.62 (3.19)	.69
CAMBI treatment participation	No	.64	19.53 (2.73)	19.76 (2.86)	-.62
	Yes	.71	20.09 (2.61)	20.22 (2.80)	-.52
CAMBI holistic health	No	.61	21.66 (3.83)	21.50 (3.07)	.34
	Yes	.71	22.42 (3.38)	22.43 (3.36)	-.03

\*p<.05 \*\*p<.01 (Effect sizes *r*=.1 weak, *r*=.3 moderate, *r*=.5 strong)

**Figure 6.4 Bar graphs to illustrate significant differences between time one and time two responses on IPQ-R scales for CAM-users and non-users**



### **6.3.3.2 Brief-COPE scales**

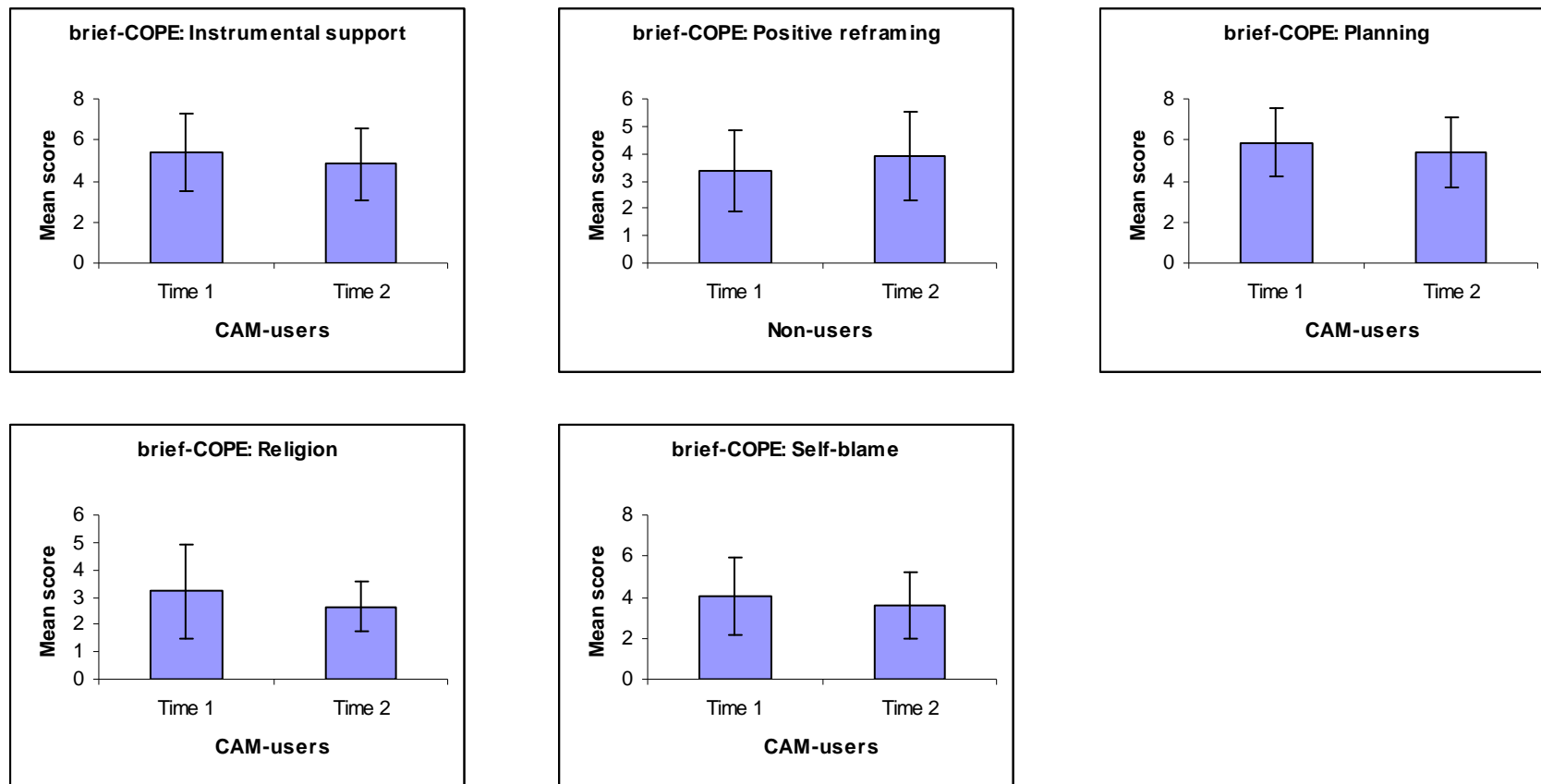
Table 6.6 shows the differences over the two time-points in the Brief-COPE scores where most of the significant differences detected were in CAM-users. In CAM-users, instrumental support scores were found to be higher at time one ( $M=5.40$ ,  $SD=1.87$ ) than at time two ( $M=4.81$ ,  $SD=1.74$ ) in responders  $t(113)= 3.35$ ,  $p<.01$ . This trend was mirrored in CAM-users scores on the planning scale, where time one scores ( $M=5.87$ ,  $SD=1.68$ ) were significantly higher than time two ( $M=5.39$ ,  $SD=1.72$ ),  $t(113)= 2.82$ ,  $p<.01$ . CAM-user scores on the self blame scale were also significantly higher at time one ( $M=4.03$ ,  $SD=3.60$ ) than at time two ( $M=3.60$ ,  $SD=1.58$ ) in responders,  $t(113)= 2.42$ ,  $p<.05$ . Time two scores on the religion scale ( $M=2.65$ ,  $SD=.89$ ) were significantly lower than at time one ( $M=3.21$ ,  $SD=1.72$ ) in CAM-users,  $t(113)= 4.38$ ,  $p<.001$ . The only difference detected in non-users was on the positive reframing scale, where time two scores were significantly higher ( $M=3.91$ ,  $SD=1.64$ ) than at time one ( $M=3.37$ ,  $SD=1.46$ ),  $t(64)= -2.63$ ,  $p<.01$ . Significant differences are also illustrated in figure 6.5. As with the IPQ-R scales, many of the significant differences between Brief-COPE ratings at time one and two approached a moderate effect size, again suggesting a sizeable difference between ratings over the two time-points.

**Table 6.6 Brief-COPE scale differences over the two study time points in CAM-users and non-users**

Brief-COPE scale	CAM use y/n	Cronbach's alpha (time 2)	Mean (SD) time 1	Mean (SD) time 2	t-value (effect size 'r')
Self distraction	No (n=65)	.50	4.03 (1.62)	3.92 (1.72)	.57
	Yes (n=114)	.66	4.67 (1.63)	4.54 (1.75)	.77
Active coping	No	.72	5.34 (1.73)	5.22 (1.70)	.60
	Yes	.73	6.05 (1.63)	5.87 (1.62)	1.14
Denial	No	.77	2.37 (.70)	2.34 (.94)	.23
	Yes	.59	2.61 (1.03)	2.44 (.89)	1.76
Substance use	No	.95	2.54 (1.29)	2.63 (1.33)	-.54
	Yes	.93	2.68 (1.43)	2.80 (1.51)	-.996
Emotional support	No	.87	4.09 (1.91)	4.46 (2.02)	-1.70
	Yes	.85	4.79 (1.81)	4.48 (1.82)	1.77
Instrumental support	No	.74	4.75 (1.88)	4.67 (1.78)	.34
	Yes	.85	5.40 (1.87)	4.81 (1.74)	<b>3.35** (.30)</b>
Behavioural disengagement	No	.90	3.29 (1.42)	3.45 (1.81)	-.69
	Yes	.73	3.42 (1.52)	3.25 (1.43)	1.03
Venting emotions	No	.59	3.37 (1.44)	3.59 (1.25)	-1.08
	Yes	.56	3.98 (1.53)	3.99 (1.54)	-.059
Positive reframing	No	.75	3.37 (1.46)	3.91 (1.64)	<b>-2.63* (.24)</b>
	Yes	.71	3.63 (1.68)	3.84 (1.57)	-1.11
Planning	No	.77	5.14 (1.89)	5.26 (1.68)	-.51
	Yes	.76	5.87 (1.68)	5.39 (1.72)	<b>2.82** (.26)</b>
Humour	No	.90	3.71 (1.81)	3.77 (1.94)	-.29
	Yes	.91	3.66 (1.76)	3.86 (1.84)	-1.09
Acceptance	No	.48	5.42 (1.53)	5.83 (1.40)	-1.75
	Yes	.68	5.90 (1.51)	5.95 (1.53)	-.30
Religion	No	.82	2.48 (.81)	2.60 (.93)	-1.24
	Yes	.92	3.21 (1.72)	2.65 (.89)	<b>4.38*** (.38)</b>
Self blame	No	.80	3.59 (1.80)	3.17 (1.63)	1.90
	Yes	.78	4.03 (1.90)	3.60 (1.58)	<b>2.42* (.22)</b>

\*p<.05 \*\*p<.01 \*\*\*p<.001 (Effect sizes  $r=.1$  weak,  $r=.3$  moderate,  $r=.5$  strong)

**Figure 6.5** Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on Brief-COPE scales at time one and time two



### 6.3.3.3 IBS-QOL scales

Table 6.6 shows the differences over the two time-points in IBS-QOL scale and subscales, where differences were observed in reported quality of life over the two time points in all IBS-QOL dimensions apart from the relationships subscale. These differences were also consistent across CAM-users and non-users and suggest reported quality of life had improved at time two in both CAM-users and non-users. However, in exploring IBS-QOL scores between CAM-users and non-users at time two, there were no significant differences found between the two groups. The trends of the group means however, suggested non-users reported better quality of life than CAM-users.

In considering CAM-users, total IBS-QOL scores were significantly higher at time two ( $M=53.05$ ,  $SD=19.70$ ) than at time one ( $M=45.89$ ,  $SD=19.81$ ),  $t(124) = -5.97$ ,  $p < .001$ . Scores on the dysphoria subscale had also significantly improved at time two ( $M=51.34$ ,  $SD=25.38$ ) than at time one ( $M=42.17$ ,  $SD=26.32$ ) in responders,  $t(124) = -5.15$ ,  $p < .001$ . Interference with activity scores were significantly lower at time one ( $M=43.66$ ,  $SD=23.45$ ) than time two ( $M=50.56$ ,  $SD=23.18$ ),  $t(124) = -5.20$ ,  $p < .001$ . Similarly, CAM-users' scores on the body image IBS-QOL subscale were lower at time one ( $M=46.07$ ,  $SD=25.15$ ) than time two ( $M=54.40$ ,  $SD=21.33$ ),  $t(124) = -4.89$ ,  $p < .001$ . Scores on the health worry subscale were also significantly lower at time one ( $M=53.10$ ,  $SD=22.46$ ) than at time two ( $M=59.45$ ,  $SD=22.84$ ),  $t(124) = -3.33$ ,  $p < .01$ . One difference unique to CAM-users was that on the food avoidance subscale, where time one-scores were significantly lower ( $M=30.76$ ,  $SD=26.96$ ) than time two ( $M=37.11$ ,  $SD=24.42$ ),  $t(124) = -3.13$ ,  $p < .01$ . On the social reaction subscale, time one scores were once again significantly lower ( $M=45.23$ ,  $SD=25.96$ ) than at time two ( $M=54.67$ ,  $SD=24.56$ ),  $t(124) = -5.63$ ,  $p < .001$ . On the IBS-QOL sexual subscale, time one scores were also significantly lower ( $M=62.60$ ,  $SD=32.16$ ) than at time two ( $M=69.42$ ,  $SD=27.89$ ),  $t(124) = -2.96$ ,  $p < .01$ .



In non-users similar trends were observed in IBS-QOL dimensions. Total IBS-QOL scores were significantly lower at time one ( $M=49.51$ ,  $SD=21.73$ ) than at time two ( $M=55.23$ ,  $SD=21.49$ ),  $t(71) = -3.31$ ,  $p < .01$ . Scores on the dysphoria subscale had also decreased significantly from time one ( $M=45.67$ ,  $SD=30.36$ ) to time two ( $M=54.09$ ,  $SD=28.60$ ) in responders,  $t(71) = -3.13$ ,  $p < .01$ . Interference with activity scores were also significantly lower at time one ( $M=46.29$ ,  $SD=27.16$ ) than at time two ( $M=50.88$ ,  $SD=25.63$ ),  $t(71) = -2.06$ ,  $p < .05$ . Body image scores were lower at time one ( $M=49.48$ ,  $SD=23.0$ ) than at time two ( $M=57.02$ ,  $SD=22.26$ ),  $t(71) = -4.12$ ,  $p < .001$ . Social reaction ratings were also significantly lower at time one ( $M=50.46$ ,  $SD=25.64$ ) than time two ( $M=57.02$ ,  $SD=25.0$ ),  $t(71) = -3.15$ ,  $p < .01$ . In examining the health worry subscale, time one scores were once again rated significantly lower ( $M=57.93$ ,  $SD=22.71$ ) than time two ( $M=64.32$ ,  $SD=21.92$ ),  $t(71) = -2.54$ ,  $p < .05$ . Lastly, in non-user scores on the IBS-QOL sexual subscale, time one scores were significantly lower ( $M=63.89$ ,  $SD=36.25$ ) than time two ( $M=72.84$ ,  $SD=28.28$ ),  $t(71) = -2.49$ ,  $p < .05$ . Many of the calculated effect sizes for IBS-QOL subscales were approaching a moderate effect size or greater, suggesting a substantial improvement in responder scores at study time two. These significant differences and the magnitude of the differences can be observed in figures 6.6 to 6.8.

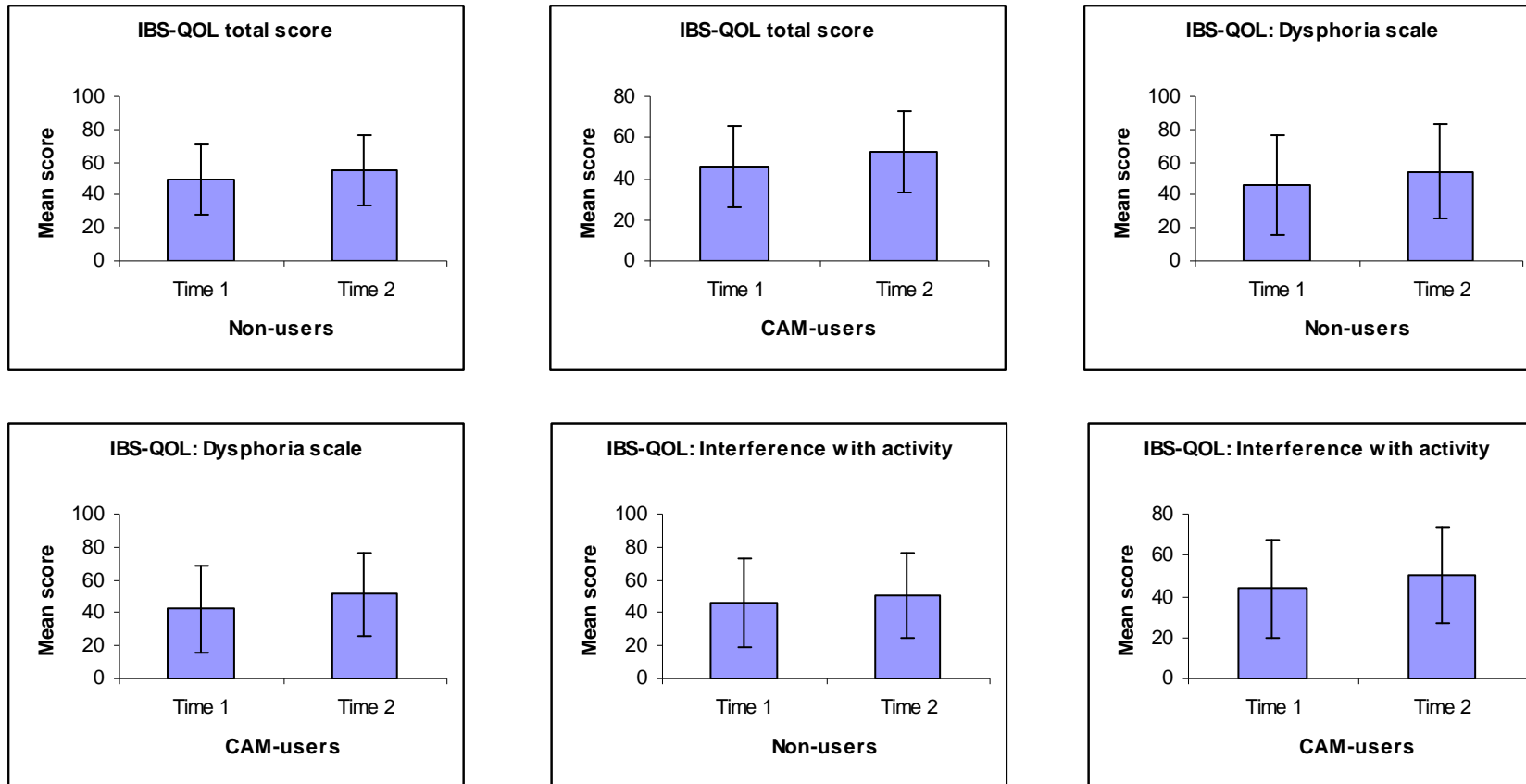
**Table 6.7 IBS-QOL scale and subscale differences over the two study time points in CAM-users and non-users**

IBS-QOL dimension	CAM use y/n	Cronbach's alpha (time 2)	Mean (SD) time 1	Mean (SD) time 2	t-value (effect size 'r')
Total IBS-QOL Score	No (n=72)	.97	49.51 (21.73)	55.23 (21.49)	<b>-3.31** (.37)</b>
	Yes (n=125)	.96	45.89 (19.81)	53.05 (19.70)	<b>-5.97*** (.47)</b>
			t-value <sup>1</sup>	.72	
Dysphoria	No	.95	45.67 (30.36)	54.09 (28.60)	<b>-3.13** (.35)</b>
	Yes	.94	42.17 (26.32)	51.34 (25.38)	<b>-5.15*** (.42)</b>
			t-value	.70	
Interference with activity	No	.90	46.29 (27.16)	50.88 (25.63)	<b>-2.06* (.24)</b>
	Yes	.85	43.66 (23.45)	50.56 (23.18)	<b>-5.20*** (.42)</b>
			t-value	.09	
Body Image	No	.77	49.48 (23.0)	57.02 (22.26)	<b>-4.12*** (.44)</b>
	Yes	.71	46.07 (25.15)	54.40 (21.33)	<b>-4.89*** (.40)</b>
			t-value	.82	
Health worry	No	.53	57.93 (22.71)	64.32 (21.92)	<b>-2.54* (.29)</b>
	Yes	.58	53.10 (22.46)	59.45 (22.84)	<b>-3.33** (.29)</b>
			t-value	1.46	
Food avoidance	No	.81	36.0 (29.0)	37.93 (25.74)	-.59
	Yes	.80	30.76 (26.96)	37.11 (24.72)	<b>-3.13** (.27)</b>
			t-value	.22	
Social reaction	No	.81	50.46 (25.64)	57.02 (25.0)	<b>-3.15** (.35)</b>
	Yes	.81	45.23 (25.96)	54.67 (24.56)	<b>-5.63*** (.45)</b>
			t-value	.64	
Sexual score	No	.85	63.89 (36.25)	72.84 (28.28)	<b>-2.49* (.28)</b>
	Yes	.83	62.60 (32.16)	69.42 (27.89)	<b>-2.96** (.26)</b>
			t-value	.83	
Relationship score	No	.77	60.88 (27.93)	62.71 (26.64)	-.66
	Yes	.62	57.93 (26.71)	60.99 (24.54)	-1.73
			t-value	.45	

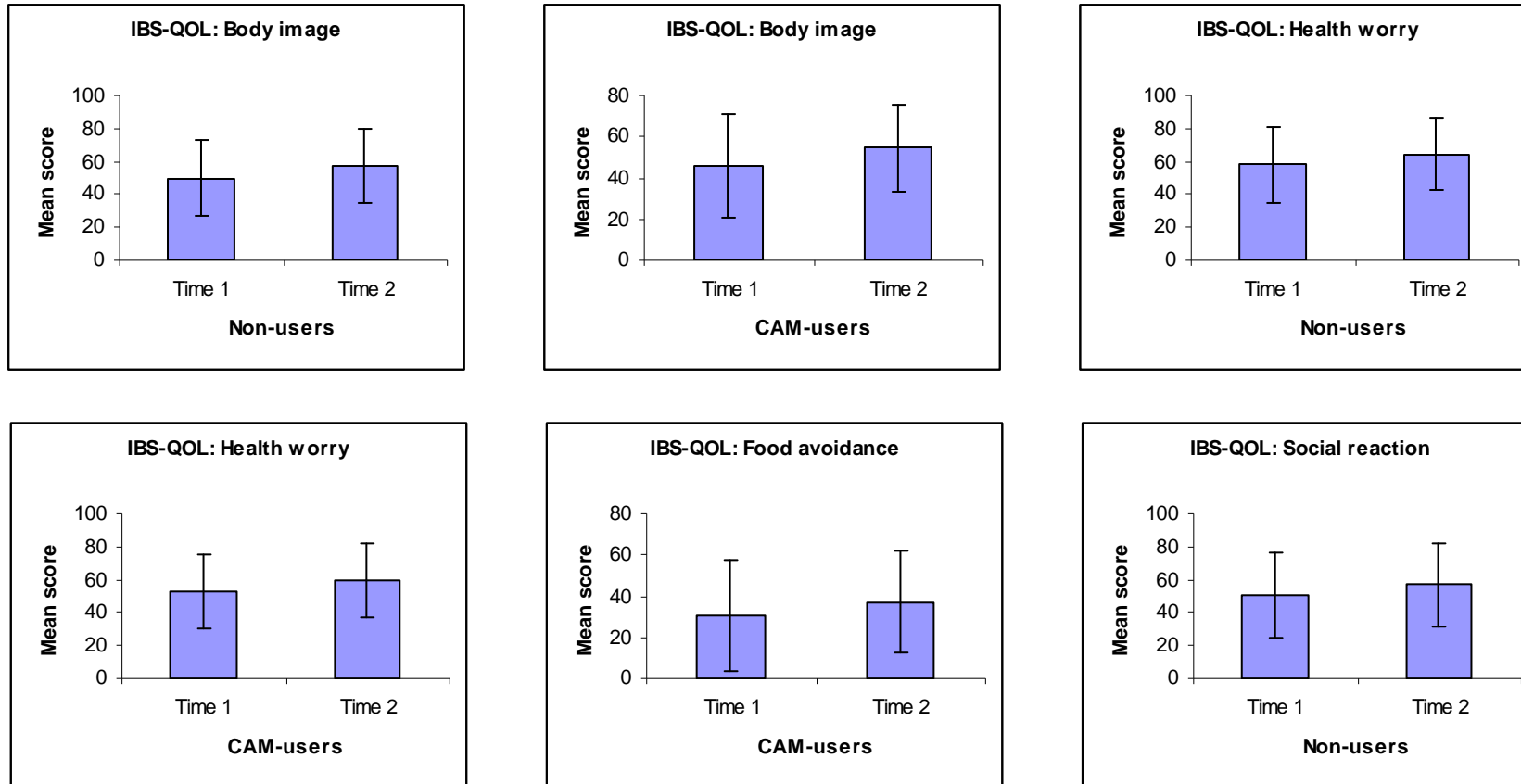
\*p<.05 \*\*p<.01 \*\*\*p<.001 (Effect sizes  $r=.1$  weak,  $r=.3$  moderate,  $r=.5$  strong)

<sup>1</sup> t-values represents comparison between CAM-users and non-users IBS-QOL scores at follow-up (study time two)

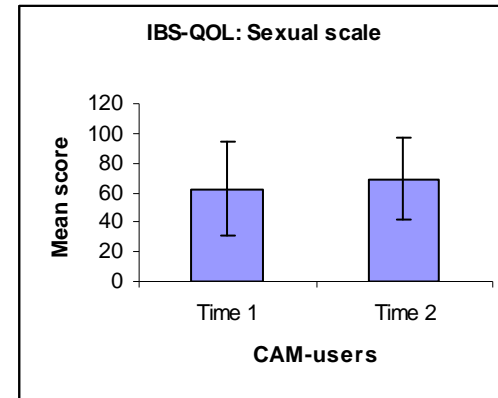
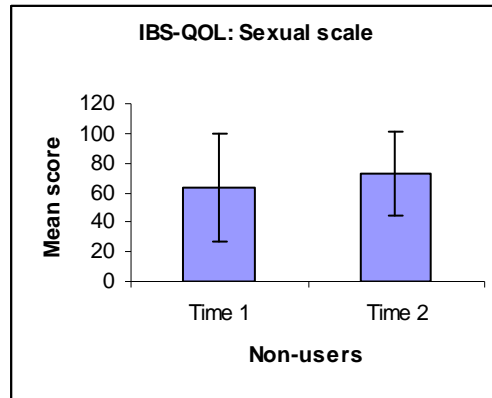
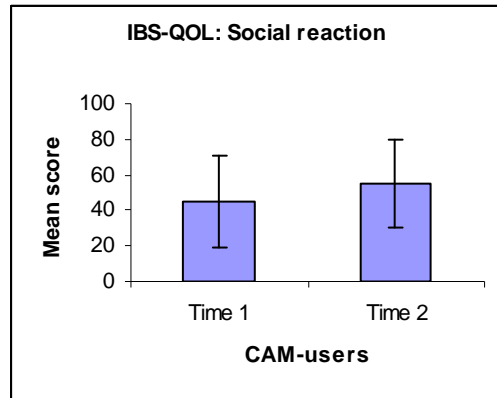
**Figure 6.6 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL scale and subscales at time one and time two**



**Figure 6.7 Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL subscales at time one and time two**



**Figure 6.8** Bar graphs to illustrate significant differences between CAM-users' and non-users' ratings on IBS-QOL subscales at time one and time two



#### **6.3.4 Mediation tests of illness and treatment perceptions at time one, and Brief-COPE and IBS-QOL scores at time two**

As with the previous chapter, this study followed the Baron and Kenny (1986) steps to test for simple mediation effects. This being a follow-up study, the first stage was to determine a significant relationship between time one predictor variables and outcome at time two. Relationships between illness representations and treatment beliefs and total scores from the IBS-QOL were examined for both CAM-users and non-users across the two time-points using simple regression analyses (including a single predictor and outcome). This also enabled non-significant pathways to be excluded from further testing of mediation. Non-significant relationships between predictor and outcome would not satisfy stage one of the Baron and Kenny steps.

##### **6.3.4.1 Step one: Predictor (time one) and outcome (time two) relationship**

Table 6.8 illustrates the relationships between time one predictors (illness and treatment perceptions) and time two outcome (IBS-QOL scores) in both CAM-users and non-users. Similar to the findings of chapter five, the trend that emerged was that 'negative' symptom-based perceptions (e.g. identity, consequences) resulted in poorer reported quality of life, whereas greater control and coherence resulted in participants reporting better quality of life. Examination of the relationships in table 6.8 showed that in both non-users and CAM-users illness identity had no significant association with total IBS-QOL score ( $Beta=-.06$ ,  $p>.05$  and  $Beta=-.11$ ,  $p>.05$  respectively), in contrast to findings reported in the previous chapter. Both non-users ( $Beta=-.45$ ,  $p<.001$ ) and CAM-users ( $Beta=-.24$ ,  $p<.01$ ) showed stronger chronic timeline perceptions at time one were related to lower IBS-QOL scores at time two. Strong perceptions of illness consequences at time one were strongly and negatively related to reported quality of life at time two, in both CAM-users ( $Beta=-.67$ ,  $p<.001$ ) and non-users ( $Beta=-.62$ ,  $p<.001$ ). Higher ratings of personal control at time one resulted in higher reported quality of life at time two, in both CAM-users ( $Beta=.25$ ,  $p<.01$ ) and non-

users ( $Beta=.45, p<.001$ ). Similarly, greater treatment control ratings at time one were positively related to reported quality of life at time two in CAM-users ( $Beta=.32, p<.01$ ) and non-users ( $Beta=.28, p<.05$ ). Greater illness coherence at time one also resulted in higher quality of life being reported at time two ( $Beta=.24, p<.01$ ) in CAM-users only.

Stronger emotional representations at time one resulted in reduced reported quality of life at time two in both CAM-users ( $Beta=-.58, p<.001$ ) and non-users ( $Beta=-.51, p<.001$ ). Stronger beliefs in external causal factors at time one were related to poorer reported quality of life in CAM-users only at time two ( $Beta=-.18, p<.05$ ). It is notable that when comparing the treatment perceptions at time one with IBS-QOL scores at time two, no significant relationships were observed.

Table 6.9 presents the linear relationships between emotional representations at time one and emotional outcome at time two (the IBS-QOL Dysphoria subscale). In both groups the relationship between stronger emotional representations and poorer reported emotional quality of life was present in both groups albeit slightly less than was observed in the previous study (CAM-users:  $Beta=-.57, p<.001$ ; non-users:  $Beta=-.50, p<.001$ ).

The illness perceptions and treatment beliefs that were significantly related to IBS-QOL scores (including emotional representations and emotional outcome) were then examined for relationships with scales on the Brief-COPE (step two of the Baron and Kenny criteria).

**Table 6.8 Beta coefficients (and R<sup>2</sup> percentages) between IPQ-R, BMQ, CAMBI scales (time one) and IBS-QOL total score (time two) for CAM-users and non-users**

<i>IPQ-R, BMQ &amp; CAMBI scales (time one)</i>	<i>Non-users: IBS-QOL time two total score (n=72)</i>	<i>CAM-users: IBS-QOL time two total score (n=123)</i>
Identity	-0.06 (.04%)	-.11 (1.21%)
Timeline chronic	<b>-.45*** (20.25%)</b>	<b>-.24** (5.76)</b>
Timeline cyclical	-.10 (1.0%)	.02 (0.4%)
Consequences	<b>-.62*** (38.44%)</b>	<b>-.67*** (44.89%)</b>
Personal control	<b>.45*** (20.25%)</b>	<b>.25** (6.25%)</b>
Treatment control	<b>.28* (7.84%)</b>	<b>.32** (10.24%)</b>
Illness coherence	.15 (2.25%)	<b>.24** (5.76%)</b>
Emotional representations	<b>-.51*** (26.01)</b>	<b>-.58*** (33.64%)</b>
Internal cause	.09 (.81%)	-.04 (.16%)
External cause	-.15 (2.25%)	<b>-.18* (3.24%)</b>
Risk factors	.13 (1.69%)	-.17 (2.89%)
BMQ Harm	.19 (3.61%)	-.10 (1.0%)
BMQ Overuse	.04 (.16%)	-.18 (3.24%)
CAMBI Natural	-.04 (.16%)	.05 (.25%)
CAMBI Participation	-.03 (.09%)	.13 (1.69%)
CAMBI Holistic	-.001 (0%)	.06 (.04%)

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

**Table 6.9 Beta coefficients (and R<sup>2</sup> percentages) between IPQ-R 'emotional representations' scale and IBS-QOL 'dysphoria' subscale (emotional outcome)**

	<i>Non-users: Dysphoria subscale (n=72)</i>	<i>CAM-users: Dysphoria subscale (n=125)</i>
Emotional Representations	<b>-.50*** (25%)</b>	<b>-.57*** (34.29%)</b>

\*\*\*  $p < .001$



#### **6.3.4.2 Step two: predictor (time one) and mediator (time two) relationships**

Predictor variables that showed significant relationships with outcome (tables 6.8 & 6.9) were then examined for significant relationships with coping strategies. Coping strategies that showed no relationship with predictor variables from table 6.8 were discarded. Therefore only Brief-COPE scales showing significant relationships with illness and treatment perceptions are presented. This analysis was to establish the second of Baron and Kenny's steps to test for mediation in that each predictor variable should be significantly related to the potential mediator. Significant relationships were then explored further with linear regression models in order to test for step three of the mediation criteria (sections 6.2.5.3 and 5.2.5.3).

##### **6.3.4.2.1 Non-users**

In non-users (table 6.10), those who had a stronger belief in a chronic timeline at time one also had higher ratings of acceptance at time two ( $r=.26, p<.05$ ). Stronger perceptions of illness consequences at time one were related to greater use of denial ( $r=.31, p<.05$ ) and venting emotions ( $r=.28, p<.05$ ) at time two. Greater personal control at time one was related to lower denial ratings ( $r=-.33, p<.01$ ) and behavioural disengagement ( $r=-.26, p<.05$ ) at time two. Stronger emotional representations at time one were positively associated with more use of venting emotions at time two ( $r=.32, p<.05$ ).

**Table 6.10 Pearson's r correlations between IPQ-R (time one) and Brief-COPE (time two) scales in non-users**

<i>IPQ-R scales (time one) (n=68)</i>	<i>Brief-COPE scale (time two)</i>				
	Denial	Behavioural disengagement	Emotional support	Venting	Acceptance
Timeline chronic	.11	.23	-.03	-.02	<b>.26*</b>
Consequences	<b>.31*</b>	.22	.06	<b>.28*</b>	.11
Personal Control	<b>-.33**</b>	<b>-.26*</b>	.11	<b>-.24*</b>	.003
Emotional representations	.23	.18	.04	<b>.32**</b>	.04

\*  $p < .05$  \*\* $p < .01$

#### **6.3.4.2.2 CAM-users**

CAM-users (table 6.11) demonstrated a greater number of relationships between IPQ-R scales at time one and Brief-COPE scales at time two. Stronger perceptions of a chronic timeline at time one were related to greater behavioural disengagement ( $r = .26$ ,  $p < .01$ ), greater acceptance ( $r = .32$ ,  $p < .01$ ) and lower positive reframing ( $r = -.19$ ,  $p < .05$ ) at time two. Stronger perceptions of consequences of IBS at time one were related to more use of self-distraction ( $r = .20$ ,  $p < .05$ ), more behavioural disengagement ( $r = .23$ ,  $p < .05$ ) and greater self blame ( $r = .26$ ,  $p < .01$ ) at time two. Stronger participant beliefs in external causes at time one resulted in greater self blame at time two ( $r = .20$ ,  $p < .05$ ).

Higher ratings of personal control at time one resulted in lower behavioural disengagement ( $r = -.27$ ,  $p < .01$ ), but greater use of instrumental support ( $r = .28$ ,  $p < .01$ ), active coping ( $r = .21$ ,  $p < .05$ ) and positive reframing ( $r = .30$ ,  $p < .01$ ) at time two. Similarly, stronger treatment control resulted in less use of behavioural disengagement ( $r = -.33$ ,  $p < .01$ ) but greater use of positive reframing ( $r = .23$ ,  $p < .05$ ) in ratings at time two. Higher coherence scores at time one were associated with less use of denial at time two ( $r = -.19$ ,  $p < .05$ ). Stronger emotional representations at time one resulted in more behavioural disengagement

( $r=.21$ ,  $p<.05$ ), more self blame ( $r=.19$ ,  $p<.05$ ) and greater substance use ( $r=.28$ ,  $p<.01$ ) at time two.

Significant relationships between illness perceptions at time one and coping at time two identified from tables 6.10 and 6.11 were used to guide which variables were entered into multiple regression analyses to test for step three of the mediation criteria.

#### **6.3.4.3 Step three: mediator–outcome relationship, controlling for predictor variable**

Correlation matrices in the preceding subsections tested the first two steps of the Baron and Kenny criteria for simple mediation. Significant relationships found between predictors at time one and outcome at time two (tables 6.8 and 6.9), guided subsequent exploration of relationships between predictors and potential mediators (tables 6.10 and 6.11). The final stage of testing for mediation determined which scales of the Brief-COPE predicted IBS-QOL scores whilst controlling for illness perceptions.

Pathways that satisfied the Baron and Kenny criteria for mediation are presented in table 6.12 with non-significant regression models omitted. The reduction of the Beta coefficient between predictor and outcome and the significant pathway between mediator and outcome whilst controlling for each predictor is illustrated. Regression coefficients from pathways  $X \rightarrow Y$  and  $M \rightarrow Y(X)$  are presented for both CAM-users and in one case, non-users. The significance of mediation effects was tested using the Sobel test (Preacher & Hayes, 2004). Z-scores (and associated significance) are also presented to indicate the statistical significance of the mediation effect. The Sobel test estimate and associated confidence intervals from the bootstrapping procedure are also provided (Preacher & Hayes, 2004). An estimate of  $R^2$  for the mediation effect in each model is also presented (Fairchild et al., 2009).

**Table 6.11 Pearson's *r* correlations between IPQ-R (time one) and Brief-COPE (time two) scales in CAM-users**

<b><i>IPQ-R scale (time one)</i></b>  <i>(n=116)</i>	<b><i>Brief-COPE scale (time two)</i></b>								
	Self distraction	Active coping	Denial	Substance use	Instrumental support	Behavioural disengagement	Positive reframing	Acceptance	Self blame
Timeline chronic Consequences	.05	.05	-.07	.05	.02	<b>.26**</b>	<b>-.19*</b>	<b>.32**</b>	.06
Personal control	<b>.20*</b>	.10	.17	.09	.001	<b>.23*</b>	.05	.02	<b>.26**</b>
Treatment control	.01	<b>.21*</b>	.03	-.02	<b>.28**</b>	<b>-.27**</b>	<b>.30**</b>	.07	.02
Illness coherence	-.02	.13	.001	-.10	.17	<b>-.33**</b>	<b>.23*</b>	-.08	-.07
Emotional representations	-.05	-.09	<b>-.19*</b>	-.12	-.11	-.04	.09	.08	-.13
External cause	.17	-.01	.14	<b>.28**</b>	.07	<b>.21*</b>	-.04	-.04	<b>.19*</b>
	-.04	-.04	.12	.16	-.01	.02	.02	-.16	<b>.20*</b>

\* p<.05 \*\*p<.01

#### **6.3.4.3.1 Step three of mediation testing: IPQ-R scales (time one) and IBS-QOL scores (time two)**

Step three of establishing mediation was considered for IPQ-R symptom based scales that were shown to be significantly related to IBS-QOL scores (outcome) and scales of the Brief-COPE (potential mediators). Table 6.12 illustrates regression coefficient values for the mediator–outcome pathway, whilst controlling for the predictor (equation 2 in each table). Coefficient values are provided for each predictor variable showing coefficient values for the direct path to outcome and to illustrate any reduction in effect due to inclusion of the mediator in each regression model. Mediation effects were detected solely in CAM-users with only one significant effect observed between behavioural disengagement and personal control in non-users.

##### ***Chronic timeline***

In CAM-users, the coping strategy of behavioural disengagement fully mediated the pathway between the IPQ-R chronic timeline scale at time one and IBS-QOL time two scores. Behavioural disengagement ( $R^2$  change = .19) demonstrated a significant mediation effect ( $z=-2.56$ ,  $p<.05$ ) reducing the effect of timeline beliefs to non-significance ( $Beta= -.13$ ,  $p>.05$ ) of which the mediation effect accounted for 4.34 (18.08%) of the total variance explained of 24%.

##### ***Illness consequences***

There were two coping strategies that partially mediated the pathway between the IPQ-R illness consequences scale at time one and IBS-QOL scores at time two in CAM-users. Behavioural disengagement ( $R^2$  change = .03) partially mediated the illness consequences–IBS-QOL pathway ( $z=-2.64$ ,  $p<.01$ ) reducing the effect of illness consequences ( $Beta= -.58$ ,  $p<.001$ ) and accounting for 13.57 (25.13%) of the overall outcome variance predicted of 54%. A similar mediation effect was detected when the role of self blame was assessed. In CAM-users, self blame ( $R^2$  change = .06) partially mediated the illness consequences–

IBS-QOL pathway ( $z=-2.48$ ,  $p<.05$ ) which explained 12.25 (24.50%) of the 50% variance in outcome predicted and reducing the effect of illness consequences ( $Beta= -.60$ ,  $p<.001$ ).

### ***IPQ-R Personal control***

There was evidence that behavioural disengagement mediated the personal control–IBS-QOL pathway in both CAM-users and non-users. In CAM-users, a significant full mediation effect of behavioural disengagement ( $R^2$  change = .18) was detected ( $z=2.82$ ,  $p<.01$ ) which reduced the effect of personal control ( $Beta= .14$ ,  $p>.05$ ) to non-significance. This effect accounted for 5.34 (22.25%) of the overall variance of 24%. In non-users however, behavioural disengagement ( $R^2$  change = .11), although suppressing the direct effect of personal control ( $Beta= .35$ ,  $p<.01$ ), the mediation effect was found to be not significant ( $z=1.89$ ,  $p>.05ns$ ).

### ***IPQ-R Treatment control***

In CAM-users behavioural disengagement was found to partially mediate the treatment control–IBS-QOL pathway. A significant partial mediation effect of behavioural disengagement ( $R^2$  change = .16) was detected ( $z=2.99$ ,  $p<.01$ ) which reduced the effect of treatment control ( $Beta= .18$ ,  $p<.05$ ) which accounted for 7.07 (28.28%) of the overall variance in IBS-QOL scores at time two of 25%.

### ***Emotional representations***

In CAM-users, both behavioural disengagement and self blame partially mediated the emotional representations–IBS-QOL pathway. Behavioural disengagement ( $R^2$  change = .13) was as a significant partial mediator ( $z=-2.37$ ,  $p<.05$ ) which reduced the effect of emotional representations ( $Beta= -.49$ ,  $p<.001$ ) and accounted for 10.57 (23.49%) of the total variance in the model of 45%. Similarly, self blame ( $R^2$  change = .10) partially mediated the emotional representations–IBS-QOL pathway ( $z=-2.08$ ,  $p<.05$ ) reducing the effect of emotional representations ( $Beta= -.51$ ,

$p < .001$ ) and accounted for 8.46 (20.14%) of the total variance explained of 42%.

#### ***IPQ-R external cause scale***

In considering the external cause (time one)–IBS-QOL (time two) pathway, self blame (time two) was found to be a significant mediator in CAM-users. Self blame ( $R^2$  change = .16) was found to fully mediate the external cause–IBS-QOL pathway ( $z = -2.06$ ,  $p < .05$ ) reducing the effect of external cause to non-significance ( $Beta = -.11$ ,  $p > .05ns$ ) and accounting for 2.5 (13.89%) of the total variance of in IBS-QOL scores at time two of 18%.

The mediation effects detected followed a similar pattern to findings in chapter five. The majority of IPQ-R scales were positively associated with maladaptive or dysfunctional coping strategies, which themselves were related to lower IBS-QOL scores at time two. There were no mediation effects detected with adaptive coping strategies. There were three models that demonstrated full mediation and more variance in outcome appeared to be explained by the addition of coping to models than reported in the previous chapter.

#### ***6.3.4.3.2 Step three of mediation testing: for IPQ-R emotional representation (time one) and emotional outcome (time two)***

As the previous chapter illustrated, emotional representations of IBS have an influence on reported emotional quality of life (represented by utilising the IBS-QOL dysphoria subscale). On testing for mediation using follow-up Brief-COPE and Dysphoria scores, there was substantially less mediation detected than documented in the previous chapter. As proposed in chapter five, this component of the research was also largely exploratory, as there is speculation that emotional representations will initiate use of different coping strategies to cognitive representations of illness (Cameron & Jago, 2008). The two mediation effects detected were again specific to CAM-users.

**Table 6.12 Mediation tests for IPQ-R scales at time one and outcome (time two IBS-QOL scores) at time two for CAM-users (non-users are indicated where applicable)**

<i>1)Predictor variable (IPQ-R) 2)Potential mediator (Brief-COPE scale)</i>	<i>Adjusted R<sup>2</sup> (R<sup>2</sup> change)</i>	<i>Beta Coefficients (Predictor without mediator)</i>	<i>Mediation effect (z) (Sobel estimate and Confidence interval)</i>	<i>R<sup>2</sup> % for mediation effect (% of total R<sup>2</sup>)</i>
1) Timeline chronic 2) Behavioural disengagement <i>F(2,122)= 20.34***</i>	.24 (.19)	-.13ns (-.24**) -.45***	-2.56* (-.59, 99%CI= -1.23, -.03)	4.34 (18.08)
1) Illness consequences 2) Behavioural disengagement <i>F(2,122)= 73.31***</i>	.54 (.10)	-.58*** (-.67***) -.33***	-2.64** (-.40, 99%CI= -.84, -.04)	13.57 (25.13)
1) Illness consequences 2) Self blame <i>F(2,122)= 63.14***</i>	.50 (.06)	-.60*** (-.67***) -.26***	-2.48* (-.34, 99%CI= -.87, -.04)	12.25 (24.5)
1) Personal control 2) Behavioural disengagement <i>F(2,122)= 20.49***</i>	.24 (.18)	.14ns (.27***) -.45***	2.82** (.57, 99%CI= .08, .117)	5.34 (22.25)
1) Treatment control 2) Behavioural disengagement <i>F(2,122)= 21.82***</i>	.25 (.16)	.18* (.32***) -.43***	2.99** (.69, 99%CI= .21, 1.30)	7.07 (28.28)
1) Emotional representations 2) Behavioural disengagement <i>F(2,122)= 51.86***</i>	.45 (.13)	-.49*** (-.58***) -.37***	-2.37* (-.37, 99%CI= -.79, -.03)	10.57 (23.49)
1) Emotional representations 2) Self blame <i>F(2,122)= 46.05***</i>	.42 (.10)	-.51*** (-.58***) -.32***	-2.08* (-.30, 95%CI= -.63, -.05)	8.46 (20.14)
1) External cause 2) Self blame <i>F(2,122)= 14.75***</i>	.18 (.16)	-.11ns (-.19*) -.41***	-2.06* (-.44, 99%CI= -1.03, -.01)	2.5 (13.89)
<b>Non-users:</b>				
1) Personal control 2) Behavioural disengagement <i>F(2,69)= 15.57***</i>	.29 (.11)	.35** (.45***) -.35**	1.89ns (.45, 95%CI= .06, .98)	- -
<b>Emotional outcome:</b>				
1) Emotional representations 2) Behavioural disengagement <i>F(2,122)= 57.91***</i>	.48 (.17)	-.47*** (-.57***) -.42***	-2.45* (-.55, 99%CI= -1.23, -.03)	11.43 (23.81)
<b>Emotional outcome:</b>				
1) Emotional representations 2) Self blame <i>F(2,366)= 46.59***</i>	.42 (.11)	-.50*** (-.57***) -.34***	-2.11* (-.40, 95%CI= -.77, -.06)	8.69 (18.10)

\* p<.05 \*\*p<.01 \*\*\* p<.001

**Key for table 6.12 (see also table 5.9):**

Outcome variable = total IBS-QOL score at time two. Emotional outcome at time two (Dysphoria IBS-QOL subscale) indicated on table.

- 1) Predictor variable (IPQ-R scale).
- 2) Mediator (Brief-COPE scale).

All figures are for CAM-users except for where indicated as non-users.



As shown in table 6.12, behavioural disengagement ( $R^2$  change = .17) was found to partially mediate the emotional representation–Dysphoria pathway ( $z=-2.45$ ,  $p<.05$ ) and reduced the effect of emotional representation ( $Beta= -.47$ ,  $p<.001$ ). The mediation effect accounted for 11.43 (23.81%) of the total variance explained of 48%. Self blame ( $R^2$  change = .11) was found to show a partial mediation effect ( $z=-2.11$ ,  $p<.05$ ) reducing the effect of emotional representations ( $Beta= -.50$ ,  $p<.001$ ) and accounting for 8.69 (18.10%) of the total variance in the model of 42%.

In the case of emotional representations and emotional outcome, the variance added by coping styles was noticeably greater than reported in the previous chapter. The variance in dysphoria scores that was predicted by emotional representations was large and patterns of relationships between the variable was consistent with previous observations. Stronger emotional representations were related to poorer emotional quality of life via greater adoption of the maladaptive coping strategies of behavioural disengagement and self blame.

#### **6.4 Discussion**

This study addressed three objectives. However with the rate of attrition between study time one and time two, drop out was also considered. Differences between responders (i.e. those that participated in this study) and non-responders on time one measures were examined between CAM-users and non-users. The first main aim of the study examined for changes in CSM variables over time in CAM-users and non-users with IBS. Secondly, the influence of illness perceptions and treatment beliefs on reported quality of life after a minimum of six months in CAM-users and non-users was examined. Thirdly, statistical testing was conducted to assess for evidence of coping strategies (time two) mediating pathways between illness and treatment perceptions (at time one) and reported quality of life (at time two) across CAM-users and non-users

with IBS. Additionally, this final objective also included examining the influence of emotional representations on emotional outcome.

#### ***6.4.1. Differences between responders and non-responders on CSM variables***

In assessing potential differences between participants that opted to take part in this research at time one and those that were recruited for follow-up, there were minimal differences across CSM measures. Most variables suggested there were no significant differences between participants taking part in both studies and those only taking part at time one. In CAM-users however, time one scores on illness identity, external cause and BMQ overuse scales were all significantly lower in responders taking part in the follow-up. The exception to this trend was noted in the CAMBI treatment participation scale in which responders' scores were significantly higher than those of non-responders. This trend on treatment participation scores was again evident in non-users, where the only other significant difference between scores was on the illness identity scale, where responders reported higher scores than non-responders. As reported, the effect sizes in these cases were small suggesting the differences were minimal.

There were also minimal differences between responder and non-responder scores on the Brief-COPE and these were limited to CAM-users. Scores on the humour, venting emotions and denial scales were all significantly lower in responders when compared to non-responders. Again, when comparing IBS-QOL scale and subscale scores in responders and non-responders in the two groups, there were two subscales where significant differences were found, and these were again isolated to CAM-users. Responders that were CAM-users reported significantly higher scores on the sexual subscale of the IBS-QOL as well as the total IBS-QOL score. This suggests that reported quality of life was significantly better for responders that were CAM-users at time one than it was for non-responders. The calculated effects sizes

for these variables were located between small and moderate, suggesting the differences were stronger than observed in the IPQ-R scales.

These findings suggest, although there were a number of significant differences between responders and non-responders detected (in both CAM-users and non-users), that any differences overall were minimal. There may to an extent also be some effect accounted for by the discrepancy in numbers in those taking part at study time one and time two. Furthermore, the similarities between responders and non-responders who were CAM-users (section 6.3.1) suggest minimal differences between responders and non-responders. These findings add weight to the decision to examine only those participants that participated at both time points.

#### ***6.4.2 Differences in CSM variable scores over time***

In examining differences between scores at time one and time two in responders, there were minimal differences observed. These were also isolated to the IPQ-R where the most notable finding was that both CAM-user and non-user emotional representations significantly 'improved' over the two study time points. This may represent a degree of acceptance or acclimatising to having IBS so it effectively becomes less distressing over time. Non-user responders also reported significantly lower illness identity scores at time two than CAM-users as well as reporting greater personal control at time two than CAM-users. It is plausible that these two components may be related although findings from chapter five showed they were related in CAM-users only. It is however possible that a declining number of IBS symptoms may be paralleled by an increase in reported personal control. The only other significant difference between time one and time two IPQ-R ratings was in CAM-users' illness consequences scores, which were significantly lower at time two, suggesting a reduction in strength of perception of wider consequences of IBS. These differences contradict findings from Rutter and Rutter (2007), where no differences over time were observed on scores of the

IPQ at three time points. Other studies in other chronic illness populations however, have shown similar findings, especially in respect of emotional representations.

In contrast to Rutter and Rutter (2007), Lee et al. (2010), examining patients recovering from traumatic injury, found that all IPQ-R components apart from the two timeline scales differed significantly over time. Similarly, Kaptein et al. (2010) found in those suffering with osteoarthritis over a six year period that timeline chronic and illness coherence scores significantly increased, whereas personal control and emotional representations scores decreased. Bijsterbosch et al. (2009) also found significantly higher scores over a six year period in osteoarthritis patients on the timeline chronic and illness coherence scales. Personal control and emotional representation scores were found to be significantly lower after six years. Similarly, Foster et al. (2008) observed positive changes in IPQ-R consequences and emotional representations in those patients with a positive clinical outcome (from a self-report disability measure) in those affected by lower back pain at six months. In those with a negative outcome at six months, increased personal and treatment control were observed.

The finding that many IPQ-R scores were relatively static over time may suggest that changes in individuals' illness perceptions take place over a longer time period or are more subtle than to be detected by a quantitative measure such as the IPQ or IPQ-R in IBS populations. Many studies have detected differences in the IPQ-R over time so it is suggested that further work is need to establish changes to illness perceptions do take place according to the CSM.

There were some observed differences in Brief-COPE scales over time, most notably in CAM-users, where it was observed there was significantly less use of the coping strategies of religion, planning and instrumental support at time two. In non-users, there was significantly

more use of positive reframing at time two. The trend of less use of what may be considered functional or adaptive coping strategies in CAM-users has a degree of concordance with Rutter and Rutter (2007) who found avoidant coping strategies more prominent in those with IBS over a 12 month period.

The most noticeable differences were observed in the IBS-QOL scale and subscales over time, where differences were observed in both CAM-users and non-users across the two time points. In both groups, IBS-QOL scores had significantly improved on all but the relationships subscale (for both groups) and the food avoidance subscale (non-users). The findings presented in table 6.4, between responders and non-responders suggest this improvement in IBS-QOL scores has little to do with any factor particular to participants who took part in both time-points of the study. It is possible that scores actually improved over time, a degree of response shift has been observed or there may be a potential confounding issue with the amount of time participants have had IBS. Response shift may take place when individuals' perceptions of what their own quality of life means may have changed during the duration of a study (Ring et al., 2005; Schwartz & Sprangers, 1999). The IBS-QOL however, was developed using several dimensions that captured the specific influence of IBS on quality of life ratings so response shift may be only a partial explanation. As many in this study reported varying lengths of time with symptoms, this may have had some effect on the reported improvement in quality of life ratings. Further study may consider if such changes occur in individuals who have been with IBS symptoms for a similar length of time and how quality of life may change over time.

It was noted that CAM-users reported IBS-QOL scores at time two were not significantly different than non-users, in contrast to what was observed at time one. The lack of difference between the groups in reported quality of life at study time two may suggest that CAM use over time, which in many participants involved the use of several different

CAM treatments, does little to positively influence quality of life ratings when compared to those with IBS not using CAM.

#### ***6.4.3 Illness perceptions, treatment beliefs, coping and outcome***

In assessing the influence of illness and treatment perceptions at time one on Brief-COPE and IBS-QOL scores at time two, it was observed that no treatment beliefs were significantly related to Brief-COPE and IBS-QOL scores at time two. This was consistent across both CAM-users and non-users. As suggested in the previous chapter, this may be because treatment beliefs may be more noticeably associated with specific coping behaviours such as repeated CAM use (Bishop et al., 2008) or adherence to conventional medication (Horne & Weinman, 2002).

In assessing the pathways from illness perceptions at time one to IBS-QOL scores at time two, it was detected that scores were similar across CAM-users and non-users, although external causal perceptions and illness coherence (time one) were related to lower and higher IBS-QOL scores at time two respectively in CAM-users. This finding is consistent with other studies that have found direct relationships between illness perceptions and outcomes in both cross-sectional and longitudinal studies (Bijsterbosch et al., 2009; Foster et al., 2008; Hagger & Orbell, 2003; Kaptein et al., 2010; Rutter & Rutter, 2002; 2007). These findings also show consistency with previous work outside the CSM framework that have argued illness related perceptions have an effect on reported quality of life in those affected with IBS (Hahn et al., 1997; Naliboff et al., 1998; Spiegel et al., 2008).

Emotional representations from time one were strongly negatively related to IBS-QOL time two scores in both groups, as well as being negatively related to emotional outcome (the IBS-QOL Dysphoria subscale). Although many studies now utilise the IPQ-R, specific measures of emotional outcome are less common. Bijsterbosch et al. (2009), Foster et al. (2008) and Kaptein et al. (2010) all found significant relationships

between emotional representations and outcome over time, but omitted explicit consideration of emotional outcomes. Furthermore, the findings in this chapter seemingly contradict findings presented in chapter five where emotional representations had a greater influence on emotional outcomes in non-users. In both groups it should be noted, the strength of relationship between emotional representation and outcome was substantially less than in the previous study (chapter five). These relationships do however support the suggestion that those with IBS 'catastrophise' (Drossman et al., 1999; Lackner et al., 2004) their symptoms, although the lower emotional representation scores at time two suggest this could be to a lesser extent over time.

Findings also showed a smaller number of correlations between time one illness perceptions and Brief-COPE scales at time two when compared with results in the previous chapter (at time one only). A greater number of relationships however, were detected in CAM-users that suggested CAM-users' illness perceptions are influencing coping strategies over time more so than non-users. However, it should be noted that most of the correlation coefficients were fairly small in size and the greater number of relationships in CAM-users may be due to the greater number of CAM-users compared to non-users.

In terms of mediation testing of pathways between time one illness perceptions and time two IBS-QOL scores, mediation effects were only detected in CAM-users. Behavioural disengagement fully mediated the pathway from chronic timeline to IBS-QOL, meaning greater timeline beliefs were related to greater use of behavioural disengagement, which led to lower IBS-QOL scores. The positive relationship between personal control and IBS-QOL scores was also fully mediated by less use of behavioural disengagement. Higher illness consequences scores were related to lower IBS-QOL ratings, and this pathway was partially mediated by both greater use of self blame and behavioural disengagement. Increased treatment control also led to higher IBS-QOL ratings, and this pathway was also partially mediated by less use of

behavioural disengagement. Higher emotional representations were related to lower IBS-QOL and Dysphoria (emotional outcome) ratings and these pathways were partially mediated by both greater use of behavioural disengagement and self blame. Greater use of self blame also fully mediated the pathway between higher external cause perceptions and lower IBS-QOL ratings. It was also observed that overall, coping strategies added more variance to the regression models testing for mediation than reported in chapter five. The only coping strategy to show a similar effect to the previous study was self blame in the illness consequences–IBS-QOL pathway. Furthermore, in contrast to findings in chapter five, self blame fully mediated the external cause and IBS-QOL pathway. In examining the same variables at time one (chapter five), this pathway demonstrated no mediation effect in CAM-users. These findings seem to contradict other studies that have found no mediation over time (e.g. Llewellyn et al., 2007; Rutter & Rutter, 2007; Treharne et al., 2008). This study appears to offer a unique finding in that mediation was detected over time in sample of people affected by IBS that were using CAM to relieve their symptoms.

It may only be speculated why ‘behavioural disengagement’ and ‘self blame’ are implicated as mediating variables in CAM-users. Based on these findings, CAM-users with stronger perceptions of chronic timeline, consequences and emotional representations may experience a greater degree of ‘giving up’ trying to adopt any behavioural strategies to deal with their IBS symptoms. One possibility is that the use of repeated CAM treatments for a number of years has resulted in many reaching a point where it is felt nothing will alleviate symptoms. It may only be speculated that the relevance of the coping strategy of self blame may be linked to use of many CAM treatments that may be seen to reduce ‘stress’ rather than IBS symptoms per se, which may be linked to causal beliefs about stress being a cause or maintaining factor in IBS (Casiday et al., 2009; Hungin et al., 2004). These findings may be contrasted with observed higher personal and treatment control ratings, which had less influence on the use of behavioural disengagement and self blame. These



pathways resulted in more adaptive outcomes where reported quality of life was seen to be higher.

#### **6.4.4 Limitations of the study**

Although this study has addressed one of the potential criticisms of studies presented in the previous two chapters in conducting a prospective follow-up, there still exist some possible methodological issues most notably that of participant attrition. The discrepancy between the number of participants in the study reported at time one (chapters four and five) and the follow-up study in this chapter is clearly evident. It should be noted that over a third of participants from time one opted not to volunteer contact information to take part in the follow-up. From those that did take part, a substantial number were not contactable, largely due to email address changes, closed email accounts or full inboxes. From those that were successfully contacted, many still only visited the study website but did not take part or dropped out during the study, as consistent with information participants were given at the study outset, participants dropping out would not have their data used in the study. Besides, this, the study was still able to demonstrate unique findings in the form of mediation effects being observed in CAM-users.

The observed mediation effects were limited to CAM-users only which may suggest a real effect that is evident only in these participants. However it should also be pointed out that the CAM-user group did outnumber the non-users by just over a third. This could have facilitated observation of significant mediation effects. Furthermore, there is the potential problem of 'response shift' in that IBS-QOL total scores improved significantly over the two time-points in both groups. This may be down to a change in perception of how individuals judged their quality of life or a genuine improvement in reported quality of life has been observed. With this in mind, it is possible over time that individuals become more accustomed to fluctuation in IBS symptoms (i.e. flare-ups and periods of relief) and are therefore rating their quality of life as 'less worse' than it was rather than feeling it had improved. This is one factor

that could be examined by further research, possibly by utilising both self-report measures and qualitative methodologies to address quality of life changes in those affected by IBS over time.

As mediation effects were only present in CAM-users, it is possible there may be some issue with the measurement of coping strategies. Leventhal et al. (1998) suggest the influence of illness perceptions on many different coping 'procedures', meaning self-report checklists of coping strategies (such as the Brief-COPE) may not be the best way to assess coping (Hagger & Orbell, 2003; Leventhal et al., 1998). However, the effects observed in CAM-users would seem to somewhat contradict the possibility of measurement issues. Although mediation effects were not common, those that were observed were largely approaching moderately strong (table 6.12, illustrates the unique variance in outcome accounted for by each mediation effect). Furthermore, the discrete scales of the Brief-COPE were used in full (as observed in chapter five), unlike other CSM studies where such discrete categories are combined to form more general coping scales (e.g. Rutter & Rutter, 2002; 2007). It may be acknowledged the Brief-COPE may not be the most effective measure of coping, it would however, seem to be sensitive enough to detect coping strategies in the context of CSM based studies. The Brief-COPE is also largely theoretically consistent with the COPE as many items and scales from the original COPE measure are included on the Brief-COPE. Furthermore, as considered in the previous chapter, it is also possible that several coping strategies may act as multiple mediators, however, the significant relationships and pathways observed in this study offer areas where intervention or future study could be targeted.

To add weight to these findings, future study could seek to control some of the possible confounding factors in this study. Firstly, measurement of illness perceptions (and treatment beliefs), coping and outcome could be conducted at standalone time points, reducing any priming effect of completing similar questionnaires. Relationships could be examined

over longer time points, possibly over a number of years as with some of the osteoarthritis studies considered earlier. Number of CAM treatments (and conventional medication treatments) could also be considered at both time one and subsequent time-points, to assess any relationship between coping strategies and specific coping behaviours (Searle et al., 2007). Furthermore, in relation to possible limitations of using an internet sample considered in chapters four and five, it may be advisable to assess the findings of this study against a sample of participants not recruited via the internet, such as from primary care or a GI outpatient clinic.

#### **6.4.5 Conclusions and implications**

This study adds both important and original findings in relation to CSM pathways in those affected by IBS. To date, no published studies have examined simple mediation effects in a group of CAM-users and non-users over two time-points. This study measured a wide range of coping strategies and as with the previous chapter tested for significance of any detected mediation effects. The extended CSM, on the basis of the findings in this chapter, appears less worthwhile in examining influence on reported quality of life over time, although further investigation is recommended. Despite this, the pathways between illness perceptions and outcome yielded some unique findings.

There were limited differences between responders and non-responders which justified using only responder data from time one which was compared with responder data collected at time two. There was also some evidence of changes in some components of illness perceptions over the two time-points most notably (in both groups) participants emotional representations significantly decreased at time two. In addition, a small number of time two Brief-COPE scores that were significantly different from time one. Several differences were observed between IBS-QOL scores at time one and time two in both groups. As considered earlier, further study may investigate if this is due to response shift or a genuine change over time. The positive change in IBS-QOL

scores across both groups at study time two when compared with time one, appeared not to be associated with CAM use.

This study has also, to a degree, added support to the CSM by demonstrating that, in certain cases, coping strategies do (often partially) mediate the pathway between illness perceptions and outcome, although this was unique to CAM-users. In this study, the notable influences on reported quality of life were illness consequences and emotional representations and this was evident in both groups. As stated, mediation effects were unique to CAM-users only, where both self blame and behavioural disengagement were implicated as mediating variables. This finding contradicts many other longitudinal CSM studies that either found no mediation over time (e.g. in IBS Rutter & Rutter, 2007) or did not test for mediation effects (e.g. Kaptein et al., 2010). Emotional representations, as found in the previous chapter, were also influences on emotional outcome, however this pathway was only partially mediated by behavioural disengagement and self blame in CAM-users.

In comparison with findings from the previous chapter, the relationships of CAM-users' and non-users' illness perceptions (time one) with reported quality of life (time two) was substantially less. It was also notable that the variances in outcome predicted by regression models testing for mediation were largely comparable in size with findings reported in the previous chapter in CAM-users. This strengthens the theory that illness perceptions are important influences on quality of life judgements. In this study, this is especially noticeable in CAM-users, where this relationship is sometimes partially explained by the coping strategies of self blame and behavioural disengagement.

This study allows a degree of causal influence to be inferred as illness perceptions were shown to influence IBS-QOL scores over time. In both groups, although to a greater extent in CAM-users, coping strategies at time two were influenced by time one illness perceptions. In CAM-users, self blame and behavioural disengagement measured at time two were

found to (largely partially) mediate the relationship between time one illness perceptions and time two IBS-QOL ratings. The inclusion of mediation testing allows both a degree of both theoretical and statistical support for the CSM in that such coping strategies are key processes in how illness perceptions influence reported quality of life in CAM-users with IBS.

These findings suggest possible pathways for interventions based on changing illness perceptions. Chapters four and five suggest those using CAM to relieve IBS appear to perceive a more severe illness experience in IBS (van Tilburg et al., 2008), something also found to be consistent with CAM-users with IBD (Langmead et al., 2002). By focusing on reducing emotional representations and illness consequences and by enhancing control perceptions, the use of such maladaptive or dysfunctional coping strategies may be reduced. This may enhance quality of life ratings in those with IBS that opt to use CAM for symptom relief.

This chapter has highlighted the importance of illness perceptions in influencing IBS-QOL scores over time. Mediation effects via coping strategies were only evident however in CAM-users. CAM-users' illness perceptions also seem to influence a greater number of coping strategies of which two maladaptive strategies were found to mediate (albeit to differing degrees) the pathway between illness perceptions and outcome. The following chapter therefore, will consider the results in context and provide a general discussion and consideration of findings.

## Chapter 7

### General discussion and conclusions

*This chapter presents an overall summary and evaluation of the empirical work presented in this thesis and thus synthesises and extends the more study-specific discussions and conclusions in chapters four to six. The general discussion highlights the practical and theoretical implications of the research, its limitations and its potential future directions in relation to both theory and practice.*

#### 7.1 Introduction

The theoretical framework adopted in this thesis has established a structured and systematic examination of psychological components of a functional chronic disorder of the GI system. Specifically, the research focused on: perceptions of illness and beliefs about treatment in people affected by IBS, and factors that are important components of self-regulation as individuals attempt to adjust to living with a chronic illness. This research was undertaken utilising a quantitative survey methodology.

The findings from this research have identified the genuine need for effective management and treatment of IBS and it is argued that psychological factors need to be considered as they have been shown to have a prominent role in this process. This chapter explores the implications of psychological components and considers CAM use in the wider context of health need. The research findings are considered in the context of the course of a chronic illness and have led to recommendations being made that are considered to be influential in addressing potentially problematic illness perceptions that may negatively influence reported quality of life and emotional outcome. Moreover, the implications of the research findings are discussed in both

practical and theoretical terms. Finally, overall limitations of the research are considered and the future direction of the research discussed and conclusions drawn.

## **7.2 Discussion of research findings**

The aim of the research was to examine which illness perceptions and treatment beliefs were influential in CAM use in those affected by IBS and to explore differences between CAM-users and non-users in terms of the influence these factors had on coping strategies and quality of life. This was conducted within an extended CSM framework. The key findings are now highlighted and discussed in relation to the wider issue of chronic illness management.

### ***7.2.1 Use of complementary and alternative medicine in IBS***

This research found CAM use was extensive for IBS (57%), higher than reported in previous studies (Kong et al., 2005; van Tilburg et al., 2008). In addition, just under half of the participants were not taking prescription medication for their IBS. These findings suggest that CAM is being used based on evident health need rather than attempting to optimise one's health (Vincent & Furnham, 1997). Furthermore, findings showed a majority of participants (75%) in this research indicated they purchased CAM 'off the shelf' rather than consulting a CAM practitioner for treatment. This finding was in contrast to other studies of participants with other functional bowel disorders and IBS potentially due to previous work predominantly focusing on CAM practitioner visits (Donker et al., 1999; Koloski et al., 2003; Smart et al., 1986; Verhoef et al., 1990). This finding may indicate that financial concerns of people self funding CAM (section 1.6) may be less relevant in populations purchasing such treatments as they are likely to cost significantly less than consultations with a CAM practitioner. However, a number of participants had visited CAM practitioners, suggesting to an extent, financial concerns are still a relevant factor for consideration. In addition, this finding also suggests that many people may be self treating via such 'off the shelf' treatments. These findings suggest that improved management from conventional

medical care is needed for those affected with IBS, however the lack of established aetiology in IBS can render conventional pharmacologic treatment problematic (Hayee & Forgacs, 2007).

The high prevalence of CAM use in this, and other, research in specific illness groups and in general populations, means wider concerns with CAM treatments remain. Many CAM treatments lack established efficacy and have potential for interaction with pharmacologic treatments (e.g. Leung et al., 2009; section 1.1.6). Patients presenting with IBS symptoms and other chronic conditions in conventional care settings should be made aware of such issues with CAM, suggesting that it would appear to be important for health care practitioners and GPs to discuss such issues with patients (NICE, 2008; Vincent & Furnham, 1997). Therefore, addressing and challenging psychological illness related factors that influence CAM use may substantially reduce the health need for CAM use (chapter four).

Demographic influences on CAM use for IBS showed some consistency with existing studies and suggested consistency with a 'CAM-user profile' found in general populations (Astin, 1998; Thomas et al., 2001). A majority of participants who used CAM were female, with a chronic condition (IBS) and CAM use was, to an extent, influenced by higher income and education levels. However, it should be pointed out that in this research, there was substantially higher female participation, and such a female predominance in healthcare seeking in IBS has been previously reported (Andrews et al., 2005; Hungin et al., 2005). Therefore, a future research objective would be to determine accurate prevalence estimates for males with IBS, as this may represent a substantial proportion of those not seeking health care (e.g. Saito et al., 2002). Moreover, it may be beneficial to examine consistency of gender prevalence rates across other functional chronic illnesses to see if female predominance in healthcare seeking is a consistent factor. Such investigations may also have implications for health care delivery and the role of health care providers in addressing the reported imbalance of



males seeking medical treatment (Robertson, Douglas, Ludbrook, Reid, & van Teijlingen, 2008). Future CSM based research may also examine the influence of social and economic factors on the formation of cognitive and emotional responses to illness and treatment.

The findings imply that in a specific chronic illness group, CAM use is prevalent which is corroborated by evidence from other chronic functional and organic bowel conditions (e.g. Jones, Maloney et al., 2007; Langmead et al., 2002). Identification of specific illness and treatment related factors that compel individuals to use CAM may indicate where conventional care may have the greatest impact through psychological based intervention (section 1.1.4). This is especially applicable in functional chronic illnesses, such as IBS, where establishing aetiology has been problematic.

### ***7.2.2 Illness perceptions and treatment beliefs***

The application of an extended CSM was an important aspect of this research as it allowed statistical examination of the process of self-regulation in response to living with a chronic illness. In the extended CSM, both illness perceptions and treatment beliefs were examined in both CAM-users and non-users. The relationships between IPQ-R components suggested theoretical consistency with previous findings in a number of chronic conditions (e.g. Hagger & Orbell, 2003). The addition of BMQ and CAMBI scales to the CSM and subsequent analysis of relationships between these components and between the IPQ-R scales, suggested these measures were also consistent with the supposition of an extended CSM.

#### ***7.2.2.1 Influence of illness perceptions and treatment beliefs on CAM use***

Several dimensions of illness perceptions were shown to predict CAM use whilst controlling for demographic factors. Stronger illness identity, consequences and cyclical timeline beliefs all predicted an increased likelihood of CAM use. Such findings may be indicative of perceived

more “severe” health status of CAM-users, a factor shown to be influential in conventional health care seeking in those with functional GI disorders (Koloski et al., 2001). Previous work found conventional care seekers with IBS and FBD report inferior health status to non-care seekers (e.g. Verhoef et al., 1990). This also appears consistent in CAM-users in the general population, who have reported poorer health to non-users (Bishop & Lewith, 2010; Testerman et al., 2004). The perceived inferior health status in those using CAM was also observed in several symptom based IPQ-R scale scores in this research (illness identity and consequences, section 4.3.5) which were found to be significantly greater than those reported by non-users. Furthermore, CAM-users reported stronger emotional representations, which is suggestive of greater emotional distress in CAM-users. Conversely, CAM-users had stronger treatment and personal control and coherence scores, albeit these components were not significantly different from non-users. In terms of treatment beliefs, stronger beliefs in harm caused by conventional medication resulted in a greater likelihood of CAM use and this was the solitary component of treatment beliefs that predicted use of CAM (section 4.3.6).

Furthermore, findings from the research present a dichotomy in that illness related factors appear instrumental in initiation of CAM use while concerns with potential harm from conventional medical treatment appear more influential in repeated use of CAM (e.g. Bishop et al, 2008). This may have implications for conventional health care, as illness related factors may prompt health care seeking and treatment initiation, while treatment beliefs may have greater influence on adherence (e.g. Horne & Weinman, 2002), therefore in conventional medical settings it may be beneficial to address concerns regarding harmful effects of conventional medication. In CAM-users, repeated use of CAM was related to more positive CAM beliefs. It is feasible that more positive beliefs about CAM, coupled with potentially lower financial impact of ‘off the shelf’ treatments may suggest an expectancy-value conceptualisation (Conner & Norman, 2005) in relation to CAM use. CAM is considered in

terms of costs and benefits, where in this case, relatively low cost treatment and positive beliefs about using CAM may influence repeated use.

The presented findings demonstrate evidence of the process of self-regulation in response to a health threat, where the individual is active in dealing with the threat to health. Psychological schemata constructed around the experience of illness and beliefs about treatment, appeared to influence an attempt at coping with the health threat (de Ridder & de Wit, 2006). In this context, CAM use can be seen as an adaptive or active form of coping behaviour (Suarez & Reese, 2000) and represents an attempt to self manage or self regulate the symptoms of IBS with the goal of removing the threat to health and maintaining normality (e.g. Leventhal et al., 1998). One notable factor inherent in the CSM is the lack of explicit recognition of goals in the system of self-regulation (de Ridder & de Wit, 2006). The CSM proposes that individuals appraise coping strategies undertaken rather than deeming if explicit goals in relation to health have been attained. In this context, it was important to delineate illness and treatment related influences on other forms of coping and reported quality of life to explore the process of self-regulation according to the CSM.

#### ***7.2.2.2 Illness perceptions, treatment beliefs, coping and quality of life***

Findings provided further evidence to suggest CAM-users' illness experience differs from that of non-users. Both groups reported the impact of IBS as substantial in terms of impaired quality of life (Amouretti et al., 2006; Dancey & Backhouse, 1993; Lea & Whorwell, 2001). CAM-users reported inferior quality of life to that of non-users, a factor consistent with previous work (van Tilburg et al., 2008), despite many of them repeatedly using CAM. This finding may be considered in the context of conventional health care seekers with IBS reporting inferior quality of life to that of non-seekers (Koloski et al., 2001; van der Horst et al., 1997). Across both groups, IBS-QOL scores were lower than in

previous work with IBS populations (Bushnell et al., 2006; Drossman et al., 2000; van Tilburg et al., 2008). This pattern was observed in the majority of the IBS-QOL scales including the Dysphoria (emotional outcome) scale.

The results presented also suggest that over time, use of CAM for IBS was not associated with improvement in quality of life and there was no association observed between CAM beliefs and reported quality of life (e.g. Lewith et al., 2002). This was most noticeable at study time two, where reported quality of life had significantly improved in both groups from time one but there was no significant difference in IBS-QOL scale scores between CAM-users and non-users. Group differences suggested non-users reported better quality of life, albeit these differences were not statistically significant. Furthermore, the cross-sectional study showed that, despite repeated use of CAM in many participants, reported quality of life was significantly lower in CAM-users. These findings may be seen in the context of the diversity in CAM philosophies (Zollman & Vickers, 1999) where repeated CAM use, possibly encompassing different CAM modalities, could mask any improvement of one particular CAM treatment in quality of life judgements. Possible beneficial effects may have been less visible due to the contrast between 'off the shelf' CAM and treatment received via a CAM practitioner. Based on the findings presented, it appeared CAM use has limited benefit in improving reported quality of life in those affected by IBS therefore emphasising the importance of the exploration of psychological influences on both CAM use and quality of life.

The research findings have shown where psychological intervention may be most effective in targeting particular components of illness perceptions. In particular, from the quantitative analysis, perceptions of the consequences of IBS and affective responses to IBS were prominent in being stronger influences on quality of life than control and coherence components and this was largely consistent across both CAM-users and non-users. It may be between these two components, the relationships

from time one, suggest a co-dependent or cyclical relationship exists between the cognitive component of perceived consequences and emotional responses to illness. It is an area that may benefit from future investigation. Furthermore, it is also conceivable to suggest, from analysis of participant use of certain CAM treatments (figure 4.3; section 4.4.1), that stress may have a role in individual causal perceptions, potentially as a factor that appears to cause or precipitate symptoms. It is notable that the lack of established aetiology potentially allows such beliefs to generate. This research has presented evidence for pathways between constructs of the CSM that could be targeted for intervention to reduce the effect of such beliefs. The bi-directional nature of the brain-gut axis (Drossman et al., 1999) illustrates how causal beliefs may influence symptoms and any GI symptoms may reinforce the particular causal belief (figure 1.1).

In both groups several trends were established where intervention could take place, albeit there were still differences between groups in the strength of a number of the associations. A more severe illness experience in terms of perceived consequences, symptoms experienced and emotional distress resulted in poorer reported quality of life. Conversely, greater control and understanding was associated with better quality of life, in line with previous CSM-based work in other chronic illness (e.g. Hagger & Orbell, 2003). Typically, causal perceptions and treatment beliefs were found to have less influence on quality of life.

Emotional representations in particular were found to be strong influences on reported quality of life and emotional outcome (Dysphoria), with evidence of stronger influence in non-users. These new and unique findings add authority to the proposition that people affected with IBS 'catastrophise' and may have 'abnormal' beliefs about their illness resulting in emotional distress (Drossman et al., 1999; Gomborone et al., 1995; Lackner et al., 2004).

Mediation testing, primarily at the cross-sectional stage, revealed substantial support for the CSM supposition that coping mediates the pathway between perceptions and outcome (Rutter & Rutter, 2002) and established which coping processes are important influences on quality of life and Dysphoria. This was consistent with previous work which has largely found evidence for mediation in cross-sectional designs (Brewer et al., 2002; Evans & Norman, 2009; Kaptein et al., 2006; Llewellyn et al., 2007; Rutter & Rutter, 2002). Illness perceptions however, were found to be weakly associated with coping strategies and these associations were predominantly with maladaptive or dysfunctional coping strategies. Such associations have been reported across a number of chronic illnesses (e.g. Hagger & Orbell, 2003). Behavioural disengagement and self blame were strongly implicated as mediating variables. There is evidence to suggest avoidant coping strategies may result in positive outcomes. For example, in people with sports related injuries, maladaptive coping strategies have been shown to facilitate regulation of emotional states during both short and long term periods of injury (Carson & Polman, 2010). In IBS however, there is evidence of negative bias in attending to somatic stimuli (Gomborone, Dewsnap, Libby & Farthing, 1993) which suggests the adoption of more adaptive coping may be beneficial.

Furthermore, this research found maladaptive coping strategies were still associated with potentially problematic illness perceptions. Such coping may influence inferior outcome and psychological morbidity (e.g. Drossman, Leserman, et al., 2000). This further supports the proposal that attempting to adjust such perceptions via intervention would have a beneficial influence on reported quality of life (e.g. van Dulmen et al., 1998).

Findings suggested evidence that more adaptive coping could be independent of the influence of illness perceptions. Brief-COPE scores, across both studies, suggested that both groups appear to use active

coping strategies to help cope with their IBS. This coping strategy appears to be largely independent of any influence of illness perceptions.

The findings demonstrated that both groups showed significant improvement in reported quality of life over the two study time points. This particular finding suggests a degree of adjustment to having chronic illness has taken place. In theoretical terms this appears inconsistent as the change in quality of life status should be reflected in an improvement in problematic illness perceptions (see figure 2.1). Findings showed there was limited change in cognitive components of illness perceptions in both groups, although illness consequences in CAM-users were significantly reduced. Non-users' illness identity ratings were significantly reduced and personal control ratings were significantly enhanced. Emotional representations however, significantly improved in both groups. This would appear to represent a decrease in emotional distress associated with IBS over the two study time points. Such factors as a reduction or absence of negative affect, lack of psychological morbidity and psychological symptoms (Larsen & Hummel, 2008) are factors indicative of positive adjustment to chronic illness.

The findings presented suggest that uncertainty remains over whether cognitive components of illness perceptions do update and change over time as found in other chronic illnesses (Bijsterbosch et al., 2009; Foster et al., 2008; Kaptein et al., 2010) or whether the relative stability shown in this study is particular to those affected by IBS. One further possibility concerns the sensitivity of the IPQ-R to assessing change over time.

Mediation effects in the follow-up study were unique only to CAM-users. This finding contradicts several longitudinal CSM studies that found no evidence of mediation over time (Llewellyn et al., 2007; Rutter & Rutter, 2007; Treharne et al., 2009). Self blame and behavioural disengagement were again implicated as mediating variables. When viewed in the context of other potentially distinguishing factors about CAM-users, such as the perceived more severe illness experience, it

may be possible that people who use CAM have a distinct psychological profile and this may influence the type of treatment or intervention that may have an effect. This may consist of specific personality factors or psychological morbidity (Drossman et al., 1999).

One of the key benefits of the establishment of mediating variables has been to demonstrate which processes explain the pathway from illness perceptions to quality of life and emotional outcome and that may be relevant to designing intervention strategies. The identification of precise pathways and processes can aid in the translation of theory based findings to practical self management techniques (Leventhal, Musumeci, & Contrada, 2007).

In the context of an extended CSM, the influence of treatment beliefs on quality of life was less clear and findings showed these constructs had less influence on reported quality of life than coping strategies. A further important factor to consider is that measurement instruments based on theoretical constructs may lack specificity where validity, in theoretical terms, may not be fully established. As indicated in previous chapters, accurate measurement of coping may be problematic and difficult to quantify in terms of the CSM (Leventhal et al., 1998; 2008). There is also the possibility that other factors have a role in regulating the impact of illness (Llewellyn et al., 2007) and may be incorporated into an extended CSM framework in future studies. Such factors as self-efficacy, (de Ridder & de Wit, 2006) and optimism (Scheier & Carver, 2003) have been associated with illness outcomes. It is also possible that these factors may be important influences on the regulation of affective response to illness.

### **7.3 Implications for theory and practice**

The findings from this research give rise to a number of possible implications in terms of translating research to potential practical measures to help in managing symptoms (section 2.6), in addition to offering support for the CSM.



### **7.3.1 Practical implications**

The theory-based findings presented have offered indication that may assist in the formulation of practical strategies for management of IBS symptoms. The observable links between illness perceptions and quality of life, via coping strategies, suggest positive change to illness perceptions would result in use of fewer maladaptive coping strategies. Consequently, quality of life judgements may improve as, even with use of more than one type of CAM, CAM-users reported inferior quality of life than non-users (chapter five). As considered in chapter five, the unique variance added by Brief-COPE scales to regression equations was small although the actual Brief-COPE Beta coefficients suggest the influence on shared variance in IBS-QOL scores (with each illness perception scale) was considerably higher. Coupled with the significance of each mediation effect (and the size of the unique variance due to the mediation effect, Fairchild et al., 2009) it is evident the indirect effect of each illness perception component on IBS-QOL scores, via Brief-COPE scales is of practical significance. Interventions focused on positively adjusting some of the maladaptive pathways detected in this research may then result in more adaptive coping strategies being adopted.

The majority of the components of illness perceptions showed no significant change over the two study time points, the most notable exception being the emotional representations of both groups. As mentioned previously, IBS-QOL and Dysphoria scores did improve significantly over the two study time points. These findings suggest that in most cases illness perceptions are comparatively less susceptible to change over time unless potentially and actively challenged by new information in the form of practical intervention strategies.

The basis of such strategies would be to attempt to address stronger and problematic symptom based illness perceptions indicative of a more severe illness experience. Conversely attempts could be made to facilitate strengthening of the illness perception components of control and coherence, which are associated with improved quality of life.

Problematic illness perceptions (i.e. those associated with poorer outcomes) have been challenged by intervention to facilitate an improvement in patient outcomes in such conditions as myocardial infarction (Petrie et al., 2002), diabetes and asthma (Petrie et al., 2003). Interventions have also targeted negative emotional representations of illness by using such techniques as written diary interventions based on emotional expression to reduce illness related emotional distress (e.g. Cameron & Jago, 2008). Emotional support may also come from other forms such as internet message boards (Coulson, 2005). It is also evident that attempts should be made to address stress in addition to providing information that stress is not the sole aetiological factor implicated in IBS.

Previous work has shown that if GPs address patient cognitions and emotional concerns during early consultations for IBS, then future use of health care services may be reduced (e.g. Oerlemans et al., 2010; van Dulmen et al., 1994; 1996). Similarly, providing detailed education about IBS has resulted in a reduction of health care service use over time, suggesting a reduction in troublesome symptoms via enhancement of feelings of control and coherence (Ringström et al., 2009; 2010; Robinson et al., 2006). It was highlighted in chapter one that a positive diagnosis of IBS may help the alleviation of emotional distress and forms part of the NICE guidelines for IBS management in the UK (NICE, 2008). Such findings imply that addressing problematic illness perceptions during conventional consultations in a patient centred manner is beneficial. It may even be possible for GPs seeing a patient with symptoms for the first time, to address patient cognitions and emotions by using IPQ-R scale items as a basis for where patient concern may be concentrated. As GPs' time is often very constricted, certain aspects, for example, the consequences and emotional representation scales as two of the most influential scales on quality of life could be addressed. Emotional representations were also influential on emotional outcome ratings.

Challenging problematic illness perceptions need not be limited to health care services. There is scope for development of e-interventions that can be delivered over the internet without the need for face-to-face interaction (section 3.1.2.1). This is perhaps one method of delivery where detailed information regarding IBS can be provided in a patient centred and accessible manner. The IBS network, where this research study advertised for participants, offer their own self-help programme designed to facilitate control and understanding of IBS accompanied with information provision about treatment options.

By addressing and reducing problematic symptom based illness perceptions and emotional representations it may be that potential and existing CAM-users may feel that CAM use is less necessary. This may help to reduce factors that may influence CAM use thus reducing any potential financial implications of self funding repeated CAM treatments, which appear not to improve reported quality of life over time when compared with those not using CAM. Evidence here supports the proposition that conventional care may be able to offer more substantial and longer lasting symptom relief through simple psychological intervention and the findings presented in this thesis provide possible discrete pathways where intervention may be best targeted.

It is possible that CAM-users, with poorer reported quality of life (time one) and stronger potentially problematic illness perceptions may be a group that could be less responsive to GP or self help intervention. It may be recommended that CAM-users would be greater beneficiaries of CBT. Evidence presented in chapter one described how CBT can benefit those with IBS (e.g. Lackner et al., 2007) and may be offered as part of conventional medical care if individuals show no improvement in symptoms after 12 months (NICE, 2008). In the case of IBS, CBT works by reducing the impact of troublesome cognitions and behaviour that may increase the likelihood of experiencing and increasing the intensity of IBS symptoms. With this in mind, it is possible that people with IBS would benefit from a top-down cognitive based approach (McAndrew et

al., 2008) to address illness perceptions with a simultaneous strategy to address emotional distress. Such an approach is weighted in terms of providing information and directing behaviours that may improve outcomes (McAndrew et al., 2008).

### ***7.3.2 Theoretical implications***

Findings across the two study time points suggest partial support for an extended CSM. Relationships between illness perceptions and treatment beliefs, across both groups, appeared consistent with previous work and expectations. In the context of predicting CAM use, a specific coping behaviour, the extended model was beneficial. Several dimensions of illness perceptions and beliefs about harm caused by conventional medication predicted CAM use in people affected by IBS when controlling for several demographic factors. In predicting quality of life however, treatment beliefs were less strongly related to IBS-QOL scores than illness perceptions and this was consistent in both CAM-users and non-users. Over the two study time points, there was no relationship between treatment beliefs at time one and IBS-QOL scores at time two. These findings suggest the extended CSM has value in explaining specific coping behaviours (e.g. Horne & Weinman, 2002), but further investigation needs to be conducted to establish the effect of treatment representations on reported quality of life.

The inclusion of CAM beliefs, as measured by the CAMBI as an additional facet of treatment beliefs, appeared to have limited impact in enhancing the potential for the CSM to predict CAM use in IBS. CAM beliefs however, were found to be positively related to the number of CAM treatments used suggesting additional work needs to be conducted in relation to the influence of CAM beliefs on CAM use. As with the BMQ-specific version (Horne et al., 1999) there may be scope to develop a specific measure of CAM beliefs which may reflect aspects of individual CAM modalities rather than more general beliefs about CAM.

Many CSM based studies have neglected study of the role of coping in explaining the pathway between illness perceptions and outcome (Rutter & Rutter, 2007). Coping strategies, where considered, have often contributed little additional variance explained to outcomes (Hagger & Orbell, 2003). This study included 14 coping strategies as measured by the brief-COPE. In several cases coping contributed greater variance in predicting outcome than some illness perceptions and treatment beliefs and evidently had in many cases, from observing Beta coefficient values, moderate influence on IBS-QOL scores. The cross-sectional study offered substantial support to the CSM supposition that coping mediates between the representation and outcome pathway, with numerous examples of largely partial mediation across both groups. Between study times one and two, mediation effects of coping however were confined to CAM-users with IBS. Further research may establish if this finding is particular to this group of participants or an artefact of observably different group sizes. There may be implications for the refinement of measurement of coping (chapter five) or measuring the CSM constructs at different points in time from individuals at the same point in illness trajectory to establish reliability of these findings.

One unique and important finding of this research was that emotional representations in IBS were found to be important influences on both reported quality of life and emotional outcome at both study time points. Many previous CSM studies have used differing affective measures of outcome (e.g. depression, anxiety) without being explicit that emotional outcomes were being considered. The use of the Dysphoria scale of the IBS-QOL however, was a unique approach to measuring emotional outcome and presents an opportunity to develop measurement of domain specific emotional outcome. In this context, this research was exploratory however the findings established a strong influence of emotional representations at time one on emotional outcome at time two. This pathway was also partially mediated by self blame and behavioural disengagement although this was only found in CAM-users. This again, suggests support for the CSM.

Over the two study time points, there were quantitative changes in a small number of illness perceptions which were specific to each group. Across both groups consistently, change was only shown in emotional representations. This appears to largely counter the proposition that the CSM is a dynamic model (Hagger & Orbell, 2003) and illness perceptions change over time as new information is used in updating representations. This lack of change may be particular to IBS. Rutter and Rutter (2007) found illness perceptions remained static over time. This does not discount the possibility that such changes are subtle and less detectable by quantitative means. It may be that future qualitative investigations may prove beneficial in this context. Alternatively, it is equally as plausible that illness perceptions in IBS, once formed, remain relatively static (Rutter & Rutter, 2007). This may offer opportunity for direct intervention at a specific time point (i.e. early in the illness process) to challenge more negative illness perceptions that may negatively influence quality of life judgements.

Development of the CSM may enhance its applicability to other chronic illnesses with the goal of establishing psychological interventions to improve outcomes. Other theories of self-regulation have cited such factors as self-efficacy and optimism as influences on illness trajectories and outcomes. It is also possible that factors such as personality and socio-economic influences should be examined in terms of their influence on the formation of illness perceptions (Leventhal et al., 1997). Such factors may be incorporated into future studies as these factors invariably have an impact on the formation of illness related schema that guide health related behaviours. Socio-economic status in particular may have a determinate bearing on if an individual is able to use CAM.

#### **7.4 Limitations of thesis**

The findings found substantial support for the CSM, especially at the cross-sectional stage. The extended CSM appeared limited (i.e. with reference to treatment beliefs) in examining influence on quality of life but was beneficial in enhancing our understanding of psychological factors

that may influence CAM use in those affected with IBS. It is therefore important to replicate these findings in other IBS populations such as GI clinic patients and other online samples (e.g. Andrews et al., 2005; Jones et al., 2007). It is paramount to establish if the findings of this research can be generalised to other IBS populations. The majority of participants were recruited from the IBS network, a self help organisation for people affected with IBS. In this respect the sample may be considered self-selecting and thus potentially restrict any application of findings. Furthermore, it should be pointed out that the majority of self-management intervention studies in chronic disease are based upon self-selected samples where individuals may be well educated and motivated to take part in such studies (e.g. Barlow, Cooke, Mulligan, Beck, & Newman, 2010) thus not being representative of specific illness populations as a whole. Some of these concerns may however, have been offset by the large number of participants recruited for this research (e.g. Marks et al., 2005).

Reported quality of life scores across both CAM-users and non-users, were found to be lower at study time one than reported in other studies (Bushnell et al., 2006; Drossman et al., 2000; van Tilburg et al., 2008). Jones et al. (2007) suggest that participants affected by IBS recruited online may potentially be more confined to staying in their homes meaning both social interaction and employment may be affected. This explanation however needs further investigation to determine if the findings from Jones et al. (2007) are consistent across different online samples. Previous research however, has suggested little difference between internet samples and paper and pencil respondents when comparing responses on established psychological measures (e.g. Birnbaum, 2004; Ritter et al., 2004; Vallejo et al., 2007) and this appeared to be the trend with other measurement instruments used in this research.

In terms of examining the pathways of the extended CSM, the findings may be limited by the lack of direct measurement of the appraisal of

coping strategies. A large proportion of the CSM based research outlined in chapter two has utilised various measures of illness outcome as oppose to appraisal. To fully test the pathways within the CSM, it may be necessary to investigate appraisal of coping that has been directed by illness perceptions and treatment beliefs. This may aid in determining how appraisal relates to illness outcome and in influencing illness perceptions (and treatment beliefs) as part of the feedback loop of the CSM (figure 2.1). A further limitation, largely due to the lack of specific focus on the appraisal stage of the CSM, concerns the point in time at which appraisal occurs and how much subsequent feedback there may be to the representation stage. One proposal could be to conduct semi-structured interviews with participants affected by IBS and ask directly about how effective their coping strategies or behaviours are, an approach utilised by Leventhal et al. (1985) in people affected by hypertension. In the context of this research, participants could also be asked if they feel using CAM has been helpful in the treatment of their condition. Such investigation may further enhance understanding of illness appraisal, not just in IBS, but in other chronic illnesses. This may result in improved application of research findings to practical interventions and further relieve the burden of chronic illness.

As considered previously, one of the key components of this research was to examine the emotional response to having IBS and how this may influence coping, reported quality of life and emotional outcome. It is plausible to suggest that negative affect generally may have had some influence on such emotional representations however this was not addressed in this research. Previous work however, has suggested a conceptual overlap between negative affect and emotional representations as measured by the IPQ-R in a number of patient samples including those affected by diabetes and asthma (Moss-Morris et al., 2002) and this is an area that may be considered more fully in future work. Furthermore, the role of adherence to conventional medication has not been considered in this research, again primarily as the research aims focused on beliefs and representations in CAM-users



as CAM use was found to be prevalent. It is plausible to suggest that adherence to any prescribed medication may have had some influence on IBS-QOL scores, emotional outcome (and possibly CAM use), although 44% of participants reported they were not taking any conventional medication. This may have allowed for further potentially interesting analyses but is beyond the scope of this thesis.

One further potential limitation comes in the form of the measurement instruments used for the various parts of the CSM. The potential shortcomings of using the generic Brief-COPE measure for example, have already been considered. In the case of illness perceptions, these were captured using the IPQ-R (Moss-Morris et al., 2002). It is suggested that researchers should adopt the IPQ-R to reflect the illness under investigation (French & Weinman, 2008), which was the case in this research. Several illness specific versions of the IPQ-R exist, however this typically consists of wording changes in addition to the symptom list for the identity scale being reflective of the illness under investigation. The fact remains that the identity scale on the IPQ-R consists of a summed number of symptoms rather than, as the CSM stipulates, recognition that a particular symptom is indicative of a particular illness (Hagger & Orbell, 2003), in this case, IBS.

It is important to consider the possibility of statistical limitations within the present data. The procedure for testing for mediation may have unintentionally omitted evidence of other mediated pathways. This research implemented the Baron and Kenny (1986) approach to 'simple' mediation which involved establishing consecutive steps to establish mediation effects between a predictor variable and outcome. This research also had the unique approach in CAM use and IBS to determine the significance of each statistical model that demonstrated mediation and also considered the strength of each mediation effect. Few pathways demonstrating mediation were therefore rejected based on significance testing as the majority were retained. Preacher and Hayes (2004) however, propose that the Baron and Kenny approach

may be outdated as there is little need to establish all 'causal' steps. The alternative is to instead simply test for evidence of an indirect effect. The indirect effect refers to the relationship of predictor and outcome through a potential mediator (Preacher & Hayes, 2004, section 3.6). This approach was included in this research to test for significance of mediation effects, only after the causal steps had been established. If testing the indirect effect was adopted without testing causal steps, it may have resulted in a differing number of instances of mediation being detected thus adding additional (or less) support to the CSM. This approach may have also uncovered unidentified significant effects between treatment beliefs, coping and quality of life. However, in this study, the Baron and Kenny approach was thought to be consistent with the CSM theory and allowed comparison with how the CSM constructs have been investigated in previous work.

As stated, this research presented a formal test of significance for mediation effects (Preacher & Hayes, 2004). Inferences of mediation however, still require a degree of caution. Firstly, it is assumed that there is no measurement error in the mediating variable (Baron & Kenny, 1986). As highlighted in previous chapters, there may be issues with the Brief-COPE being an accurate measure of domain specific coping. Secondly, it is possible that CAM use over time actually represented moderated mediation. Moderators typically represent an interaction effect (Baron & Kenny, 1986); in the case of this research, over the two study time points, CAM-users demonstrated mediation whereas in non-users, over time, there was no mediation effects detected. One of the criteria for measuring moderators is that this should be conducted prior to study onset (Baron & Kenny, 1986), which did not occur in this research. This may be investigated in future by selecting CAM-users and non-users for recruitment prior to any investigation commencing.

There may have been further implications regarding the timing of measures. Between study times one and two there was a minimum of six months, however it is unclear from existing CSM research how the

influence of illness and treatment representation delineates over time. It may be inferred however, that the CSM specifies a causal pathway between representations and outcome, therefore longitudinal research is preferable to test the causal pathways outlined by CSM theory. It may be that in order to provide more specific guidelines on study time points, qualitative approaches may prove productive in determining when best to assess coping, outcomes and appraisal. With these issues in mind, it may be beneficial to measure the three constructs of the CSM, representation, coping and appraisal/outcome, at separate time points in future studies.

### **7.5 Future directions**

One of the primary challenges for conventional medical care is to successfully address and manage IBS symptoms. IBS is a functional chronic illness with no established aetiology and people affected are burdened with a number of bothersome and distressing symptoms that are hard to treat (e.g. Hayee & Forgacs, 2007). It appears, from the research presented here, that CAM-users with IBS perceive a more severe illness experience than non-users. It remains to be established if CAM-users have a distinctive psychological profile or personality traits that influence their perceived illness experience. Furthermore, although the present research was able to isolate psychological pathways to reported quality of life judgements, no investigation was conducted that isolated IBS subtypes or those at different timelines of illness. It is recommended that future research examine these important factors to assess the impact on the trajectory and experience of IBS.

The prominence of components of illness perceptions in influencing CAM use and quality of life in this research suggests where intervention may be most successful. Intervention could attempt to challenge and modify components of illness perceptions that influence enhanced or poorer quality of life and emotional outcome. Based on the findings of this research, it is recommended as a first point of investigation, to assess the impact of intervening in perceived consequences and emotional

responses to having IBS, as these components of the illness perceptions described by Leventhal et al. (1998) had the consistently strongest influence on reported quality of life in both CAM-users and non-users. Emotional representations also demonstrated significant associations with emotional outcome (Dysphoria). Consideration of the type of CAM treatments used may suggest 'stress' is a concern to those with IBS as a factor that is perceived to precipitate and potentially worsen IBS symptoms. From the findings presented here it is possible that individuals attempt to make subjective inferences regarding causes of IBS which may influence the type of CAM treatment sought. Such causal perceptions may be more pronounced in IBS and possibly other functional conditions where aetiology is uncertain (e.g. Casiday et al., 2009; Hungin et al., 2005). It may be important to challenge such beliefs by encouraging more expansive causal beliefs via a range of explanations related to aetiology (e.g. Petrie & Weinman, 2002).

Addressing both cognitive and emotional representations in parallel also appears of paramount importance. In previous work for example, where attention has focused on dealing with cognitive representations of illness in MI patients the lasting effects of intervention were not as pronounced for those with negative affect (Cameron, Petrie, Ellis, Buick, & Weinman, 2005).

There has been little specific CSM based intervention in IBS although parallels are drawn with CBT based interventions for IBS (Oerlemans et al., 2010). In previous work problematic cognitions and emotional distress have been challenged resulting in reduction in affective reactions and use of health care services post treatment (Lackner et al., 2007; Oerlemans et al., 2010; van Dulmen et al., 1997; 1998). In terms of a CSM based intervention focusing on the positive modification of problematic illness perceptions, evidence from other chronic illnesses suggests methodological approaches that can influence positive outcomes across a number of illnesses (McAndrew et al., 2008; Petrie et al., 2002). Furthermore, the therapeutic benefits of a positive health care

consultation in patients presenting with IBS in reducing future use of health care services have been documented previously (Ilnyckyj et al., 2003). In addition, NICE guidelines stress the importance of offering a positive diagnosis (NICE, 2008). Improved outcomes to positive conventional medical consultations have been recorded in patients with non-specific symptoms (Thomas, 1987) and acute tonsillitis (Olsson, Olsson, & Tibblin, 1989) and it suggested this may be through a variety of pathways including expectancy and therapeutic relationship with the health care provider (Hyland, 2003). Such patient centred approaches are well received by the relevant user groups (Little et al., 2001).

One possible route of investigating change in illness perceptions and outcome would be to take a multiconvergent approach to treatment (e.g. Thomas, Sadler, & Smith, 2008). Such an approach incorporates CBT, physical activity and meditation and has been found to be beneficial in those with chronic fatigue (Thomas et al., 2008) and chronic pain (Watson, 2002). The approach seeks to manage beliefs, emotions and behaviour through the introduction of gradual exercise, meditation to focus thoughts on the present and to disconnect from symptoms. CBT is used to counteract thought patterns associated with symptoms and has shown lasting benefits in enhancing self management of IBS (Moss-Morris, McAlpine, Didsbury, & Spence, 2010). In a comparison with regular (control group) care and relaxation training, the multiconvergent approach was far superior in terms of outcome measurement (Thomas et al., 2008). As chronic fatigue syndrome and chronic pain are both disorders where aetiology may be more difficult to establish, it is reasonable to assume that such an approach would be beneficial to those experiencing more severe IBS, which from the findings in this study may be those using CAM. Shaw et al. (1991), utilising a multiconvergent approach for stress management in IBS, found all 35 participants benefited from fewer IBS symptoms of less severity over the following 12 months. Using a multiconvergent approach with measures of illness perceptions, coping and outcome throughout the study, may give further important insight into pathways of influence outlined by the

CSM and how problematic illness perceptions may be changed in those with IBS, potentially resulting in more adaptive coping and improved quality of life judgements.

The differences in the way interventions are implemented may affect outcomes. In the case of progressive muscle relaxation training, this technique may promote relaxation and as a by-product, enhance perceptions of control rather than directly challenging strong emotional distress brought on by illness. However, the interrelations found between illness perception components are consistent with other studies (e.g. Hagger & Orbell, 2003) and implies that if a specific psychological component is challenged (e.g. consequences) related psychological components (e.g. personal control) may change and potentially improve. Conversely, CBT may seek to directly challenge stronger emotional representations thus indirectly enhancing feelings of control. Such influences may be delineated with close examination of the relationships between illness perception components at specific time points during an intervention study for IBS. It is proposed that a similar multiconvergent approach may be used to test and harness the most effective components of a variety of techniques to maximise a positive outcome.

Petrie et al. (2002) suggested one possible methodological approach to addressing problematic illness perceptions within a CSM framework and this could be adapted with reference to the findings of this thesis. The amendment proposed to Petrie et al's. (2002) methodological approach is presented in figure 7.1., and highlights a three phase cognitive-behavioural based intervention, where components of illness perceptions are challenged and assessed at each phase. This approach is centred upon a top-down, information driven mechanism as previously illustrated by McAndrew et al. (2008) as information driven approaches have demonstrated positive effects in previous studies (e.g. Oerlemans et al., 2010; Ringström et al., 2010; Robinson et al., 2006). It is predicted that if more positive outcomes are achieved, the implementation of such an

intervention would be beneficial and could be further extended to map across stages of chronic illness.

The delivery of an intervention could take place on recommendation from General Practitioners or other health care providers if patients are deemed suitable. It is suggested referral to such an intervention occurs early in the health care seeking process as the findings from this thesis clearly demonstrate that cognitive perceptions of illness appear to remain largely static over time even though quality of life judgements improved at time point two within the study. This implies that the perceptions formed in the early stages of a chronic disorder remain static. Therefore it is proposed that in the initial phase of the proposed intervention, baseline measures of cognitive and emotional representations are measured (for example purposes, the measures proposed are unchanged from this research, figure 7.1). Additional screening for psychological morbidity would also be undertaken as there is some evidence that those with psychological problems, may respond less well to such intervention (Hayee & Forgacs, 2007; Whorwell, 2006). The measurement of illness perceptions at baseline may also enable tailoring of the intervention to best fit individual needs.

It is essential that attention is paid to both emotional and cognitive aspects at phase one of the intervention. During this phase, information may be offered explaining a range of potential causes of IBS in order to reduce the focus on stress as a causal factor. Further information may be beneficial outlining the benefits of a balanced diet and taking regular exercise. This would ensure regular activities are maintained and provide a more positive focus as opposed to rumination about the causes and consequences of living with a chronic functional bowel condition.

An additional initiative would be to develop an action plan encouraging exercise and activity, whilst stressing the importance of maintaining activity levels again with the goal of reducing focus on illness 'consequences' (Petrie et al., 2002). In addressing some of the

emotional aspects of IBS, reassurance regarding visceral symptoms and the nature of functional illnesses could be made more prominent, which may supplement a positive diagnosis given by the GP. The diary writing intervention cited by Cameron and Jago (2008) may also have benefit here as individuals may articulate their emotional responses to IBS through written expression.

To monitor any change in illness perceptions from baseline, measurement could be conducted at subsequent intervention time points. Having addressed possible influences on perceptions of consequences, cause and emotions, the second phase could focus on relieving stress through suggested means of meditation or progressive muscle relaxation training (PMRT) which has been shown to have benefits in relieving stress, nausea and vomiting in those receiving chemotherapy treatment (Burish & Jenkins, 1992; Burish & Tope, 1992) and has been shown to have long term benefits in people affected by IBS (Lahmann et al., 2010). The third phase should monitor progress and seek to consolidate activity and emotional regulation through written expression.

It is proposed that the most effective way to implement such a programme would be via the internet. This is suggested for a number of reasons. Firstly, internet availability and use is widespread; the ONS has reported 73% of UK households now have access to the internet (ONS, 2010). This research successfully recruited a large number of those with IBS to participate in the study through the internet. Secondly, the internet is routinely used by many individuals searching for health based information which ranges from searching for illness specific information (McMullan, 2006) to seeking support from other individuals through online illness discussion forums (e.g. Coulson, 2005). Thirdly, e-interventions have already successfully been implemented in other chronic conditions (Robinson & Serfaty, 2003; Winzelberg et al., 2003, see also section 3.1.2.1). In people affected by IBS, commencing an intervention in individuals' own time may facilitate a reduction in stress as



they would not necessarily have to leave their homes to take part as there is further suggestion that those affected by IBS who are recruited for online studies have reduced quality of life when compared with individuals recruited through other methods (Jones et al., 2007). Such intervention may also be beneficial where IBS is perceived by individuals to be less severe. There is evidence that, where chronic illness is regarded as less severe, negative illness perceptions may still be associated with a greater number of health care consultations (Petrie & Weinman, 2006).

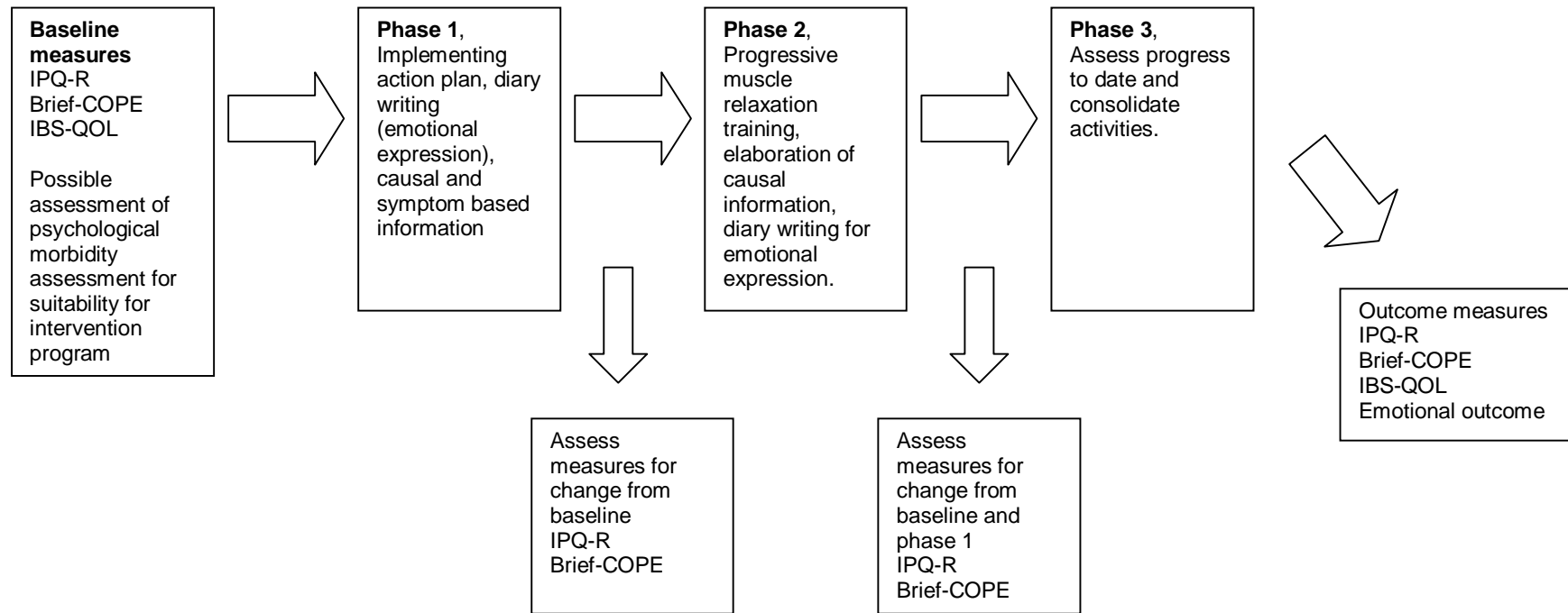
An important feature of this intervention would be to assess changes in coping strategies in relation to changes in illness perceptions and quality of life through each phase. Furthermore, it would be beneficial to determine which method of intervention works best for known sub groups of affected individuals. It is possible, by using clinical diagnoses, that individuals with IBS subtypes IBS-D or IBS-C for example, may be offered particular aspects of the intervention deemed effective for their subtype. Additionally, conventional medication beliefs may be addressed in the case of prescription medication being used for specific symptoms of IBS.

It is plausible to suggest that any intervention may be directed primarily towards CAM-users as it appears from findings presented here (sections 4.3.5 and 5.3.1) and existing work (e.g. Bishop et al., 2006; Langmead et al., 2002), that users of such treatments may perceive a more severe illness experience. Baseline testing would be advantageous to examine in greater detail the psychological characteristics of CAM-users. One potential reason for the “inferior” perceived illness experience could lie in the influence of psychological correlates such as depression, anxiety or personality traits (Drossman et al., 1999) that have been implicated in the onset and maintenance of IBS. It is plausible that CAM-users may have underlying psychological morbidity (e.g. depression) or personality traits that may lead to a distinctive response to IBS symptoms in addition to potentially poorer affective responses to IBS where catastrophising

thoughts become predominant (e.g Lackner et al., 2004). Population studies conducted over time may be able to delineate if such psychological morbidity influences onset or is influenced by IBS.

With such an approach in mind, future work may assess the most effective methods of implementing change to perceptions of consequences and emotional representations and, by improving these components, more adaptive coping may be adopted and consequently outcomes may improve. Harmonising CBT, patient centred health care consultations, education based strategies and electronic delivery (via the internet) may lead to enhanced care provision to those affected by IBS. Furthermore, at present, evidence for CAM is limited for the treatment of IBS (e.g. Ernst, 2009; NICE, 2008) so addressing psychological factors may reduce use/need for CAM in addition to improving outcome. Such methods of intervention as proposed here would need assessment to determine the most effective and efficient means of improving outcomes in IBS.

**Figure 7.1 Provisional study protocol for CSM based pilot intervention for IBS**



## **7.6 Conclusion**

The main aim of the thesis was to examine the role of illness perceptions and treatment beliefs in influencing CAM use in those affected by IBS and how these factors affected reported quality of life in CAM-users and non-users. This thesis has provided robust and unique evidence that illness perceptions are important factors in IBS in influencing CAM use and reported quality of life in both CAM-users and non-users. In terms of reported quality of life, findings do not support CAM use as a beneficial therapy for those affected with IBS. Moreover, treatment beliefs have been found to have a greater influence on CAM use as a specific coping behaviour as opposed to directly influencing quality of life.

Further investigation may show that CAM treatments will prove to be efficacious in treating IBS and could be incorporated into a multiconvergent approach as described within this chapter (e.g. Thomas et al., 2008). However, it is important to note that CAM treatments are subject to many of the same problems faced by conventional care, where treatments may be seen to potentially have an effect on specific symptoms rather than impacting on the overall improvement of this chronic disorder.

In addition, the research findings offer support for the theoretical supposition of the CSM, opportunities for future study and areas of potential intervention to improve outcomes in those with IBS. The research has also provided some unique and beneficial findings to supplement existing understanding about the role of illness perceptions and treatment beliefs in those affected by IBS. With the absence of effective conventional treatments for IBS, it is hoped this research will influence further study and possible development of self-management strategies.

Substantial support for the mediating role of coping strategies in both CAM-users' and non-users' illness perceptions and reported quality of life was observed from the cross-sectional study. Participants' perceptions

of illness consequences and emotional representations were found to be strong influences on IBS-QOL scores, with the latter also strongly influencing emotional outcome. Over time, such evidence was limited to CAM-users where the coping strategies of self blame and behavioural disengagement were shown to act as mediating variables.

If the findings presented in this thesis can be replicated in other groups of participants with IBS, then it is hoped intervention and management strategies may be formulated. It is clear from this research that perceptions of consequences and emotional representations have a key role in the formation of quality of life judgements and represent possible points of intervention. The need to challenge these perceptions appears greater in those using or considering using CAM as it is indicative of a more severe illness experience. A CSM based electronic intervention has been proposed and it is considered that this may be beneficial to those with IBS and may have wider implications for those with other functional chronic illnesses. By addressing the psychological aspects of IBS in this manner it is hoped quality of life may improve. This would potentially leave the role of CAM to be one of a complementary treatment for those affected with IBS, rather than being used primarily based on health need.

## References

- Aakster, C. W. (1986). Concepts in alternative medicine. *Social Science & Medicine* (1982), 22(2), 265-273.
- Abraham, C., & Sheeran, P. (2005). The health belief model. In M. Conner & P. Norman (Eds). *Predicting Health Behaviour: Research and Practice with Social Cognition Models* (2nd ed., pp. 28-80). Buckingham: Open University Press.
- Agrawal, A., & Whorwell, P. J. (2006). Irritable bowel syndrome: diagnosis and management. *British Medical Journal*, 332(7536), 280-283. doi:10.1136/bmj.332.7536.280
- Ahern, N. R. (2005). Using the Internet to conduct research. *Nurse Researcher*, 13(2), 55-70.
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50, 179-211.
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice-Hall.
- Amouretti, M., Le Pen, C., Gaudin, A. F., Bommelaer, G., Frexinos, J., Ruszniewski, P., Poynard, T., et al. (2006). Impact of irritable bowel syndrome (IBS) on health-related quality of life (HRQOL). *Gastroentérologie Clinique Et Biologique*, 30(2), 241-246.
- Andrews, E. B., Eaton, S. C., Hollis, K. A., Hopkins, J. S., Ameen, V., Hamm, L. R., Cook, S. F., et al. (2005). Prevalence and demographics of irritable bowel syndrome: results from a large web-based survey. *Alimentary Pharmacology & Therapeutics*, 22(10), 935-942.
- Antonius, R. (2003). *Interpreting quantitative data with SPSS* (1st ed.). Sage Publications Ltd.
- Astin, J. A. (1998). Why patients use alternative medicine: results of a national study. *JAMA: The Journal of the American Medical Association*, 279(19), 1548-1553.
- Bansil, P., Keenan, N. L., Zlot, A. I., & Gilliland, J. C. (2006). Health-related information on the web: results from the Health Styles Survey, 2002-2003. *Preventing Chronic Disease*, 3(2), A36.
- Barlow, C., Cooke, D., Mulligan, K., Beck, E., & Newman, S. (2010). A critical review of self-management and educational interventions in inflammatory bowel disease. *Gastroenterology Nursing*, 33(1), 11-18. doi:10.1097/SGA.0b013e3181ca03cc

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51(6), 1173-1182.

Barry, D. T. (2001). Assessing culture via the Internet: methods and techniques for psychological research. *Cyberpsychology & Behavior: The Impact of the Internet, Multimedia and Virtual Reality on Behavior and Society*, 4(1), 17-21.

Basnov, M., Kongsved, S. M., Bech, P., & Hjollund, N. H. (2009). Reliability of short form-36 in an Internet- and a pen-and-paper version. *Informatics for Health & Social Care*, 34(1), 53-58. doi:10.1080/17538150902779527

Becker, M. H. (1974). The Health Belief Model and Personal Health Behavior. *Health Education Monographs*, 2, 324-473.

Bennett, E. J., Tennant, C. C., Piesse, C., Badcock, C. A., & Kellow, J. E. (1998). Level of chronic life stress predicts clinical outcome in irritable bowel syndrome. *Gut*, 43(2), 256-261.

Bensoussan, A., Talley, N. J., Hing, M., Menzies, R., Guo, A., & Ngu, M. (1998). Treatment of irritable bowel syndrome with Chinese herbal medicine: a randomized controlled trial. *JAMA: The Journal of the American Medical Association*, 280(18), 1585-1589.

Bijsterbosch, J., Scharloo, M., Visser, A. W., Watt, I., Meulenbelt, I., Huizinga, T. W. J., Kaptein, A. A., et al. (2009). Illness perceptions in patients with osteoarthritis: change over time and association with disability. *Arthritis and Rheumatism*, 61(8), 1054-1061. doi:10.1002/art.24674

Birnbaum, M. H. (2004). Human research and data collection via the internet. *Annual Review of Psychology*, 55, 803-832. doi:10.1146/annurev.psych.55.090902.141601

Bishop, F. L., Yardley, L., & Lewith, G. (2005). Developing a measure of treatment beliefs: the complementary and alternative medicine beliefs inventory. *Complementary Therapies in Medicine*, 13(2), 144-149. doi:10.1016/j.ctim.2005.01.005

Bishop, F. L., Yardley, L., & Lewith, G. T. (2004). Associations and explanations: Who uses complementary medicine and why? *Health Psychology Update*, 13(3), 12-19.

Bishop, F. L., Yardley, L., & Lewith, G. T. (2007). A systematic review of beliefs involved in the use of complementary and alternative medicine. *Journal of Health Psychology*, 12(6), 851-867.

Bishop, F. L., Yardley, L., & Lewith, G. T. (2010). Who Uses CAM? A narrative review of demographic characteristics and health factors associated with CAM Use. *Evidence-Based Complementary and Alternative Medicine*, 7(1), 11-28.

Bishop, F. L., Yardley, L., & Lewith, G. T. (2006). Why do people use different forms of complementary medicine? Multivariate associations between treatment and illness beliefs and complementary medicine use. *Psychology & Health*, 21(5), 683.

Bishop, F. L., Yardley, L., & Lewith, G. T. (2008). Treatment appraisals and beliefs predict adherence to complementary therapies: a prospective study using a dynamic extended self-regulation model. *British Journal of Health Psychology*, 13(4), 701-718. doi:10.1348/135910707X249570

de Boer, M. J., Versteegen, G. J., & van Wijhe, M. (2007). Patients' use of the Internet for pain-related medical information. *Patient Education and Counseling*, 68(1), 86-97. doi:10.1016/j.pec.2007.05.012

Bowling, A. (2009). *Research Methods in Health: Investigating Health and Health Services* (3rd ed.). Open University Press.

Boyatzis, R. E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Sage Publications, Inc.

Boyce, P. M., Koloski, N. A., & Talley, N. J. (2000). Irritable bowel syndrome according to varying diagnostic criteria: are the new Rome II criteria unnecessarily restrictive for research and practice? *The American Journal of Gastroenterology*, 95(11), 3176-3183.

Boyce, P. M., Talley, N. J., Burke, C., & Koloski, N. A. (2006). Epidemiology of the functional gastrointestinal disorders diagnosed according to Rome II criteria: an Australian population-based study. *Internal Medicine Journal*, 36(1), 28-36. doi:10.1111/j.1445-5994.2006.01006.

Boyce, P. M., Talley, N. J., Balaam, B., Koloski, N. A., & Truman, G. (2003). A randomized controlled trial of cognitive behavior therapy, relaxation training, and routine clinical care for the irritable bowel syndrome. *The American Journal of Gastroenterology*, 98(10), 2209-2218. doi:10.1111/j.1572-0241.2003.07716.

Boynton, P. M., & Greenhalgh, T. (2004). Selecting, designing, and developing your questionnaire. *British Medical Journal*, 328(7451), 1312-1315. doi:10.1136/bmj.328.7451.1312

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.



Breakwell, G. M., & Rose, D. (2006). Theory, Method and Research Design. In Breakwell, G. M., Fife-Schaw, C., Hammond, S. & Smith, J., (Eds). *Research Methods in Psychology* (3rd ed., pp. 1-23). London: Sage

Brewer, B. W., Van Raalte, J. L., & Cornelius, A. E. (2007). Electronic CommunKNEEations: A descriptive analysis of anterior cruciate ligament message board postings. *Physical Therapy in Sport: Official Journal of the Association of Chartered Physiotherapists in Sports Medicine*, 8(1), 3-6. doi:10.1016/j.ptsp.2006.09.020

Brewer, N. T., Chapman, G. B., Brownlee, S., & Leventhal, E. A. (2002). Cholesterol control, medication adherence and illness cognition. *British Journal of Health Psychology*, 7(4), 433-447.

British Psychological Society. (2009). *Code of Ethics and Conduct*. Leicester: British Psychological Society.

Broadbent, E., Petrie, K, Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637.

Bryman, A. (2008). *Social Research Methods* (3rd ed.). OUP Oxford.

Bundorf, M. K., Wagner, T. H., Singer, S. J., & Baker, L. C. (2006). Who searches the internet for health information? *Health Services Research*, 41(3 Pt 1), 819-836. doi:10.1111/j.1475-6773.2006.00510.

Burish, T. G., & Jenkins, R A. (1992). Effectiveness of biofeedback and relaxation training in reducing the side effects of cancer chemotherapy. *Health Psychology*, 11(1), 17-23.

Burish, T. G., & Tope, D. M. (1992). Psychological techniques for controlling the adverse side effects of cancer chemotherapy: findings from a decade of research. *Journal of Pain and Symptom Management*, 7(5), 287-301.

Bushnell, D. M., Reilly, M. C., Galani, C., Martin, M. L., Ricci, J. F., Patrick, D. L., & McBurney, C. R. (2006). Validation of electronic data capture of the Irritable Bowel Syndrome-Quality of Life Measure, the Work Productivity and Activity Impairment Questionnaire for Irritable Bowel Syndrome and the EuroQol. *Value in Health*, 9(2), 98-105.

Caldarella, M. P., Serra, Jordi, Azpiroz, Fernando, & Malagelada, J. R. (2002). Prokinetic effects in patients with intestinal gas retention. *Gastroenterology*, 122(7), 1748-1755.

Cameron, L. D., & Jago, L. (2008). Emotion regulation interventions: A common - sense model approach. *British Journal of Health Psychology*, 13(2), 215-221.

- Cameron, L. D., Petrie, Keith J., Ellis, C., Buick, D., & Weinman, J. A. (2005). Symptom experiences, symptom attributions, and causal attributions in patients following first-time myocardial infarction. *International Journal of Behavioral Medicine*, 12(1), 30-38.
- Cantrell, M. A., & Lupinacci, P. (2007). Methodological issues in online data collection. *Journal of Advanced Nursing*, 60(5), 544-549. doi:10.1111/j.1365-2648.2007.04448.
- Carlisle, A. C. S., John, A. M. H., Fife-Schaw, C., & Lloyd, M. (2005). The self-regulatory model in women with rheumatoid arthritis: relationships between illness representations, coping strategies, and illness outcome. *British Journal of Health Psychology*, 10(4), 571-587.
- Carson, F., & Polman, R. C. J. (2010). The facilitative nature of avoidance coping within sports injury rehabilitation. *Scandinavian Journal of Medicine & Science in Sports*, 20(2), 235-240.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92-100.
- Carver, C S, Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-283.
- Carver, C. S, & Connor-Smith, J. (2010). Personality and coping. *Annual Review of Psychology*, 61, 679-704.
- Casebeer, A. L., & Verhoef, M J. (1997). Combining qualitative and quantitative research methods: considering the possibilities for enhancing the study of chronic diseases. *Chronic Diseases in Canada*, 18(3), 130-135.
- Cash, B., Sullivan, S., & Barghout, V. (2005). Total costs of IBS: employer and managed care perspective. *The American Journal of Managed Care*, 11(1 Suppl), S7-16.
- Casiday, R. E., Hungin, A. P. S., Cornford, C. S., de Wit, N. J., & Blell, M. T. (2009). Patients' explanatory models for irritable bowel syndrome: symptoms and treatment more important than explaining aetiology. *Family Practice*, 26(1), 40-47. doi:10.1093/fampra/cmn087
- Chang, L. (2004). Review article: epidemiology and quality of life in functional gastrointestinal disorders. *Alimentary Pharmacology & Therapeutics*, 20, 31-39. doi:10.1111/j.1365-2036.2004.02183.
- Clarke-Carter, D. (2007). Effect size and statistical power in psychological research. *Irish Journal of Psychology*, 28, 3-12.

- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20(1), 37-46.
- Conner, M., & Norman, P. (2005). *Predicting Health Behaviour* (2nd ed.). Open University Press.
- Corazziari, Enrico. (2004). Definition and epidemiology of functional gastrointestinal disorders. *Best Practice & Research. Clinical Gastroenterology*, 18(4), 613-631. doi:10.1016/j.bpg.2004.04.012
- Coulson, N. S. (2005). Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychology & Behavior*, 8(6), 580-584.
- Dancey, C. P., Hutton-Young, S. A., Moye, S., & Devins, G. M. (2002). Perceived stigma, illness intrusiveness and quality of life in men and women with irritable bowel syndrome. *Psychology, Health & Medicine*, 7(4), 381. doi:10.1080/1354850021000015203
- Dancey, C. P., & Backhouse, S. (1993). Towards a better understanding of patients with irritable bowel syndrome. *Journal of Advanced Nursing*, 18(9), 1443-1450. doi:10.1046/j.1365-2648.1993.18091443.
- Danivat, D., Tankeyoon, M., & Sriratanaban, A. (1988). Prevalence of irritable bowel syndrome in a non-Western population. *British Medical Journal*, 296(6638), 1710.
- Dean, B. B., Aguilar, D., Barghout, V., Kahler, K. H., Frech, F., Groves, D., & Ofman, J. J. (2005). Impairment in work productivity and health-related quality of life in patients with IBS. *The American Journal of Managed Care*, 11(1 Suppl), S17-26.
- Department of Health. (2001). Government response to the House of Lords Select Committee on Science and Technology's report on complementary and alternative medicine. Retrieved 11 August 2011, from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4025509](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4025509)
- de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, 372(9634), 246-255. doi:10.1016/S0140-6736(08)61078-8
- Derogatis, L R. (1993). *BSI Brief Symptom Inventory. Administration, Scoring, and Procedures Manual* (4th ed.). Baltimore, MD: Clinical Psychometric Research

Derogatis, L. R. (1977). *SCL-90-R: administration, scoring & procedures manual for the R (revised) version and other instruments of the psychopathology rating scale series*. Baltimore MD: John Hopkins University, School of Medicine.

Donker, G. A., Foets, M., & Spreeuwenberg, P. (1999). Patients with irritable bowel syndrome: health status and use of health care services. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, 49(447), 787-792.

Donnelly, L. S., Shaw, R. L., & van den Akker, O. B. A. (2008). eHealth as a challenge to "expert" power: a focus group study of internet use for health information and management. *Journal of the Royal Society of Medicine*, 101(10), 501-506. doi:10.1258/jrsm.2008.080156

Dorn, S. D., Kaptchuk, T. J., Park, J. B., Nguyen, L. T., Canenguez, K., Nam, B. H., Woods, K. B., et al. (2007). A meta-analysis of the placebo response in complementary and alternative medicine trials of irritable bowel syndrome. *Neurogastroenterology and Motility*, 19(8), 630-637. doi:10.1111/j.1365-2982.2007.00937.

Drossman, D. A. (1998). Presidential address: Gastrointestinal illness and the biopsychosocial model. *Psychosomatic Medicine*, 60(3), 258-267.

Drossman, D. A. (1999). The functional gastrointestinal disorders and the Rome II process. *Gut*, 45(S2), ii1-ii5.

Drossman, D. A., Creed, F. H., Olden, K. W., Svedlund, J., Toner, B. B., & Whitehead, W. E. (1999). Psychosocial aspects of the functional gastrointestinal disorders. *Gut*, 45(Supplement 2), ii25-ii30. doi:10.1136/gut.45.2008.ii25

Drossman, D. A., Leserman, J., Li, Z., Keefe, F., Hu, Y. J., & Toomey, T. C. (2000). Effects of coping on health outcome among women with gastrointestinal disorders. *Psychosomatic Medicine*, 62(3), 309-317.

Drossman, D. A., McKee, D. C., Sandler, R. S., Mitchell, C. M., Cramer, E. M., Lowman, B. C., & Burger, A. L. (1988). Psychosocial factors in the irritable bowel syndrome. A multivariate study of patients and nonpatients with irritable bowel syndrome. *Gastroenterology*, 95(3), 701-708.

Drossman, D. A., Patrick, D. L., Whitehead, W. E., Toner, B. B., Diamant, N. E., Hu, Y., Jia, H., et al. (2000). Further validation of the IBS-QOL: a disease-specific quality-of-life questionnaire. *The American Journal of Gastroenterology*, 95(4), 999-1007.

Drossman, D. A., Richter, J. E., Talley, N. J., Corazziari, E., Thompson, W. G., & Whitehead, W. E. (1994). *Functional gastrointestinal disorders*. Boston: Little, Brown.

- Drossman, D. A., Whitehead, W. E., & Camilleri, M. (1997). Irritable bowel syndrome: a technical review for practice guideline development. *Gastroenterology*, *112*(6), 2120-2137.
- Drossman, D. A., & Dumitrascu, D. L. (2006). Rome III: New standard for functional gastrointestinal disorders. *Journal of Gastrointestinal and Liver Diseases: JGLD*, *15*(3), 237-241.
- Duffy, M. E. (2002). Methodological issues in web-based research. *Journal of Nursing Scholarship*, *34*(1), 83-88.
- Eisenberg, D. M., Davis, R. B., Ettner, S. L., Appel, S., Wilkey, S., Van Rompay, M., & Kessler, R. C. (1998). Trends in alternative medicine use in the United States, 1990-1997: results of a follow-up national survey. *JAMA: The Journal of the American Medical Association*, *280*(18), 1569-1575.
- Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science (New York, N.Y.)*, *196*(4286), 129-136.
- Erceg-Hurn, D. M., & Mirosevich, V. M. (2008). Modern robust statistical methods: an easy way to maximize the accuracy and power of your research. *The American Psychologist*, *63*(7), 591-601. doi:10.1037/0003-066X.63.7.591
- Ernst, E. (2009). How much of CAM is based on research evidence? *Evidence-based Complementary and Alternative Medicine*. doi:10.1093/ecam/nep044
- Evans, D., & Norman, P. (2009). Illness representations, coping and psychological adjustment to Parkinson's disease. *Psychology & Health*, *24*(10), 1181-1196. doi:10.1080/08870440802398188
- Fairchild, A. J., Mackinnon, D. P., Taborga, M. P., & Taylor, A. B. (2009). R2 effect-size measures for mediation analysis. *Behavior Research Methods*, *41*(2), 486-498. doi:10.3758/BRM.41.2.486
- Faresjö, A., Grodzinsky, E., Foldevi, M., Johansson, S., & Wallander, M.-A. (2006). Patients with irritable bowel syndrome in primary care appear not to be heavy healthcare utilizers. *Alimentary Pharmacology & Therapeutics*, *23*(6), 807-814. doi:10.1111/j.1365-2036.2006.02815.x
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G\*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175-191.
- Field, A. (2009). *Discovering statistics using SPSS* (3rd ed.). Sage Publications Ltd.

Fletcher, P. C., Schneider, M. A., Van Ravenswaay, V., & Leon, Z. (2008). I am doing the best that I can!: Living with inflammatory bowel disease and/or irritable bowel syndrome (part II). *Clinical Nurse Specialist*, 22(6), 278-285. doi:10.1097/01.NUR.0000325382.99717.

Ford, A. C., Talley, Nicholas J, Spiegel, B. M. R., Foxx-Orenstein, A. E., Schiller, L., Quigley, Eamonn M. M., & Moayyedi, P. (2008). Effect of fibre, antispasmodics, and peppermint oil in the treatment of irritable bowel syndrome: systematic review and meta-analysis. *British Medical Journal*, 337, a2313.

Fortune, D. G., Smith, J. V., & Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self - regulation theory. *British Journal of Clinical Psychology*, 44(3), 319-331.

Foster, N. E., Bishop, A., Thomas, E., Main, C., Horne, Rob, Weinman, John, & Hay, E. (2008). Illness perceptions of low back pain patients in primary care: what are they, do they change and are they associated with outcome? *Pain*, 136(1-2), 177-187. doi:10.1016/j.pain.2007.12.007

Fowler, C., & Baas, L. S. (2006). Illness representations in patients with chronic kidney disease on maintenance hemodialysis. *Nephrology Nursing Journal*, 33(2), 173-174, 179-186.

Foxx-Orenstein, A. (2006). IBS-review and what's new. *Medscape General Medicine*, 8(3), 20.

Francis, C. Y., Morris, J., & Whorwell, P J. (1997). The irritable bowel severity scoring system: a simple method of monitoring irritable bowel syndrome and its progress. *Alimentary Pharmacology & Therapeutics*, 11(2), 395-402.

French, D. P., & Weinman, J. (2008). Assessing illness perceptions: beyond the IPQ. *Psychology and Health*, 23, 5-9.

French, D. P., Cooper, A., & Weinman, J. (2006). Illness perceptions predict attendance at cardiac rehabilitation following acute myocardial infarction: a systematic review with meta-analysis. *Journal of Psychosomatic Research*, 61(6), 757-767. doi:10.1016/j.jpsychores.2006.07.029

Furnham, A., & Kirkcaldy, B. (1996). The health beliefs and behaviours of orthodox and complementary medicine clients. *The British Journal of Clinical Psychology*, 35 (1), 49-61.

Furnham, A., & Lovett, J. (2001). The Perceived Efficacy and Risks of Complementary and Alternative Medicine and Conventional Medicine: A Vignette Study. *Journal of Applied Biobehavioral Research*, 6(1), 39-63. doi:10.1111/j.1751-9861.2001.tb00106.

- Gard, P. (2000). *A behavioural approach to pharmacy practice*. Oxford; Malden Mass.: Blackwell Science.
- Giese, L. A. (2000). A study of alternative health care use for gastrointestinal disorders. *Gastroenterology Nursing*, 23(1), 19-27.
- Glasgow, R. E., Barrera, M., Jr, McKay, H. G., & Boles, S. M. (1999). Social support, self-management, and quality of life among participants in an internet-based diabetes support program: a multi-dimensional investigation. *Cyberpsychology & Behavior*, 2(4), 271-281.
- Glattacker, M., Opitz, U., & Jäckel, W. H. (2010). Illness representations in women with fibromyalgia. *British Journal of Health Psychology*, 15(2), 367-387. doi:10.1348/135910709X466315
- Goldberg, D. P., & Hillier, V. F. (1979). A scaled version of the General Health Questionnaire. *Psychological Medicine*, 9(1), 139-145.
- Goldberg, D. (1972). *The detection of psychiatric illness by questionnaire*. London, Oxford University Press.
- Gomborone, J., Dewsnap, P., Libby, G., & Farthing, M. (1995). Abnormal illness attitudes in patients with irritable bowel syndrome. *Journal of Psychosomatic Research*, 39(2), 227-230.
- Gomborone, J. E., Dewsnap, P. A., Libby, G. W., & Farthing, M. J. (1993). Selective affective biasing in recognition memory in the irritable bowel syndrome. *Gut*, 34(9), 1230-1233. doi:10.1136/gut.34.9.1230
- Gonsalkorale, W. M., Miller, V., Afzal, A., & Whorwell, P J. (2003). Long term benefits of hypnotherapy for irritable bowel syndrome. *Gut*, 52(11), 1623-1629.
- Goodman, D., Morrissey, S., Graham, D., & Bossingham, D. (2005). Illness representations of systemic lupus erythematosus. *Qualitative Health Research*, 15(5), 606-619. doi:10.1177/1049732305275167
- Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *The American Psychologist*, 59(2), 93-104. doi:10.1037/0003-066X.59.2.93
- Graham, A. L., & Papandonatos, G. D. (2008). Reliability of internet-versus telephone-administered questionnaires in a diverse sample of smokers. *Journal of Medical Internet Research*, 10(1), e8. doi:10.2196/jmir.987
- Gray, S., & Rutter, D. (2007). Illness representations in young people with chronic fatigue syndrome. *Psychology & Health*, 22(2), 159-174.

Guthrie, E., & Thompson, D. (2002). Abdominal pain and functional gastrointestinal disorders. *British Medical Journal*, *325*(7366), 701-703.

Hagger, M. S., Chatzisarantis, N. L. D., Griffin, M., & Thatcher, J. (2005). Injury representations, coping, emotions, and functional outcomes in athletes with sports related injuries: A test of self regulation theory. *Journal of Applied Social Psychology*, *35*(11), 2345-2374. doi:10.1111/j.1559-1816.2005.tb02106.x

Hagger, M.S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, *18*(2), 141-184.

Hagger, M.S., & Orbell, S. (2005). A confirmatory factor analysis of the revised illness perception questionnaire (IPQ-R) in a cervical screening context. *Psychology & Health*, *20*(2), 161-173.

Hahn, B. A., Kirchdoerfer, L. J., Fullerton, S., & Mayer, E. (1997). Patient-perceived severity of irritable bowel syndrome in relation to symptoms, health resource utilization and quality of life. *Alimentary Pharmacology & Therapeutics*, *11*(3), 553-559.

Halder, S. L. S., Locke, G. R., 3rd, Talley, N. J., Fett, S. L., Zinsmeister, A. R., & Melton, L. J., 3rd. (2004). Impact of functional gastrointestinal disorders on health-related quality of life: a population-based case-control study. *Alimentary Pharmacology & Therapeutics*, *19*(2), 233-242.

Hale, E. D., Treharne, G. J., & Kitas, G. D. (2007). The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology*, *46*(6), 904 -906. doi:10.1093/rheumatology/kem060

Halpert, A., & Drossman, D. (2005). Biopsychosocial issues in irritable bowel syndrome. *Journal of Clinical Gastroenterology*, *39*(8), 665-669.

Hammerle, C. W., & Surawicz, C. M. (2008). Updates on treatment of irritable bowel syndrome. *World Journal of Gastroenterology*, *14*(17), 2639-2649.

Hayee, B., & Forgacs, I. (2007). Psychological approach to managing irritable bowel syndrome. *British Medical Journal*, *334*(7603), 1105-1109. doi:10.1136/bmj.39199.679236.AE

Hayes, A. F. (2009). Beyond Baron and Kenny: statistical mediation analysis in the new millennium. *Communication Monographs*, *76*(4), 408-420. doi:10.1080/03637750903310360

Heijmans, M. J. (1998). Coping and adaptive outcome in chronic fatigue syndrome: importance of illness cognitions. *Journal of Psychosomatic Research*, *45*(1 Spec No), 39-51.



- Hillilä, M. T., & Färkkilä, M. A. (2004). Prevalence of irritable bowel syndrome according to different diagnostic criteria in a non-selected adult population. *Alimentary Pharmacology & Therapeutics*, 20(3), 339-345. doi:10.1111/j.1365-2036.2004.02034.
- Hilsden, R. J., Scott, C. M., & Verhoef, M. J. (1998). Complementary medicine use by patients with inflammatory bowel disease. *The American Journal of Gastroenterology*, 93(5), 697-701. doi:10.1111/j.1572-0241.1998.208\_a.
- Hilsden, R. J., Verhoef, M. J., Rasmussen, H., Porcino, A., & DeBruyn, J. C. C. (2011). Use of complementary and alternative medicine by patients with inflammatory bowel disease. *Inflammatory Bowel Diseases*, 17(2), 655-662. doi:10.1002/ibd.21360
- Hinchcliffe, V., & Gavin, H. (2008). Internet mediated research: a critical reflection upon the practice of using instant messenger for higher educational research interviewing. *Psychology and Society*, 1(1), 91-104.
- Hiskey, S., & Troop, N. A. (2002). Online longitudinal survey research. *Social Science Computer Review*, 20(3), 250 -259.
- Horne, R. (1997). Representation of medication and treatment. In K. Petrie & J. Weinman (Eds.) *Perceptions of health and illness*. (pp. 155-187). London: Harwood.
- Horne, R. (2001). Non-adherence to medication: Causes and implications for care. In P. Gard (ed.), *A Behavioural Approach to Pharmacy Practice* (pp. 111-129). Blackwell Science, Oxford.
- Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of Psychosomatic Research*, 47(6), 555-567.
- Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology & Health*, 17(1), 17-32.
- Horne, R., Weinman, J., & Hankins, M. (1999). The beliefs about medicines questionnaire: The development and evaluation of a new method for assessing the cognitive representation of medication. *Psychology & Health*, 14(1), 1-24.
- Hosman, C. (1983). *Psychosocial problems and help seeking. A social-psychological study for preventive mental health care*. Lisse: Swets & Zeitlinger.
- Hosmer, D. W., & Lemeshow, S. (2000). *Applied logistic regression*. John Wiley and Sons, Inc.

Hruschka, D. J., Schwartz, D., St.John, D. C., Picone-Decaro, E., Jenkins, R. A., & Carey, J. W. (2004). Reliability in coding open-ended data: lessons learned from HIV behavioral research. *Field Methods*, 16(3), 307-331. doi:10.1177/1525822X04266540

Hungin, A. P. S., Chang, L., Locke, G. R., Dennis, E. H., & Barghout, V. (2005). Irritable bowel syndrome in the United States: prevalence, symptom patterns and impact. *Alimentary Pharmacology & Therapeutics*, 21(11), 1365-1375. doi:10.1111/j.1365-2036.2005.02463.x

Hussain, Z., & Quigley, E. M. M. (2006). Systematic review: Complementary and alternative medicine in the irritable bowel syndrome. *Alimentary Pharmacology & Therapeutics*, 23(4), 465-471.

Hyland, M. E., Lewith, G. T., & Westoby, C. (2003). Developing a measure of attitudes: the holistic complementary and alternative medicine questionnaire. *Complementary Therapies in Medicine*, 11(1), 33-38.

Hyland, M. E. (2003). Using the placebo response in clinical practice. *Clinical Medicine (London, England)*, 3(4), 347-350.

Ilnyckyj, A., Graff, L. A., Blanchard, J. F., & Bernstein, C. N. (2003). Therapeutic value of a gastroenterology consultation in irritable bowel syndrome. *Alimentary Pharmacology & Therapeutics*, 17(7), 871-880.

Im, E. O., Lee, S. H., Liu, Y., Lim, H.-J., Guevara, E., & Chee, W. (2009). A national online forum on ethnic differences in cancer pain experience. *Nursing research*, 58(2), 86-94. doi:10.1097/NNR.0b013e31818fcea4

Data protection Act 1998. Retrieved from, <http://www.legislation.gov.uk/ukpga/1998/29/contents>

Internet World Stats. (n.d.). *Internet World Stats. European Union*. Retrieved July 31, 2011, from <http://www.internetworldstats.com/stats9.htm>

Jarrett, M. E., Cain, K. C., Burr, R. L., Hertig, V. L., Rosen, S. N., & Heitkemper, M. M. (2009). Comprehensive self-management for irritable bowel syndrome: randomized trial of in-person vs. combined in-person and telephone sessions. *The American Journal of Gastroenterology*, 104(12), 3004-3014. doi:10.1038/ajg.2009.479

Jones, J., Boorman, J., Cann, P., Forbes, A., Gomborone, J., Heaton, K., Hungin, P., et al. (2000). British Society of Gastroenterology guidelines for the management of the irritable bowel syndrome. *Gut*, 47 (S2), ii1-19.

Jones, J. F., Maloney, E. M., Boneva, R. S., Jones, A.-B., & Reeves, W. C. (2007). Complementary and alternative medical therapy utilization by people with chronic fatiguing illnesses in the United States. *BMC Complementary and Alternative Medicine*, 7, 12. doi:10.1186/1472-6882-7-12

Jones, M. P., Bratten, J., & Keefer, L. (2007). Quality of life in patients with inflammatory bowel disease and irritable bowel syndrome differs between subjects recruited from clinic or the internet. *The American Journal of Gastroenterology*, 102(10), 2232-2237. doi:10.1111/j.1572-0241.2007.01444.x

Jones, R., & Lydeard, S. (1992). Irritable bowel syndrome in the general population. *British Medical Journal*, 304(6819), 87 -90.

Kaptchuk, T. J. (2002). The placebo effect in alternative medicine: can the performance of a healing ritual have clinical significance? *Annals of Internal Medicine*, 136(11), 817-825.

Kaptein, A. A., Bijsterbosch, J., Scharloo, M., Hampson, S. E., Kroon, H. M., & Kloppenburg, M. (2010). Using the common sense model of illness perceptions to examine osteoarthritis change: a 6-year longitudinal study. *Health Psychology*, 29(1), 56-64. doi:10.1037/a0017787

Kaptein, A. A., Helder, D. I., Scharloo, M., Van Kempen, G. M. J., Weinman, J., Van Houwelingen, H. J. C., & Roos, R. A. C. (2006). Illness perceptions and coping explain well-being in patients with Huntington's disease. *Psychology & Health*, 21(4), 431-446.

Keeter, S., Kennamer, J. D., Ellis, J., & Green, R. (2002). Does the use of colored paper improve response rate to mail surveys? *Journal of Social Service Research*, 28(1), 69-78. doi:10.1300/J079v28n01\_04

Kelner, M., & Wellman, B. (1997). Who seeks alternative health care? A profile of the users of five modes of treatment. *Journal of Alternative and Complementary Medicine*, 3(2), 127-140.

Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: do illness representations play a role? *The British Journal of Clinical Psychology*, 38(1), 43-58.

Kline, P. (1999). *Handbook of Psychological Testing* (2nd ed.). London, Routledge.

Koloski, N. A., Talley, N. J., & Boyce, P. M. (2001). Predictors of health care seeking for irritable bowel syndrome and nonulcer dyspepsia: a critical review of the literature on symptom and psychosocial factors. *The American Journal of Gastroenterology*, 96(5), 1340-1349. doi:10.1111/j.1572-0241.2001.03789.x

- Koloski, N. A., Talley, N. J., Huskic, S. S., & Boyce, P. M. (2003). Predictors of conventional and alternative health care seeking for irritable bowel syndrome and functional dyspepsia. *Alimentary Pharmacology & Therapeutics*, 17(6), 841-851.
- Kong, S. C., Hurlstone, D. P., Pocock, C. Y., Walkington, L. A., Farquharson, N. R., Bramble, M. G., McAlindon, M. E., et al. (2005). The Incidence of self-prescribed oral complementary and alternative medicine use by patients with gastrointestinal diseases. *Journal of Clinical Gastroenterology*, 39(2), 138-141.
- Lackner, J. M., Jaccard, J., Krasner, S. S., Katz, L. A., Gudleski, G. D., & Blanchard, E. B. (2007). How does cognitive behavior therapy for irritable bowel syndrome work? A mediational analysis of a randomized clinical trial. *Gastroenterology*, 133(2), 433-444.
- Lackner, J. M., Mesmer, C., Morley, S., Dowzer, C., & Hamilton, S. (2004). Psychological treatments for irritable bowel syndrome: a systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology*, 72(6), 1100-1113. doi:10.1037/0022-006X.72.6.1100
- Lackner, J. M., Quigley, B. M., & Blanchard, E. B. (2004). Depression and abdominal pain in IBS patients: the mediating role of catastrophizing. *Psychosomatic Medicine*, 66(3), 435-441.
- Lacy, B. E., Weiser, K., Noddin, L., Robertson, D. J., Crowell, M. D., Parratt-Engstrom, C., & Grau, M. V. (2007). Irritable bowel syndrome: patients' attitudes, concerns and level of knowledge. *Alimentary Pharmacology & Therapeutics*, 25(11), 1329-1341. doi:10.1111/j.1365-2036.2007.03328.
- Lahmann, C., Röhrich, F., Sauer, N., Noll-Hussong, M., Ronel, J., Henrich, G., von Arnim, A., et al. (2010). Functional relaxation as complementary therapy in irritable bowel syndrome: a randomized, controlled clinical trial. *Journal of Alternative and Complementary Medicine*, 16(1), 47-52. doi:10.1089/acm.2009.0084
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33(1), 159-174.
- Langmead, L., Chitnis, M., & Rampton, D. S. (2002). Use of complementary therapies by patients with IBD may indicate psychosocial distress. *Inflammatory Bowel Diseases*, 8(3), 174-179.
- Larsen, P. D., & Hummel, F. (2008). Adaptation. In Larsen P.D. & Lubkin I.M. (Eds.). *Chronic illness impact and interventions* (8th ed., pp. 6-84). Boston: Jones and Bartlett.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Co Inc. New York.

- Lea, R., & Whorwell, P. J. (2001). Quality of life in irritable bowel syndrome. *PharmacoEconomics*, *19*(6), 643-653.
- Lea, R., & Whorwell, P. J. (2004). Psychological influences on the irritable bowel syndrome. *Minerva Medica*, *95*(5), 443-450.
- Lea, R., & Whorwell, P. J. (2003). New insights into the psychosocial aspects of irritable bowel syndrome. *Current Gastroenterology Reports*, *5*(4), 343-350.
- Lee, B. O., Chaboyer, W., & Wallis, M. (2010). Illness representations in patients with traumatic injury: a longitudinal study. *Journal of Clinical Nursing*, *19*(3-4), 556-563. doi:10.1111/j.1365-2702.2009.02972.x
- Lerman, J. (1996). Study design in clinical research: sample size estimation and power analysis. *Canadian Journal of Anaesthesia*, *43*(2), 184-191. doi:10.1007/BF03011261
- Lesbros-Pantoflickova, D., Michetti, P., Fried, M., Beglinger, C., & Blum, A. L. (2004). Meta-analysis: The treatment of irritable bowel syndrome. *Alimentary Pharmacology & Therapeutics*, *20*(11-12), 1253-1269. doi:10.1111/j.1365-2036.2004.02267.x
- Leung, V. W. Y., Shalansky, S. J., Lo, M. K., & Jadusingh, E. A. (2009). Prevalence of use and the risk of adverse effects associated with complementary and alternative medicine in a cohort of patients receiving warfarin. *The Annals of Pharmacotherapy*, *43*(5), 875-881. doi:10.1345/aph.1L631
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K.J. Petrie & J.A. Weinman (Eds.), *Perceptions of health and illness* (pp. 19-45). Amsterdam: Harwood Academic Publishers.
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In L. D. Cameron, & H. Leventhal, (Eds.). *The self-regulation of health and illness behaviour* (pp. 42-65). London, Routledge.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, *16*(2), 143-163.
- Leventhal, H., Leventhal, E. A., & Contrada, R. J. (1998). Self-regulation, health, and behavior: A perceptual-cognitive approach. *Psychology & Health*, *13*(4), 717.

- Leventhal, H., Musumeci, T. J., & Contrada, R. J. (2007). Current issues and new directions in Psychology and Health: Theory, translation, and evidence-based practice. *Psychology and Health, 22*(4), 381-386. doi:10.1080/03932720601160476
- Leventhal, H., Weinman, J., Leventhal, E. A., & Phillips, L. A. (2008). Health Psychology: The Search for Pathways between Behavior and Health. *Annual Review of Psychology, 59*(1), 477-505.
- Levy, R. L., Jones, K. R., Whitehead, W. E., Feld, S. I., Talley, N. J., & Corey, L. A. (2001). Irritable bowel syndrome in twins: heredity and social learning both contribute to etiology. *Gastroenterology, 121*(4), 799-804.
- Lewith, G. T., Hyland, M. E., & Shaw, S. (2002). Do attitudes toward and beliefs about complementary medicine affect treatment outcomes? *American Journal of Public Health, 92*(10), 1604-1606.
- Lingard, L., Albert, M., & Levinson, W. (2008). Grounded theory, mixed methods, and action research. *British Medical Journal, 337*, a567.
- Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K., et al. (2001). Preferences of patients for patient centred approach to consultation in primary care: observational study. *British Medical Journal, 322*(7284), 468. doi:10.1136/bmj.322.7284.468
- Llewellyn, C. D., McGurk, M., & Weinman, J. (2007). Illness and treatment beliefs in head and neck cancer: is Leventhal's common sense model a useful framework for determining changes in outcomes over time? *Journal of Psychosomatic Research, 63*(1), 17-26. doi:10.1016/j.jpsychores.2007.01.013
- Llewellyn, C., Miners, A., Lee, C., Harrington, C., & Weinman, J. (2003). The illness perceptions and treatment beliefs of individuals with severe haemophilia and their role in adherence to home treatment. *Psychology & Health, 18*(2), 185-200.
- Luscombe, F. A. (2000). Health-related quality of life and psychosocial factors in irritable bowel syndrome: a review. *Quality of Life Research, 9*(2), 161-176.
- Madden, M. (2006). *Internet penetration and impact*. Washington DC: Pew Internet & American Life Project. Retrieved 15 July 2008 from, [http://www.pewinternet.org/~media/Files/Reports/2006/PIP\\_Internet\\_Impact.pdf.pdf](http://www.pewinternet.org/~media/Files/Reports/2006/PIP_Internet_Impact.pdf.pdf)
- Manning, A. P., Thompson, W. G., Heaton, K. W., & Morris, A. F. (1978). Towards positive diagnosis of the irritable bowel. *British Medical Journal, 2*(6138), 653-654.

Marks, D. F., Murray, M. P., Evans, B., Willig, C., Sykes, C. M., & Woodall, C. (2005). *Health Psychology: Theory, Research and Practice* (Second Edition.). Sage Publications Ltd.

Mayberry, M. K., & Mayberry, J. F. (1993). An information booklet for employers on inflammatory bowel disease: an evaluation by patients. *Journal of the Royal Society of Medicine*, 86(9), 530-532.

McAndrew, L. M., Musumeci - Szabó, T. J., Mora, P. A., Vileikyte, L., Burns, E., Halm, E. A., Leventhal, E. A., et al. (2008). Using the common sense model to design interventions for the prevention and management of chronic illness threats: From description to process. *British Journal of Health Psychology*, 13(2), 195-204. doi:10.1348/135910708X295604

McColl, E., Jacoby, A., Thomas, L., Soutter, J., Bamford, C., Steen, N., Thomas, R., et al. (2001). Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment*, 5(31), 1-256.

McMullan, M. (2006). Patients using the Internet to obtain health information: how this affects the patient-health professional relationship. *Patient Education and Counseling*, 63(1-2), 24-28. doi:10.1016/j.pec.2005.10.006

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: the example of hypertension. *Health Psychology*, 4(2), 115-135.

Moss-Morris, R, McAlpine, L., Didsbury, L. P., & Spence, M. J. (2010). A randomized controlled trial of a cognitive behavioural therapy-based self-management intervention for irritable bowel syndrome in primary care. *Psychological Medicine*, 40(1), 85-94. doi:10.1017/S0033291709990195

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health*, 17(1), 1-16.

Mulak, A., & Bonaz, B. (2004). Irritable bowel syndrome: a model of the brain-gut interactions. *Medical Science Monitor*, 10(4), RA55-62.

Nahin, R. L., Dahlhamer, J. M., Taylor, B. L., Barnes, P. M., Stussman, B. J., Simile, C. M., Blackman, M. R., et al. (2007). Health behaviors and risk factors in those who use complementary and alternative medicine. *BMC Public Health*, 7, 217-217. doi:10.1186/1471-2458-7-217

Naliboff, B. D., Balice, G., & Mayer, E. A. (1998). Psychosocial moderators of quality of life in irritable bowel syndrome. *The European Journal of Surgery. Supplement*, (583), 57-59.

National Institute of Clinical Excellence. (2008). Irritable bowel syndrome in adults (CG61). Diagnosis and management of irritable bowel syndrome in primary care. London: National Institute for Health and Clinical Excellence.

Nefzger, M. D., & Drasgow, J. (1957). The needless assumption of normality in Pearson's  $r$ . *American Psychologist*, 12(10), 623-625. doi:10.1037/h0048216

Nyrop, K. A., Palsson, O. S., Levy, R. L., Korff, M. V., Feld, A. D., Turner, M. J., & Whitehead, W. E. (2007). Costs of health care for irritable bowel syndrome, chronic constipation, functional diarrhoea and functional abdominal pain. *Alimentary Pharmacology & Therapeutics*, 26(2), 237-248. doi:10.1111/j.1365-2036.2007.03370.x

O'Cathain, A., & Thomas, K. J. (2004). "Any other comments?" Open questions on questionnaires - a bane or a bonus to research? *BMC Medical Research Methodology*, 4, 25. doi:10.1186/1471-2288-4-25

Oerlemans, S., van Cranenburgh, O., Herremans, P. J., Spreeuwenberg, P., & van Dulmen, S. (2010). Intervening on cognitions and behavior in irritable bowel syndrome: A feasibility trial using PDAs. *Journal of Psychosomatic Research*, 70(3), 267-77

Office for National Statistics. (2010). *Internet Access 2010: Households and Individuals*. Statistical Bulletin. Retrieved 15 August 2011 from, <http://www.statistics.gov.uk/pdfdir/iahi0810.pdf>

Office for National Statistics, & Williams, M. (ed). (2011). *Internet Access (quarterly update)*. Retrieved 15 August 2011 from, <http://www.statistics.gov.uk/articles/nojournal/internet-access-q1-2011.pdf>

Office of Communications. (2007). *Communications Market Special Report: Ethnic minority groups and communications services*. Retrieved 11 July 2010 from, [http://stakeholders.ofcom.org.uk/binaries/research/cmr/ethnic\\_grps.pdf](http://stakeholders.ofcom.org.uk/binaries/research/cmr/ethnic_grps.pdf)

Olsson, B., Olsson, B., & Tibblin, G. (1989). Effect of patients' expectations on recovery from acute tonsillitis. *Family Practice*, 6(3), 188-192.

Oppenheim, A. N. (1992). *Questionnaire design, interviewing and attitude measurement* (2nd ed.). London UK: Continuum International Publishing.

Orbell, S., Hagger, M., Brown, V., & Tidy, J. (2006). Comparing two theories of health behavior: a prospective study of noncompletion of treatment following cervical cancer screening. *Health Psychology*, 25(5), 604-615. doi:10.1037/0278-6133.25.5.604



- Palsson, O S. (2002). *Irritable bowel syndrome and quality of life*. Digest, Newsletter of the UNC Center for Functional GI and Motility Disorders (pp. 8-11).
- Patrick, D. L., Drossman, D. A., Frederick, I. O., DiCesare, J., & Puder, K. L. (1998). Quality of life in persons with irritable bowel syndrome: development and validation of a new measure. *Digestive Diseases and Sciences*, 43(2), 400-411.
- Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science*, 8(3), 162 -166.
- Petrie, K. J., Broadbent, E., & Meechan, G. (2003). Self-regulatory interventions for improving the management of chronic illness. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 257-227). London: Routledge.
- Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, 6(6), 536-539.
- Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosomatic Medicine*, 64(4), 580-586.
- Polgar, S., & Thomas, S. A. (1995). *Introduction to research in the health sciences*. New York: Churchill Livingstone.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 320(7227), 114-116.
- Posserud, I., Ersryd, A., & Simrén, M. (2006). Functional findings in irritable bowel syndrome. *World Journal of Gastroenterology*, 12(18), 2830-2838.
- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers*, 36(4), 717-731.
- Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, 40(3), 879-891.
- Puleo, E., Zapka, J., White, M. J., Mouchawar, J., Somkin, C., & Taplin, S. (2002). Caffeine, cajoling, and other strategies to maximize clinician survey response rates. *Evaluation & the Health Professions*, 25(2), 169-184.

- Quigley, E. M. M. (2006). Changing face of irritable bowel syndrome. *World Journal of Gastroenterology: WJG*, 12(1), 1-5.
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16(2), 234-243. doi:10.1111/j.1365-2702.2006.01573
- Ring, L., Höfer, S., Heuston, F., Harris, D., & O'Boyle, C. A. (2005). Response shift masks the treatment impact on patient reported outcomes (PROs): the example of individual quality of life in edentulous patients. *Health and Quality of Life Outcomes*, 3, 55. doi:10.1186/1477-7525-3-55
- Ringström, G., Störsrud, S., Lundqvist, S., Westman, B., & Simrén, M. (2009). Development of an educational intervention for patients with Irritable Bowel Syndrome (IBS): a pilot study. *BMC Gastroenterology*, 9, 10. doi:10.1186/1471-230X-9-10
- Ringström, G., Störsrud, S., Posserud, I., Lundqvist, S., Westman, B., & Simrén, M. (2010). Structured patient education is superior to written information in the management of patients with irritable bowel syndrome: a randomized controlled study. *European Journal of Gastroenterology & Hepatology*, 22(4), 420-428. doi:10.1097/MEG.0b013e32833333b61
- Ritter, P., Lorig, K., Laurent, D., & Matthews, K. (2004). Internet versus mailed questionnaires: a randomized comparison. *Journal of Medical Internet Research*, 6(3), e29. doi:10.2196/jmir.6.3.e29
- Robertson, L. M., Douglas, F., Ludbrook, A., Reid, G., & van Teijlingen, E. (2008). What works with men? A systematic review of health promoting interventions targeting men. *BMC Health Services Research*, 8, 141. doi:10.1186/1472-6963-8-141
- Robinson, A., Lee, V., Kennedy, A., Middleton, L., Rogers, A., Thompson, D. G., & Reeves, D. (2006). A randomised controlled trial of self-help interventions in patients with a primary care diagnosis of irritable bowel syndrome. *Gut*, 55(5), 643-648. doi:10.1136/gut.2004.062901
- Robinson, P. H., & Serfaty, M. A. (2001). The use of e-mail in the identification of bulimia nervosa and its treatment. *European Eating Disorders Review*, 9(3), 182-193. doi:10.1002/erv.411
- Robinson, P., & Serfaty, M. (2003). Computers, e-mail and therapy in eating disorders. *European Eating Disorders Review*, 11(3), 210-221. doi:10.1002/erv.516
- Rodríguez, C. F., & Fernández, N. A. (2003). Quality of life in patients with irritable bowel syndrome. *Psychology in Spain*, 7(1), 66-76.

Rutter, C. L., & Rutter, D. R. (2007). Longitudinal analysis of the illness representation model in patients with irritable bowel syndrome (IBS). *Journal of Health Psychology, 12*(1), 141-148. doi:10.1177/1359105307071748

Rutter, C. L., & Rutter, D. R. (2002). Illness representation, coping and outcome in irritable bowel syndrome (IBS). *British Journal of Health Psychology, 7*(4), 377-391. doi:10.1348/135910702320645372

Saito, Y. A., Schoenfeld, P., & Locke, G Richard, 3rd. (2002). The epidemiology of irritable bowel syndrome in North America: a systematic review. *The American Journal of Gastroenterology, 97*(8), 1910-1915. doi:10.1111/j.1572-0241.2002.05913.x

Sapsford, R. (1999). *Survey research*. London: SAGE.

Sawilowsky, S. S., & Blair, R. C. (1992). A more realistic look at the robustness and Type II error properties of the t test to departures from population normality. *Psychological Bulletin, 111*(2), 352-360. doi:10.1037/0033-2909.111.2.352

Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N., Bergman, W., & Rooijmans, H. G. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research, 44*(5), 573-585.

Scheier, M. F., & Carver, C S. (2003). Self-regulatory processes and responses to health threats: Effects of optimism on well-being. In J. Suls & K. Wallston (Eds.). *Social psychological foundations of health* (pp. 395-428). Oxford UK: Blackwell.

Schwartz, C. E., & Sprangers, M. A. (1999). Methodological approaches for assessing response shift in longitudinal health-related quality-of-life research. *Social Science & Medicine (1982), 48*(11), 1531-1548.

Schwarzer, R., & Schwarzer, C. (1996). A critical survey of coping instruments. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research and applications* (pp. 107-132). New York: Wiley.

Scott, C. M., Verhoef, M J, & Hilsden, R J. (2003). Inflammatory bowel disease patients' decisions to use complementary therapies: links to existing models of care. *Complementary Therapies in Medicine, 11*(1), 22-27.

Scott, W. G., Scott, H. M., & Auld, T. S. (2005). Consumer access to health information on the internet: health policy implications. *Australia and New Zealand Health Policy, 2*, 13. doi:10.1186/1743-8462-2-13

Searle, A., & Murphy, S. (2000). Representations of illness: their relationship with an understanding of and adherence to homoeopathic treatment. *Psychology, Health and Medicine*, 5(2), 179-191.

Searle, A., Norman, P., Thompson, R., & Vedhara, K. (2007). A prospective examination of illness beliefs and coping in patients with type 2 diabetes. *British Journal of Health Psychology*, 12(4), 621-638. doi:10.1348/135910706X164935

Serra, J., Azpiroz, F., & Malagelada, J. R. (2001). Impaired transit and tolerance of intestinal gas in the irritable bowel syndrome. *Gut*, 48(1), 14-19.

Shane-McWhorter, L., & Geil, P. (2002). Interactions between complementary therapies or nutrition supplements and conventional medications. *Diabetes Spectrum*, 15(4), 262 -266. doi:10.2337/diaspect.15.4.262

Shaw, G., Srivastava, E. D., Sadlier, M., Swann, P., James, J. Y., & Rhodes, J. (1991). Stress management for irritable bowel syndrome: a controlled trial. *Digestion*, 50(1), 36-42.

Shrout, P., & Bolger, N. (2002). Mediation in experimental and nonexperimental studies: New procedures and recommendations. *Psychological Methods*, 7(4), 422-445.

Smart, H. L., Mayberry, J. F., & Atkinson, M. (1986). Alternative medicine consultations and remedies in patients with the irritable bowel syndrome. *Gut*, 27(7), 826-828.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.). *Qualitative Health Psychology: Theories and Methods* (pp. 218–240). London: Sage Publications.

Snelling, N. (2006). Do any treatments work for irritable bowel syndrome? *International Journal of Osteopathic Medicine*, 9(4), 137-142. doi:10.1016/j.ijosm.2006.11.001

Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. *Sociological Methodology*, 13, 290-312. doi:10.2307/270723

Sperber, A. D., Shvartzman, P., Friger, M., & Fich, A. (2007). A comparative reappraisal of the Rome II and Rome III diagnostic criteria: are we getting closer to the “true” prevalence of irritable bowel syndrome? *European Journal of Gastroenterology & Hepatology*, 19(6), 441-447. doi:10.1097/MEG.0b013e32801140e2

Spiegel, B. M. R., Gralnek, I. M., Bolus, R., Chang, Lin, Dulai, G. S., Mayer, Emeran A, & Naliboff, B. (2004). Clinical determinants of health-related quality of life in patients with irritable bowel syndrome. *Archives of Internal Medicine*, 164(16), 1773-1780. doi:10.1001/archinte.164.16.1773

Suarez, T., & Reese, F. L. (2000). Coping, psychological adjustment, and complementary and alternative medicine use in persons living with HIV and AIDS. *Psychology & Health*, 15(5), 635.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using Multivariate Statistics* (5th ed.). Pearson Education.

Talley, N. J. (2008). Functional gastrointestinal disorders as a public health problem. *Neurogastroenterology and Motility*, 20 Suppl 1, 121-129. doi:10.1111/j.1365-2982.2008.01097

Talley, N. J., Boyce, P. M., & Jones, M. (1997). Predictors of health care seeking for irritable bowel syndrome: a population based study. *Gut*, 41(3), 394-398.

Talley, N., Boyce, P., & Jones, M. (1998). Identification of distinct upper and lower gastrointestinal symptom groupings in an urban population. *Gut*, 42(5), 690-695.

Testerman, J. K., Morton, K. R., Mason, R. A., & Ronan, A. M. (2004). Patient motivations for using complementary and alternative medicine. *Complementary Health Practice Review*, 9(2), 81 -92.

Thomas, K. B. (1987). General practice consultations: is there any point in being positive? *British Medical Journal*, 294(6581), 1200-1202.

Thomas, K. J., Coleman, P., & Nicholl, J. P. (2003). Trends in access to complementary or alternative medicines via primary care in England: 1995-2001 results from a follow-up national survey. *Family Practice*, 20(5), 575-577.

Thomas, K. J., Nicholl, J. P., & Coleman, P. (2001). Use and expenditure on complementary medicine in England: a population based survey. *Complementary Therapies in Medicine*, 9(1), 2-11. doi:10.1054/ctim.2000.0407

Thomas, M. A., Sadlier, M. J., & Smith, A. P. (2008). A multiconvergent approach to the rehabilitation of patients with chronic fatigue syndrome: a comparative study. *Physiotherapy*, 94(1), 35-42. doi:16/j.physio.2007.04.013

Thompson, W. G., Heaton, K. W., Smyth, G. T., & Smyth, C. (2000). Irritable bowel syndrome in general practice: prevalence, characteristics, and referral. *Gut*, 46(1), 78-82.

Tindle, H. A., Davis, R. B., Phillips, R. S., & Eisenberg, D. M. (2005). Trends in use of complementary and alternative medicine by US adults: 1997-2002. *Alternative Therapies in Health and Medicine*, 11(1), 42-49.

Treharne, G. J., Lyons, A. C., Hale, E. D., Goodchild, C. E., Booth, D. A., & Kitas, G. D. (2008). Predictors of fatigue over 1 year among people with rheumatoid arthritis. *Psychology, Health & Medicine*, 13(4), 494-504. doi:10.1080/13548500701796931

Vallejo, M. A., Jordán, C. M., Díaz, M. I., Comeche, M. I., & Ortega, J. (2007). Psychological assessment via the internet: a reliability and validity study of online (vs paper-and-pencil) versions of the General Health Questionnaire-28 (GHQ-28) and the Symptoms Check-List-90-Revised (SCL-90-R). *Journal of Medical Internet Research*, 9(1), e2. doi:10.2196/jmir.9.1.e2

van der Horst, H. E., van Dulmen, A. M., Schellevis, F. G., van Eijk, J. T., Fennis, J. F., & Bleijenberg, G. (1997). Do patients with irritable bowel syndrome in primary care really differ from outpatients with irritable bowel syndrome? *Gut*, 41(5), 669-674.

van Dulmen, A. M., Fennis, J. F., Mokkink, H. G., & Bleijenberg, G. (1996). The relationship between complaint-related cognitions in referred patients with irritable bowel syndrome and subsequent health care seeking behaviour in primary care. *Family Practice*, 13(1), 12-17.

van Dulmen, A. M., Fennis, J. F., Mokkink, H. G., van der Velden, H. G., & Bleijenberg, G. (1994). Doctors' perception of patients' cognitions and complaints in irritable bowel syndrome at an out-patient clinic. *Journal of Psychosomatic Research*, 38(6), 581-590.

van Dulmen, A. M., Fennis, J. F., Mokkink, H. G., van der Velden, H. G., & Bleijenberg, G. (1997). Persisting improvement in complaint-related cognitions initiated during medical consultations in functional abdominal complaints. *Psychological Medicine*, 27(3), 725-729.

van Dulmen, A. M., Fennis, J. F. M., & Bleijenberg, G. (1998). Towards effective reassurance in irritable bowel syndrome: The importance of attending to patients' complaint-related cognitions. *Psychology, Health & Medicine*, 3(4), 405.

van Tilburg, M. A. L., Palsson, O. S., Levy, R. L., Feld, A. D., Turner, M. J., Drossman, D. A., & Whitehead, W. E. (2008). Complementary and alternative medicine use and cost in functional bowel disorders: a six month prospective study in a large HMO. *BMC Complementary and Alternative Medicine*, 8, 46. doi:10.1186/1472-6882-8-46

Verhoef, M. J., Sutherland, L. R., & Brkich, L. (1990). Use of alternative medicine by patients attending a gastroenterology clinic. *Canadian Medical Association Journal*, 142(2), 121-125.

Vickers, A. (2005). Parametric versus non-parametric statistics in the analysis of randomized trials with non-normally distributed data. *BMC Medical Research Methodology*, 5(1), 35. doi:10.1186/1471-2288-5-35

Vincent, C., & Furnham, A. (1996). Why do patients turn to complementary medicine? An empirical study. *The British Journal of Clinical Psychology*, 35 (1), 37-48.

Vincent, C, Furnham, A, & Willsmore, M. (1995). The perceived efficacy of complementary and orthodox medicine in complementary and general practice patients. *Health Education Research*, 10(4), 395-405.

Vincent, C., & Furnham, A. (1997). *Complementary medicine: a research perspective*. John Wiley and Sons, Chichester.

Wagner, P. J., Jester, D., LeClair, B., Taylor, A. T., Woodward, L., & Lambert, J. (1999). Taking the edge off: why patients choose St. John's Wort. *The Journal of Family Practice*, 48(8), 615-619.

Ware, J. E., Jr, & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). Conceptual framework and item selection. *Medical Care*, 30(6), 473-483.

Watson, P. J. (2002). Psychophysiological models of pain. In Gifford, L., (Ed.). *Topical issues in pain* (3rd ed.). Falmouth: CNS Press.

Weinman, J., Petrie, K. J., Moss-morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology & Health*, 11(3), 431.

Wersch, A. V., Forshaw, M., & Cartwright, T. (2009). *Complementary Medicine and Health Psychology* (1st ed.). Open University Press, Berkshire.

Whitehead, W. E., Burnett, C. K., Cook, E. W., 3rd, & Taub, E. (1996). Impact of irritable bowel syndrome on quality of life. *Digestive Diseases and Sciences*, 41(11), 2248-2253.

Whitehead, W. E., Crowell, M. D., Robinson, J. C., Heller, B. R., & Schuster, M. M. (1992). Effects of stressful life events on bowel symptoms: subjects with irritable bowel syndrome compared with subjects without bowel dysfunction. *Gut*, 33(6), 825 -830. doi:10.1136/gut.33.6.825

Whitehead, W. E, Palsson, O., & Jones, K. R. (2002). Systematic review of the comorbidity of irritable bowel syndrome with other disorders: what are the causes and implications? *Gastroenterology*, 122(4), 1140-1156.

- Whitmarsh, A., Koutantji, M., & Sidell, K. (2003). Illness perceptions, mood and coping in predicting attendance at cardiac rehabilitation. *British Journal of Health Psychology*, 8(2), 209-221. doi:10.1348/135910703321649178
- Whorwell, P. J. (2006). Effective management of irritable bowel syndrome-the Manchester Model. *The International Journal of Clinical and Experimental Hypnosis*, 54(1), 21-26.
- Wilhelmsen, I. (2000). The role of psychosocial factors in gastrointestinal disorders. *Gut*, 47(Suppl 4), iv73-iv75. doi:10.1136/gut.47.suppl\_4.iv73
- Wilson, S., Maddison, T., Roberts, L., Greenfield, S., & Singh, S. (2006). Systematic review: the effectiveness of hypnotherapy in the management of irritable bowel syndrome. *Alimentary Pharmacology & Therapeutics*, 24(5), 769-780. doi:10.1111/j.1365-2036.2006.03028.x
- Wilson, S., Roberts, L., Roalfe, A., Bridge, P., & Singh, S. (2004). Prevalence of irritable bowel syndrome: a community survey. *The British Journal of General Practice*, 54(504), 495-502.
- Winzelberg, A. J., Classen, C., Alpers, G. W., Roberts, H., Koopman, C., Adams, R. E., Ernst, H., et al. (2003). Evaluation of an internet support group for women with primary breast cancer. *Cancer*, 97(5), 1164-1173. doi:10.1002/cncr.11174
- World Health Organization. (1997). *Composite International Diagnostic Interview (CIDI), Core Version 2.1, Interviewer's Manual*. Geneva: World Health Organization.
- Wu, R. C., Thorpe, K., Ross, H., Micevski, V., Marquez, C., & Straus, S. E. (2009). Comparing administration of questionnaires via the internet to pen-and-paper in patients with heart failure: randomized controlled trial. *Journal of Medical Internet Research*, 11(1), e3. doi:10.2196/jmir.1106
- Yadav, S. K., Jain, A. K., Tripathi, S. N., & Gupta, J. P. (1989). Irritable bowel syndrome: therapeutic evaluation of indigenous drugs. *Indian Journal of Medical Research*, 90, 496-503.
- Yale, S. H., Musana, A. K., Kieke, A., Hayes, J., Glurich, I., & Chyou, P.-H. (2008). Applying case definition criteria to irritable bowel syndrome. *Clinical Medicine & Research*, 6(1), 9-16. doi:10.3121/cm.2008.788
- Zollman, C., & Vickers, A. (1999). What is complementary medicine? *British Medical Journal*, 319(7211), 693-696.



## Appendix I: advertisement posted on the IBS Network website



### **Can you spare some time to participate in an online research study?**

Lee Usher, a PhD student at Thames Valley University<sup>6</sup>, is interested in recruiting people with Irritable Bowel Syndrome to take part in an online study about what it is like to live with IBS and the types of treatments that they have used.

If you have IBS and are over the age of 18 then your participation in the study would be most welcome.

If you can spare around 25-40 minutes to help further the understanding of these issues then you will find the study at the link below:

Click [here](#) to take the survey

*[Advert contained a direct link to the study webpage]*

If you have any questions about the research or require further information about the study you are invited to contact Lee Usher, at Thames Valley University via *[email address included]*

---

<sup>6</sup> Since the research was conducted, Thames Valley University has been re-named, the University of West London

## **Appendix II: Study information**

### **Exploring the illness and treatment beliefs of those affected by IBS that use complementary therapies**

#### **Aims of the study**

This study has been developed to discover more about the role of perceptions of illness and medication in those people affected by irritable bowel syndrome (IBS).

#### **What we hope to achieve with the study**

It is expected that if certain perceptions about illness or medication will relate to better coping and this could form the basis of a new strategies to help relieve the symptoms of IBS.

#### **How can I help?**

Your responses to the study will be of great value to the outcome and implications of the research. Your help therefore, is greatly appreciated.

#### **What do I do during the study?**

We would like you to navigate through the website answering a series of questionnaires as you go along. These will assess various aspects of your perceptions to your illness, medication as well as other aspects related to your illness such as your quality of life. The questions should take no longer than 30-40 minutes to complete and it would be really appreciated if possible, that you answered the questions when you are alone.

#### **Your rights**

It is up to you to decide if you wish to commence and take part. If you do decide to commence you are still free to withdraw from the study at any time by simply closing your internet browser window or navigating away from the study web pages, this will ensure your data is not used in the study. Although you have provided your email address to get in touch with the researcher, this is in no way connected to the responses you will give on this website. You are also advised that this information will be transmitted (via encryption) and stored securely on a computer in line with the Data Protection Act 1998. It will be treated as strictly confidential, anonymous and will only be used for research purposes.

#### **Contacts and further information**

If you are willing to participate in the study then you are free to move to the following page which will ask for confirmation of your consent. If however, you would like to discuss the project further please contact Lee Usher at Thames Valley University on (*telephone number*) or via email at [*email address included*]

I would like to take this opportunity to thank you for your participation in this study.



**Appendix III: Consent to participate and introductory survey questions**

	<b>Please click here</b>
I confirm that I have read and understood the information on the previous page and can contact the researcher should I have any questions.	Yes
I understand that my participation is voluntary and that I am free to withdraw from the study at any time.	Yes
I therefore agree to take part in the study.	Yes

**Have you been diagnosed with Irritable bowel syndrome (IBS) by a health care professional (such as your doctor or a specialist)?**

[Yes]      [No]

**If yes, how long ago were you diagnosed?**

0-6 months	
6-12 months	
12-18 months	
18 months-2 years	
2-3 years	
Over 3 years	

**If no, how long do you feel you have had symptoms of IBS?**

0-6 months	
6-12 months	
12-18 months	
18 months-2 years	
2-3 years	
Over 3 years	

## Appendix IV: The illness perceptions questionnaire revised version

Listed below are a number of symptoms that you may or may not have experienced since your IBS began. Please indicate by selecting YES or NO, whether you have experienced any of these symptoms since your IBS. Select **one** answer for each symptom listed.

	Yes, I have experienced this symptom since my IBS	No, I have not experienced this symptom since my IBS
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Sore throat	<input type="checkbox"/>	<input type="checkbox"/>
Nausea	<input type="checkbox"/>	<input type="checkbox"/>
Breathlessness	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Stiff joints	<input type="checkbox"/>	<input type="checkbox"/>
Sore eyes	<input type="checkbox"/>	<input type="checkbox"/>
Wheeziness	<input type="checkbox"/>	<input type="checkbox"/>
Headaches	<input type="checkbox"/>	<input type="checkbox"/>
Upset stomach	<input type="checkbox"/>	<input type="checkbox"/>
Sleep difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Dizziness	<input type="checkbox"/>	<input type="checkbox"/>
Loss of strength	<input type="checkbox"/>	<input type="checkbox"/>

Listed below are a number of symptoms that may or may not be related to your IBS. Please indicate by selecting YES or NO whether you believe that these symptoms are related to your IBS. Select **one** answer to indicate if you think the symptom is related to your IBS.

	Yes, this symptom is related to my IBS	No, this symptom is not related to my IBS
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Sore throat	<input type="checkbox"/>	<input type="checkbox"/>
Nausea	<input type="checkbox"/>	<input type="checkbox"/>
Breathlessness	<input type="checkbox"/>	<input type="checkbox"/>

Weight loss	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Stiff joints	<input type="checkbox"/>	<input type="checkbox"/>
Sore eyes	<input type="checkbox"/>	<input type="checkbox"/>
Wheeziness	<input type="checkbox"/>	<input type="checkbox"/>
Headaches	<input type="checkbox"/>	<input type="checkbox"/>
Upset stomach	<input type="checkbox"/>	<input type="checkbox"/>
Sleep difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Dizziness	<input type="checkbox"/>	<input type="checkbox"/>
Loss of strength	<input type="checkbox"/>	<input type="checkbox"/>

We are interested in your own personal views on how you now see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS by clicking the appropriate box.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
My IBS will last a short time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS is likely to be permanent rather than temporary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS will last a long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This IBS will pass quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I expect to have IBS for the rest of my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS is a serious condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS has major consequences on my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS does not have much effect on my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS strongly affects the way others see me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS has serious financial consequences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS causes difficulties for those that are close to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is a lot I can do to control my IBS symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What I do can determine whether my IBS gets better or worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The course of my IBS depends on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Nothing I do will affect my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have the power to influence my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My actions will have no affect on the outcome of my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS will improve in time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is very little that can be done to improve my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My treatment will be very effective in curing my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The negative effects of my IBS can be prevented (avoided) by my treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My treatment can control my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is nothing which can help my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The symptoms of my IBS are puzzling to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS is a mystery to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't understand my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS doesn't make any sense to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a clear picture or understanding of my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The symptoms of my IBS change a great deal from day to day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My symptoms come and go in cycles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS is very unpredictable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I go through cycles in which my IBS gets better and worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get depressed when I think about my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I think about my IBS I get upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS makes me feel angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS does not worry me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having IBS makes me feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My IBS makes me feel afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We are interested in what you consider may have been the cause of your IBS. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your IBS rather than what others (including Doctors or family) may have suggested to you. Below is a list of possible causes for your IBS. Please indicate how much you agree or disagree that they were causes for you by clicking the appropriate option.

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
Stress or worry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hereditary - it runs in my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A germ or virus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diet or eating habits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chance or bad luck	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor medical care in my past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pollution in the environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My own behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My mental attitude e.g. thinking about life negatively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family problems or worries caused my IBS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My emotional state e.g. feeling down, lonely, anxious, empty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ageing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accident or injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Altered immunity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the boxes below, please list in rank-order the three most important factors that you now believe caused **your IBS**. You may use any items from the statements above or you may have additional ideas of your own. The most important causes for me are:-

	The most important causes for me:
1	
2	
3	

## Appendix V: The Brief-COPE

These items deal with ways you have been coping with the stress in your life since you have had IBS. There are many ways to deal with problems - these items ask you what you have been doing to cope with this one (i.e. your IBS). We are interested in how *you* have tried to deal with it. Each item says something about a particular way of coping. We would like to know to what extent you have been doing what the item says. Please only answer as to whether you are doing it or not. Try to rate each item in your mind quickly but separately from the others. Make your answers as true for *you* as you can.

	I haven't been doing this at all	I've been doing this a little	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been concentrating my efforts on doing something about the situation I'm in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying to myself this isn't real.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to make myself feel better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting emotional support from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been giving up trying to deal with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been taking action to try to make the situation better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been refusing to believe that it has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying things to let my unpleasant feelings escape	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting help and advice from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to help me get through it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to see it in a different light, to make it seem more positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been criticizing myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to come up with a strategy about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting comfort and understanding from someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been giving up the attempt to cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been looking for something good in what is happening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making jokes about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been doing something to think about it less, such as going to the cinema, watching TV, reading, daydreaming, sleeping or shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been accepting the reality of the fact that it has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



I've been expressing my negative feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to find comfort in my religion or spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to get advice or help from other people about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been learning to live with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been thinking hard about what steps to take	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been blaming myself for things that happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been praying or meditating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making fun of the situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Appendix VI: The IBS-QOL**

The following note was included on the webpage:

The Irritable Bowel Syndrome - Quality of Life questionnaire (IBS-QOL) was developed by Donald L. Patrick Ph.D. at The University of Washington, Douglas A. Drossman, MD at The University of North Carolina, Novartis Pharmaceuticals Corporation, and Novartis Pharma AG. Authors hold joint copyright over the IBS-QOL and all its translations.

Due to the above copyright statement, this measure is omitted from the appendices in this thesis.

## Appendix VII: Questions about healthcare

We would like to ask you about your consultations with your GP or the health care professional you see most often about your IBS (not a complementary therapist).

My Doctor is:      [Male]      [Female]

**In the past 12 months, how many times have you seen your Doctor about your IBS?**

None	Once or twice	Three or four times	Five or six times	Seven or more times

**On average, how long do you spend with your Doctor? (Please enter in minutes)**

**Is the time you have with your Doctor sufficient for you? [Yes] [No]**

**Appendix VIII: The beliefs about medicines questionnaire (general version)**

We would like to ask you about your personal views about medicines in general. The statements below are what other people have made about medicines in general. Please indicate the extent to which you agree or disagree with them by clicking the appropriate box.

**There are no right or wrong answers. We are interested in your personal views.**

	Strongly Agree	Agree	Uncertain	Disagree	Strongly Disagree
Doctors use too many medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People who take medicines should stop their treatment every now and then.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Most medicines are addictive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Natural remedies are safer than medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicines do more harm than good.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All medicines are poisons.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doctors place too much trust on Medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If Doctors had more time with patients they would prescribe fewer medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you currently taking any prescribed medication for your IBS symptoms?

**[Yes]**

**[No]**

## Appendix IX: The complementary and alternative medicine beliefs inventory

The following questions all relate to beliefs about holistic health, complementary medicines and patients participation in treatment. Please decide the extent to which you agree or disagree with each statement and then click the appropriate box. Remember there are no right or wrong answers. Please answer all of the items.

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
Treatments should have no negative side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is important to me that treatments are non-toxic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatments should only use natural ingredients.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is important for treatments to boost my immune system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatments should enable my body to heal itself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatments should increase my natural ability to stay healthy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment providers should treat patients as equal partners.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients should take an active role in their treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment providers should make all the decisions about treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment providers should help patients make their own decisions about treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment providers should control what is talked about during consultations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health is about harmonizing your body, mind and spirit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imbalances in a person's life are a major cause of illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatments should concentrate only on symptoms rather than the whole person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatments should focus on peoples overall well being.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think my body has a natural ability to heal itself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is no need for treatments to be concerned with natural healing powers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Appendix X: Questions about complementary and alternative medicine use**

Do you use now, or have you ever used, any complementary therapies?

[Yes]                      [No]

*[If participants answered ‘no’ they were automatically directed to the demographic section of the survey]*

*[the previous and following questions about CAM use were only asked at study time one]*

Which of the following complementary or alternative medicines have you used to relieve your IBS? (please click the box next to the name of the treatment if you have used it at *any* point and please click *all* that apply)

Treatment	Yes/No	Treatment	Yes/No	Treatment	Yes/No
Acupuncture		Acupressure		Aromatherapy	
Chiropractic		Meditation		Herbs	
Hypnotherapy		Massage		Shiatsu	
Osteopathy		Reiki		Nutritional therapy	
Reflexology		Homeopathy		Spiritual healing	
Other (please name/describe):					

Have you been directed to take any complementary medicines by your practitioner – such as nutritional supplements or homeopathic solutions/tablets?\*

[Yes]                      [No]

Have you purchased any complementary medicines ‘off the shelf’ from a health food shop for example?\*

[Yes]                      [No]

[\* Note: If both questions were answered ‘No’, participants were automatically to the demographics section]

Have you visited a complementary practitioner for a consultation or treatment session on more than one occasion in the last 12 months?

[Yes] [No]

(If no, participants were automatically directed to demographic questions)

We would like to ask you about your consultation/treatment session with the Complementary practitioner (e.g. acupuncturist or herbalist) you see most often. In the table below please indicate how far you agree/disagree with each statement.

**My Complementary practitioner is:**

[Male] [Female]

**On average, how long do you spend with your Complementary practitioner?**

[ ] minutes

**Is the time you have with your Complementary practitioner sufficient for you?**

[Yes] [No]

**Appendix XI: Demographic information and thank you message**

**Are you:**  [Male]  Female]

**Please could you give your age** [  ]

**Which of the following is your highest educational qualification?**

Qualification	
GCSE's O'levels or equivalent	
A levels or equivalent	
First degree (e.g. BA, BSc)	
Postgraduate qualification	
No qualifications	

**Are you currently employed?**  [Yes]  [No]

**What is the total annual income for your household?**

£0 to £9,999	
£10,000 to £14,999	
£15,000 to £19,999	
£20,000 to £29,999	
£30,000 to £39,999	
£40,000 to £49,999	
£50,000 and above	

**What is your religion?**

Christian		Jewish	
Buddhist		Muslim	
Hindu		None	
Sikh		Other (please name)	



**How would you describe your ethnic group?**

<b>White:</b>		<b>Black or Black British:</b>	
British		Caribbean	
Irish		African	
Other white background		Other Black Background	
<b>Mixed:</b>		<b>Asian or Asian British:</b>	
White & Black Caribbean		Indian	
White & Black African		Pakistani	
White & Asian		Bangladeshi	
Other Mixed background		Chinese	
<b>Any other ethnic group (please list)</b>		Other Asian Background	

Do you suffer with any other medical complaints apart from your IBS? These can be listed in the boxes below.

You may use the space below to comment on anything you would like to say about having IBS

Thank you for your responses. Would you be willing to take part in a proposed follow up study?

[Yes]      [No]

*[Participants answering 'yes' were directed to the space below, if they declined, they were presented with a thank you message. This section was not included in the follow-up study]*

Thank you for offering to take part in a proposed follow up study. You can enter your email in the box below, so you can be contacted when the study takes place. (Your email address will be stored separately from your survey responses)

[*Thank you message*]

I would like to take this opportunity to sincerely thank you for taking part. Your responses will be of great value in contributing to a greater understanding of the psychological issues that accompany Irritable Bowel Syndrome.

If you have any comments about the survey (if you felt it was too long for example) you can use the email address below. [*email address included*]

There is also a possibility that a short follow up study may run later on in the year. If you would be willing to take part (and you missed submitting your email address previously) then you can also use the email below to register your willingness to participate in this follow up study.

Once again, many thanks for your time and participation.

Lee Usher, PhD student, Thames Valley University.

email: [*email address included*]

To close your browser window you can now click on the 'thank you' icon below.

## **Appendix XII: First email sent to participants regarding the follow-up study**

*[first email]*

Dear Participants,

Hopefully you all received my recent email regarding the follow up study - that is, to the one you recently took part in online.

The follow up study website address can be found below (and at the end of the email). You can click the link directly or copy it and then paste into your web browser address bar. Do have a read through the first page - it will hopefully answer any questions you may have.

**The study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

Once again, I am extremely grateful for your time and participation. And I need to thank everyone that responded to my last email (and apologise for not getting back to you all). It has been very interesting hearing about how IBS affects people on a personal level. With this in mind, do use the 'box' at the end of the study to enter any additional comments you may want to express.

I just wanted to say a final thank you - and do send me an email if you have any questions or queries.

Many thanks,

Lee Usher

Thames Valley University  
School of Human and Psychological Sciences

**The follow-up study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

## **Appendix XIII: First email reminder sent to participants regarding the follow-up study**

Dear Participants,

I wanted to thank everyone who has taken part in the follow up - thank you (you don't need to take part again) - your participation will hopefully go some way to influencing future self management programs and General Practitioner consultations for those with IBS.

For those of you that have yet been unable to take part - the study will remain open for a little longer. The more responses are collected the more can be gained from the study, so if you can spare 20 minutes or so (at any time) - do see if you can take the time to take part. Your responses are highly valued and can go a long way to improving health care in the future.

The study website address can be found below (and at the end of the email). You can click the link directly or copy it and then paste into your web browser address bar. Do have a read through the first page - it will hopefully answer any questions you may have.

**The study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

Do feel free to pass on the study link to anyone who you know took part in the first study but I have been unable to contact.

Once again, I am extremely grateful for your time and participation and do send me an email if you have any questions.

Many thanks,

Lee Usher

Thames Valley University  
School of Human and Psychological Sciences

**The follow-up study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

## **Appendix XIV: Second email reminder sent to participants regarding the follow-up study**

Dear Participants,

I wanted to thank, once again everyone who has taken part in the follow up - thank you (you don't need to take part again) and hopefully this is the last email you will receive from me (so thank you also for your patience).

If you have so far been unable to take part, were interrupted whilst doing the survey or just did not have enough time - the study will remain open for at least another 10 days. As I mentioned, the more responses that are collected, the more can be gained from the study - so if you can spare approximately 20-25 minutes - do see if you can take the time to take part. As I mentioned, your responses are highly valued and can go a long way to improving health care in the future.

The study website is below. You can click the link directly or copy it and then paste into your web browser address bar. Do have a read through the first page - it will hopefully answer any questions you may have.

**The study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

Do feel free to pass on the study link to anyone who you know took part in the first study but I have been unable to contact.

Once again, I am extremely grateful for your time, participation and interest. Do please send me an email if you have any questions.

Many thanks,

Lee Usher

Thames Valley University  
School of Human and Psychological Sciences

**The follow-up study link is here:**

**<http://www.questionpro.com/akira/TakeSurvey?id=1221704>**

## **Appendix XV: Write-up for thematic analysis of participants' open text responses**

*This provisional write up consists of a thematic analysis conducted participants' responses to the open text section of the survey reported in chapters four and five. Participants were asked if there was anything else they would like to add about their IBS at the end of the survey. Responses were collated and a theory-based top-down thematic analysis on participant text was conducted to examine for evidence of perceptions of illness according to the CSM.*

### **Introduction**

The results presented in chapter's four to six have indicated that illness perceptions are important factors in influencing specific coping behaviour and reported quality of life. Chapter four showed the benefits of adopting an extended CSM (e.g. Horne & Weinman, 2002), which incorporated treatment beliefs, in predicting CAM use (i.e. a specific coping behaviour in the context of the CSM) in those affected by IBS. Chapter four also illustrated that IPQ-R scores were typically higher in CAM-users than non-users.

Chapter five highlighted the influence of illness perceptions and, to a lesser degree, treatment beliefs, on reported quality of life. Many of the direct pathways between the components of illness perceptions and quality of life were found to be partially mediated by, for the most part, maladaptive or dysfunctional coping strategies. This finding was largely consistent across both CAM-users and non-users,

Over time, the influence of treatment beliefs on quality of life appeared to diminish (chapter six). Chapter six examined the influence of illness perceptions on reported quality of life over time and delineated relationships between illness perceptions measured at time one, and reported quality of life at time two in both CAM-users and non-users. In testing for mediation effects however, mediation was only detected in

CAM-users, with the coping strategy of behavioural disengagement being the most prominent and largely partial mediator. This may be contrasted with the findings of Rutter and Rutter (2007), who found no evidence of mediation over three time points in people affected by IBS.

The findings from chapter six in particular suggest that illness perceptions have a greater influence than treatment beliefs on quality of life in those affected by IBS in both CAM-users and non-users. Treatment beliefs may be more (directly) influential on specific coping behaviours such as adherence to conventional medication (Bishop et al., 2008) or use of CAM (chapter four).

These findings informed the rationale of this analysis to investigate evidence of illness perceptions, as specified by the CSM, in participants' text responses to the open question at the end of the online survey (section 3.1.1.2). Finding evidence of illness perceptions in participant text would further corroborate the benefit of applying the CSM to this participant group as well as providing further support for the CSM. As highlighted in chapter two, many early CSM studies derived findings from qualitative methodology (e.g. Meyer et al., 1985) and the development of the IPQ was conducted using extensive pilot work which included some qualitative investigation (Weinman et al., 1996). In the context of this provisional write up, the use of a qualitative approach represented a degree of triangulation to substantiate the importance of illness perceptions in those affected by IBS.

O'Cathain and Thomas (2004) propose guidelines for including such open questioning in quantitative research. Firstly, there should be a clear rationale for including the open question. There may be issues relevant to the study that may be missed by using existing measures. An additional open question may act as an exploratory tool to identify any further relevant issues, or in the case of this research, issues particularly relevant to individuals with IBS (i.e. illness perceptions) may be further substantiated by analysis of open text responses. Second, enough

space should be provided for participants to express their thoughts. O’Cathain and Thomas (2004) further recommend the use of demographic information in analysing such open text. Specifically, in this research a selection of CAM-users and non-users (i.e. those not using CAM) were subject to analysis.

This approach represents a ‘novel’ way of obtaining qualitative data rather than what might be considered a formal multiple-methods approach (Bowling, 2009; Casebeer & Verhoef, 1997). Although there may be concerns with the quantity and quality of such data collected via open questions on largely quantitative measures (O’Cathain & Thomas, 2004), similarities with other studies that have utilised postings on internet message boards may be drawn. Analysis of internet postings often comprises the examination of a substantial quantity of short, often concisely written messages, rather than transcriptions of interviews where the researcher has directly questioned participants (Bryman, 2008).

Studies have examined such diverse areas as concerns of cruciate ligament surgery patients (Brewer, Raalte & Cornelius, 2007), ethnic differences in cancer pain (Im et al., 2009) and those affected by IBS (Coulson, 2005) using a thematic analysis approach. This provisional write up therefore, sought to examine participants’ text responses for evidence that illness perceptions were present.

The aim of this provisional investigation was to examine participants’ text responses to the open question included in the survey (at time one) which invited participants to volunteer any information about being affected by IBS. Responses were analysed for themes that may be relevant in terms of components of illness perceptions. This was conducted to examine for evidence that illness perceptions were evident in participants’ written expression about their IBS according to the CSM (Leventhal et al., 2003). A top-down thematic analysis (Boyatzis, 1998) involving the application of illness perception components from Leventhal



et al. (1998) and revisions by Moss-Morris et al. (2002) was conducted on participant text.

**Method: *Design and materials***

From the cross-sectional study reported in chapters four and five (study time one) and the procedure outlined in section 3.4, participant responses were collected from asking an open question at the end of the online survey. At the end of the survey described in section 3.3, participants were asked an open 'question' about their IBS: 'You may use the space below to comment on anything you would like to say about having IBS'. Responses were collated alongside demographic information so it was possible to describe participants that had responded to the open question. Responses were then analysed using a theory-based top-down thematic analysis (Boyatzis, 1998).

Braun and Clarke (2006) argue that thematic analysis may be thought of as an approach that underpins much of perhaps more theory-based qualitative analysis. Thematic analysis shares, for example, the technique of coding with other more Interpretative techniques such as Interpretative Phenomenological Analysis (IPA) (e.g. Smith et al., 1999). Thematic analysis may both generate 'themes' within participant data, representing a 'bottom-up' or data-driven approach or, thematic analysis is equally able to apply pre-determined codes upon data in a 'top-down' approach whereupon multiple presences of such codes in participant data may then be classified as themes (Braun & Clarke, 2006). In considering the aims of this provisional write up, a top-down deductive approach was deemed the most suitable to examine for evidence of the components of illness perceptions, which in this context, may be considered 'themes' that were applied to participant text.

***Participants***

Responses were collected from 175 participants who had taken part in the survey (at time one). This consisted of 147 females and 28 males and represented 26.8% of the total sample of 653 participants. 159

responses came from people in the UK, nine responses from the US, two were from Canada and one response each came from participants in Denmark, France, Holland, Ireland and Spain. Approximately 66% (n=115) had used CAM to relieve their IBS with sixty participants (34%) indicating they had not used CAM. Over half of participants also felt they had been affected by IBS for over five years (n=110). The demographics in the sample of participants used in this study suggest similarities with participant data reported in chapters four and five. Participant ages were largely between 20 and 60 years.

### ***Analysis***

Participant responses were taken verbatim from the survey and analysed using thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006; Bryman, 2008).

### ***Process of coding and inter-rater reliability***

Components of illness perceptions were selected as coding categories. This namely consisted of perceptions of identity, timeline, consequences, control/cure and cause. As the IPQ-R (Moss-Morris et al., 2002) was utilised in studies at time one and time two (chapters four through to six), these codes were revised slightly to reflect the development in understanding of illness perceptions. The timeline 'theme' was expanded to incorporate both chronic and cyclical beliefs. The control component was expanded to include both treatment and personal control. In addition, the 'theme' of emotional representations was included to examine any reference to emotional distress caused by IBS. A summary of codes can be found in table 1.

The primary researcher read all participant responses and indicated initial codes, based on the components of illness perceptions illustrated in table 1. Passages of text that reflected each of the codes were consequently clustered into themes representative of components of illness perceptions.

Inter-rater agreement was tested in a similar way to a method described by Hruschka et al. (2004), where short open ended survey responses were analysed by two researchers. Approximately 20% of text was analysed by more than one researcher, and several revisions of coding was conducted until a high level of agreement was reached (Hruschka et al., 2004).

A similar approach was conducted in this study with the assistance of a senior colleague, who independently analysed 50% of participant responses using application of the codes in table 1. Once completed, inter-rater reliability amongst the codes was tested using Cohen's Kappa statistic (Cohen, 1960). The Kappa statistic adjusts for agreement by chance (Hruschka et al., 2004) and typically results in a value of between 0 (agreement, but no better than chance) to 1 (perfect agreement). Values below zero are possible, and represent a degree of disagreement (Landis & Koch, 1977).

**Table 1: Illness perception codes used in the application of Thematic Analysis of participants' text responses**

<i>Illness perceptions</i>	<i>Description</i>
Identity	Naming or labelling of IBS and recognised symptoms
Timeline	Cyclical: reference to symptoms fluctuating Chronic: reference to ongoing symptoms
Consequences	Perceived consequences of IBS
Control	Personal control: reference to self-efficacy, is the individual in control of their IBS? Treatment control: can medication control IBS?
Coherence	Perceived coherent understanding of IBS
Emotional representations	Emotional responses to IBS
Causes	Reference to perceived causal mechanisms

Coding data from each rater was entered into SPSS. Each component of illness perceptions was entered on the same data sheet, once for each rater. Data were then coded (numerically) 'yes' if the code was observed and 'no' if the code was not seen to be present in each participant's text. Data from each participant was input into SPSS. Consequently, a Kappa statistic was generated for each component of illness perceptions illustrated in table 1. Results can be found in table 2 below.

Table 2 shows inter-rater reliability was high for all components of illness perceptions. Typically figures of greater than .81 indicate almost perfect agreement between coders (Landis & Koch, 1977). These figures were therefore deemed acceptable with no further inter-rater coding required. These findings therefore indicate there was strong inter-rater agreement on the presence of illness perception components in participant open responses.

**Table 2: Kappa inter-rater reliability values from analysis of participant text responses for illness perception components**

<i>Illness perceptions</i>	<i>Kappa statistic</i>
Identity	.94***
Timeline	.91***
Consequences	.83***
Control	.80***
Coherence	.85***
Emotional representations	.88***
Causes	.95***

\*\*\*p<.001

## Results

Evidence of all seven over-arching codes as outlined in table 1, were identified from the coding process applied to all 175 responses. Responses varied in length from a single line to several lines of text. Some participants entered substantially more text, although this was less common. The numerous occurrences of each code from participant

responses were clustered into themes. The themes represented components of illness perceptions and suggested that participants do perceive their IBS in a structured way according to CSM theory (e.g. Leventhal et al., 2003) and the IPQ-R (Moss-Morris et al., 2002) and this was apparent in both CAM-users and non-users. Each theme is outlined and illustrated by verbatim quotations from participant text. A summary of themes and short illustrative quotations can be found in table 3. Quotations are coded by participant and line number and are provided verbatim. Participant responses are provided in full in appendix XVI.

**Table 3: Table of themes extracted from participant text responses (table continues on next page)**

<i>Theme</i>	<i>Description</i>	<i>Examples</i>
<b>Identity</b>	Reference to naming or labelling of IBS. Recognition of IBS symptoms	<p><i>"I have the runs all the time..."</i> Participant 43, line 37</p> <p><i>"My symptoms include frequent visits to the toilet..."</i> P46, line 2</p> <p><i>"during a really bad bout of IBS it is bloating and dhiarrae."</i> P77, line 8</p>
<b>Timeline</b>	Included two sub-categories: <b>cyclical</b> (reference to fluctuation of symptoms) and <b>chronic</b> (reference to ongoing symptoms)	<p><i>"My IBS may have large gaps inbetween flare ups"</i> P34, line 40</p> <p><i>"I feel I have had IBS since early on in childhood"</i> P35, line 38</p> <p><i>"constant abdominal pain for nearly four years..."</i> P90, line 6</p>
<b>Consequences</b>	Perceived consequences of IBS on day to day life such as finance, occupation and social activities	<p><i>"It is a dreadful condition that tries to rule your life...."</i> P9, line 42</p> <p><i>"My IBS is seriously affecting my career..."</i> P96, line 36</p> <p><i>"This has ruined my life...."</i> P107, line 50</p>
<b>Control</b>	Included two sub-categories of <b>personal control</b> (does the individual feel in control of their IBS?) and <b>treatment control</b> (can medication control IBS?)	<p><i>"I feel I've managed to control my IBS fairly successfully..."</i> P28, line 8</p> <p><i>"... accidents during the night and cannot control them..."</i> P40, line 18</p> <p><i>"...it will not stop even with my medication..."</i> P43, line 38</p> <p><i>"Some treatments only work for a short time."</i> P49, lines 17-18</p>

(Continues on next page)

**Table 3 (continued) Table of themes extracted from participant text responses**

<b>Coherence</b>	Perceived coherent understanding of IBS	<p>“...I have not been provided with enough information on IBS...” P70, line 13</p> <p>“...am really baffled ...so severely.” P136, lines 35-36</p> <p>“I knew that I could take an antispasmodic...” P14, lines 28-29</p>
<b>Emotional representations</b>	Emotional responses to IBS	<p>“...very fed up with it.” P58, line 24</p> <p>“... feel frustrated about is how my IBS comes in different forms...” P77, lines 6</p> <p>“... felt ashamed, worthless and severely depressed...” P118, lines 30-31</p>
<b>Causes</b>	Reference to perceived causal mechanisms or what might trigger an ‘episode’ of IBS	<p>“I think it is a lot to do with being nervous” P81, lines 31-32</p> <p>“I experienced a stomach virus....never came back to normal health.” P83, lines 44-45</p> <p>“stress triggers my IBS...” P118, lines 35-36</p>

### ***Illness identity***

The CSM stipulates that the component of illness identity is concerned with the labelling of symptoms and identifying symptoms as part of an illness. This was primarily reflected in participant text by knowing and identifying what the symptoms of IBS were. This was evident across both CAM-users and non-users. It was also evident that participants were affected by both constipation and diarrhoea prominent IBS. The following examples show evidence of illness identity.

P43 (Female, 50, non-user): *I have the runs all the time and the pain is just awful* (Line 37)

P39 (F 59, CAM-user): *The most annoying thing is the constipation (sometimes a week) then diorreha (sometimes 6 times in day) and the wind.* (Lines 14-15)

P77 (F 28, CAM-user): *I hate that on a daily basis I have to worry about constipation but then during a really bad bout of IBS it is bloating and dhiaarrea.* (Lines 6-8)

P140 (F 27, CAM-user): *I have noticed my IBS symptoms are worse in the days before my period starts. I suffer badly from fatigue.* (Lines 7-8)

It was also evident that participants demonstrating the theme of illness identity were aware that IBS is not limited to one symptom and may even include potentially related symptoms such as fatigue. The final two quotation examples in particular, also demonstrate evidence of an awareness of the cyclical timeline of symptoms.

### ***Timeline (cyclical and chronic)***

Both timeline dimensions were observed in participant text. Many participants remarked solely on the symptoms following a cycle or periods where they are more intense.



P170 (M 33, CAM-user): *the symptoms seem to follow a cycle....* (Line 6)

P34 (F29, CAM-user): *My IBS symptoms may have large gaps in between flare ups.* (Line 40)

Many participants had been affected by IBS symptoms for a number of years and seemed to be able to be precise as to how long ago symptoms commenced. The following examples illustrate that IBS was firmly perceived as a chronic condition.

P32 (F 46, non-user): *I have actually had the condition for over 30 years* (Lines 31-32)

P74 (F 43, CAM-user): *I have suffered with IBS for 22 years...* (Line 35)

P78 (F 40, CAM-user): *20 years I've been like this* (Lines 19-20)

P63 (F 72, non-user): *have had the symptoms since my mid-teens (1950's).* (Lines 7-8)

P113 (M 34, CAM-user): *I still get the odd flare up but it passes as quickly as it arrives.* (Line 46)

Participants also acknowledged both dimensions of the timeline theme in their text, reflecting on both the duration and the propensity for fluctuation of symptoms.

P82 (M 34, CAM-user): *It's a vicious cycle and one that I have not been able to deal with for 20 years.* (Lines 39-40)

P104 (F 47, CAM-user): *My IBS is completely random in its frequency. I can have it badly every day for weeks and then it will stop apart from the usual menstrual cycle attack.* (Lines 33-35)

## **Consequences**

The consequences of IBS were acknowledged in many responses, being one of the most important components of illness perceptions in terms of being influential on CAM use and IBS-QOL scores (chapters four and five). Again perceptions of illness consequences were common across both CAM-users and non-users.

P9 (F 49, CAM-user): *It is a dreadful condition which tries to rule your life and makes all aspects difficult and sometimes embarrassing.* (Lines 42-43)

P59 (F 20, CAM-user): *It completely affects my quality of life. I sit and think about all the missed opportunities and thing I could have done if I didn't suffer with this disease.* (Lines 27-29)

P69 (M 25, non-user): *I feel that businesses and organisations I have been with since having IBS do not understand IBS and the effect it has on staff. They offer little or no support to staff ...* (Lines 6-8)

P96 (F 28, non-user): *My IBS is seriously affecting my career, due to the time off I have had due to my IBS.* (Lines 36-37)

P116 (F 29, CAM-user): *It effects every single area of my life and I hate it. I'm off with it nearly a month every year so it affects my employment opportunities.* (Lines 12-14)

P134 (F 38, CAM-user): *...I have had 11 weeks off sick in the past year.* (Lines 23-24)

Several participants focused on the impact of IBS on their occupation and other activities. There was also reflection on a perceived lack of understanding from employers. This illustrates how external factors may influence illness perceptions and subsequently have an effect on the coping strategies adopted. In the case of perceptions of consequences,

occupation issues may actually contribute to the cycle of IBS symptoms as work related worry or anxiety may also contribute to the experience of symptoms.

***Control (personal and treatment)***

As with the timeline component, evidence for perceptions of control was expressed as representations of two sub-dimensions related to personal and treatment control. Treatment control was evident in terms of both having control over symptoms and seemingly desiring control over one's symptoms.

P37 (F 51, CAM-user): *I would like to know how successful my medication is compared to other people's experiences.* (Lines 6-7)

P49 (F 43, CAM-user): *Some treatments only work for a short time.* (Lines 17-18)

P51 (F 52, CAM-user): *...no effective conventional medication for bloating swelling ...* (Line 28)

P170 (M 33, CAM-user): *Imodium has made the single biggest improvement, taking it as a preventative measure when needed has restored a lot of my confidence and made the condition manageable to an extent....* (Lines 10-13)

Many participants reflected on their lack of personal control over their situation, perhaps feeling unable or lacking the self-efficacy to do anything about their symptoms. This is clearly reflected in the following examples of participant text.

P5 (F 56, CAM-user): *It's down to me to deal with it, feel helpless at times to change the lifestyle.* (Lines 26-27)

P28 (F 42, CAM-user): *I feel I've managed to control my ibs fairly successfully without the continual use of conventional drugs for the past 15 years...* (Lines 8-9)

P113 (M 34, CAM-user): *I undertook a 8 week course of Hypnosis recently and my symptoms of IBS have all but disappeared.* (Lines 42-43)

P17 (F 20, CAM-user): *Living with IBS is waking up every day fighting a losing battle. You can't beat it.* (Lines 47-48)

P115 (F 44, non-user): *I am currently self managing, using stress management and relaxation exercises.* (Lines 6-7)

Many participants demonstrated evidence of both dimensions of control. In the text below, it appeared this participant had a degree of personal and treatment control over their IBS.

P1 (F 83, non-user): *I treat my IBS attacks with Gravol. I stay in bed and sleep as much as possible until the attack is over.* (Lines 3-4)

### **Coherence**

The theme of illness coherence, or beliefs representing a coherent understanding of IBS was reflected with both positive and negative connotations. It was clear some participants demonstrated they either had little understanding or wanted a greater understanding of their IBS. This theme or component of illness perceptions was notably the least evident in participant text.

P16 (F 60, CAM-user): *I feel as if all the help and focus is on the people who suffer with the constant need for the toilet rather than those of us who have the chronic constipation side...* (Lines 40-42)

P136 (F 21, non-user): *I have never been allergic to anything and am really baffled as to why this condition rears its ugly head randomly and so severely.* (Lines 35-36)

P42 (F 30, non-user): *The most annoying thing about being diagnosed as having IBS, is the lack of advise in trying to help make the problem more manageable.* (Lines 29-30)

Several participants expressed a desire for more information about IBS; at the same time some participants acknowledged they had conducted their own research. The first participant below stated they had conducted their own research and appeared concerned that not everyone would take this step.

P44 (F 26, CAM-user): *I feel that I have had little/no formal education on diet. I am concerned that others will not think to complete their own research to elivate their symptoms.* (Lines 42-44)

P70 (F 22, non-user): *I feel I have not been provided with enough information on IBS...* (Line 13)

P134 (F 38, CAM-user): *I would like to understand more about IBS I don't understand why I have the illness and I don't understand if it will get better or not.* (Lines 20-21)

One participant remarked that taking part in the survey actually helped their knowledge of IBS by making some aspects of the illness clearer for them.

P88 (F 28, CAM-user): *Your survey is very thorough and answering the questions makes some things seem more clear....* (Lines 48-49)

### ***Emotional representations***

There were many examples of emotional representations detected in participant text. There also appeared to be evidence of influences on emotional reactions to IBS based on factors or agents external to the illness.

P94 (F 45, CAM-user): *I only go out to work IBS has ruined my life and I am very often in tears over it, my relationship is suffering and at present no one understands and after 4 years I have had enough.* (Lines 40-42)

P118 (F 38, CAM-user): *In fact, one doctor actually counted out the number of times that I had been to visit the surgery in one year, in front of me, and told me this was unacceptable! As a result I felt ashamed, worthless and severely depressed (no surprises there then!).....Thank you for this opportunity to get my frustrations off my chest.* (Lines 27-31 & line 44)

P175 (F32, non-user): *...basically you are sent away and told to live with it, basically live in misery!!! I am so ill and exhausted with it and have no live!!* (Lines 37-39)

It was also noted there were more extreme emotional reactions in the form of apparent despair when participants were thinking about their situation and outlining how such feelings may have originated.

P107 (M36, CAM-user): *Doctors don't listen when I try to explain. They don't know the effect this illness has on people. They don't even understand cause. This has ruined my life and I feel as if there is no help available to me.* (Lines 48-50)

P159 (F 76, non-user): *IBS attacks are totally unpredictable and cause me a great deal of depression...* (Lines 40-41)

P141 (F 23, non-user): *had a nervous breakdown because of my IBS*  
(Line 11)

There was also some implication of emotions in maintaining symptoms. The following male participant suggested emotion was a crucial factor in his illness experience.

P133 (M 22, CAM-user): *That the most annoying thing is that it seems to be my emotions that control it, like excitement or worry..... emotions such as worry are hard to control at the best of times, even more so when you feel cramps and you are on a bus half way towards your destination.* (Lines 13-17)

### **Causes**

There were several reflections on possible causes of IBS. Both stress and food or diet related causes were recurrent themes in those participants that expressed beliefs in causal agents.

P5 (F 56, CAM-user): *I feel that it is due to lack of exercise.* (Line 25)

P24 (F 36, CAM-user): *very much food related.* (Line 36)

P28 (F 40, non-user): *...sufferers often find that they are not taken seriously with their health issues and the impacts on their mental and social well being.* (Lines 3-5)

P50 (F 24, non-user): *Was brought about by a very stressful job and overreliance on dairy.* (Line 23).

P54 (F 60, CAM-user): *... I wonder if it's a nerve pathway that got turned on and now won't turn off..... Also wonder if epigenetics play a role, which would include environmental contaminants...* (Lines 48-50 & 1-2).

P7 (F 50, CAM-user): *The symptoms increase with the stress of work and decrease when away from work for holidays – my case work related.* (Lines 34-35)

P149 (F 23, non-user): *I think peoples perception of IBS is a contributing factor. If IBS comes from stress then making people feel nervous and anxious about their problems heightens stress levels.* (Lines 46-48)

P170 (M 33, CAM-user): *...gets into a vicious circle of anxiety and that triggers it then it gets worse from the symptoms.* (Lines 6-7)

Other participants made reference to specific incidents or illnesses that they felt had a role in starting or triggering their IBS.

P65 (M 33, CAM-user): *my IBS started while I was working away from home on nights and I got food poisoning from reheated fish.* (Lines 21-22).

P75 (F 36, CAM-user): *My IBS first occurred after I suffered from a spastic duodenum for three months.... I believe this started the IBS which has been with me since.* (Lines 45-48)

P81 (M 62, non-user): *I think it is a lot to do with being nervous.* (Lines 31-32)

P83 (M 28, CAM-user): *I experienced a stomach virus while travelling and my stomach just never came back to normal health. I believe I have the Post-Viral IBS.* (Lines 44-45)

P99 (F 53, non-user): *I feel contributory factors of the onset of my IBS are stress related combined with poor diet and general quality of life.* (Lines 2-3)



One participant, despite stating their colon had been removed, appeared confused as to why they were still experiencing symptoms and appeared unsure of any specific causal factor.

P85 (F 75, non-user): .... *with an ablation of colon I STILL have IBS symptoms? although I have a cool and relaxed mind and am pleased with my quality of life.* (Lines 30-32)

As well as evidence of each of the themes as outlined in table 1, it was also clear that many participants had a positive experience of both being able to take part in a research study and that there was opportunity to express some feelings beyond responding to quantitative measures. Many also thanked the researcher for taking the time to conduct a study.

## **Discussion**

Thematic analysis was used to analyse participant responses to the open question included in the survey conducted at time one (chapters four and five). This was used as an attempt to highlight the importance of illness perceptions in those affected by IBS. Seven key themes were derived from previous work on the CSM (e.g. Leventhal et al., 1992) and work on the IPQ-R (Moss-Morris et al., 2002). The analysis of participant text does add support to the CSM theory that individuals do conceive specific schematic representations of their IBS. Each of the themes is considered separately.

### ***Illness identity***

Illness identity is concerned with the labelling of symptoms and attributing them to IBS rather than any other conditions. In applying this theme to the text analysed, the purpose was to determine how participants expressed IBS symptoms and referred to IBS as an illness.

Overall participants expressed their perceptions of their symptoms by referring to them as 'symptoms' or by specific symptom. Some

participants stated they suffered with a particular sub-type of IBS, either constipation or diarrhoea predominant. The way that symptoms were expressed was done so with an apparent implicit reference to the impact of IBS on individuals' quality of life. This seems to concur with other findings that perception of IBS symptoms may influence quality of life (e.g. Chang, 2004; Naliboff et al., 1998; Rutter & Rutter, 2002).

Illness identity was also referred to in the context of the timeline of IBS symptoms with comments referring to specific symptoms and how long they might last or how soon they may be relieved and return. In other illness populations there is suggestion that illness identity is one of the most prominent of the components of illness perceptions to influence outcome (Hagger & Orbell, 2003), although results from chapter five suggested identity to be less important in this sample. The comments were fairly consistent between both CAM-users and non-users as there was no noticeable expression of greater illness identity in CAM-users.

### ***Timeline***

The timeline theme reflected the sub-components as outlined by Moss-Morris et al. (2002), in that participants expressed their IBS in both cyclical and chronic terms. Throughout the text, it was noted that there was almost unanimous acknowledgement that IBS is a chronic condition, although a small number of participants expressed they were uncertain how long symptoms would last for. Stronger perceptions of a chronic timeline were shown to have an influence on impaired quality of life ratings (chapter five) and these findings give an indication of how such representations may be conceptualised by those affected by IBS.

In representing cyclical beliefs about IBS, participants often referred to 'cycles' or 'flare-ups' of symptoms and many seemed aware that this was considered normal for someone affected by IBS. Although implicated as less important in influencing reported quality of life (chapter five), stronger perceptions of a cyclical timeline were influential on whether participants would use CAM to treat their IBS (chapter four).

### ***Consequences***

The 'theme' of illness consequences has been shown to be important both in influencing specific coping behaviour (CAM use, chapter four) and on reported quality of life. There were a number of expressions and reflections on the consequences of IBS. This ranged from the impact of symptoms on the various aspects of everyday life and how this was considered a hindrance. Such consequences have been reported in previous work (Amouretti et al., 2006; Chang, 2004; Dancey & Backhouse, 1993; Luscombe, 2000).

Other participants expressed the consequences theme in respect of their occupation or citing concern with a lack of understanding from their employers regarding their IBS. It may appear that for many affected with IBS, they perceive their employers as lacking understanding about IBS and do not regard the condition as legitimate. In this instance parallels may be drawn with early medical perspectives of IBS, when the medical profession failed to acknowledge IBS as a legitimate medical condition (Rutter & Rutter, 2002). It appears a similar boundary is perceived for many with their employers.

### ***Control***

Both dimensions of control were observed in participant responses as outlined by Moss-Morris et al. (2002). In terms of expressing treatment control, a small number of participants indicated that they managed to control their IBS using medication or other treatments they had discovered worked well for them. More frequently found was that many participants disclosed that they had not been able to control their symptoms with medication they had either purchased themselves or had been prescribed. The fact that many CAM-users also expressed this suggests that CAM treatments were no more successful in controlling symptoms than conventional treatments. This seems to add support to findings from chapter five where CAM-users reported poorer quality of life, which has also been found in previous work (van Tilburg et al., 2008). However, in both CAM-users and non-users, those with stronger

representations of treatment control, reported better quality of life (chapter five).

A similar scenario existed for the theme of personal control. Many participants, including CAM-users, expressed modest or limited control over their IBS. Those that did express a degree of control seemed to refer to a specific or personal regimen of either a specific treatment or behaviour they would undertake until symptoms had passed. As with treatment control, stronger perceptions of personal control were found to be related to better reported quality of life (chapter five).

### ***Coherence***

In terms of the theme of illness coherence, participants expressed this in both positive and negative connotations. Several participants stated that they understood their IBS and seemed to know what the condition entailed while others seemed uncertain about their IBS. Several participants seemed keen to know more about IBS, especially treatments and why they had IBS. It would appear from participants' responses that there is a need for better information about IBS and to make this information universally available. Findings presented in chapter five, showed that, as with the control components, stronger coherence ratings were related to better reported quality of life scores.

### ***Emotional representations***

Chapter five showed that emotional representations were important influences on both reported quality of life and emotional quality of life (Dysphoria). The reflections from participant text showed the emotional distress that those affected by IBS go through. Many participants expressed that they felt miserable and unhappy, which sometimes came from lack of interest from their GP. Other participants expressed more severe emotional reactions to their IBS with one participant stating they had a nervous breakdown due to their IBS. Perhaps this is reflection on previous understanding that those affected by IBS are liable to 'catastrophise' about their symptoms (Drossman et al., 1999; Lackner et

al., 2004). The excerpts of text do illustrate emotional representations are important aspects of the CSM and in forming representations about illness (Leventhal et al., 2003).

### ***Causes***

There were several references in participant text to potential causes of each case of IBS. This seemed to range from stress or anxiety to diet or food related causes (Casiday et al., 2008; Hungin et al., 2005; Lacy et al., 2007). Some responses indicated a specific incident or illness triggered their IBS symptoms and these were sometimes related in the text to other components of illness perceptions, such as how long ago symptoms started. Other participants referred to stress and anxiety triggering symptoms or an attack. One of the most prominent beliefs in the responses analysed seemed to be that stress is implicated in IBS, if not as a cause then as something that could enhance symptoms which has been found in existing work (Dancey & Backhouse, 1993; Hungin et al., 2005). This belief may have come from a lack of or conflicting information about IBS, in that those affected may be informed to reduce stress and subsequently make a connection between such advice and forming a causal belief.

### ***Limitations of analysis***

The text analysed for the purposes of this write up illustrated evidence that individuals had constructed schematic representations of their IBS in line with components of illness perceptions according to the CSM (Leventhal et al., 2003). There are however a number of limitations concerning the number of respondents, the length of responses and the top down approach to analysis that need to be considered.

Firstly, not all participants responded to this section in the survey. In terms of participation, 26.8% of the sample responded to the open survey question at the cross-sectional stage of the research. It may be that in trying to corroborate findings from previous chapters in the thesis that crucial data may have been effectively lost. However, the number of

participants whose responses were collated could be considered substantial for a qualitative study (Bryman, 2008).

Furthermore, participant responses generally consisted of a few lines of text, rather than longer amounts of text that may typically be associated with qualitative data from interviews or focus groups (Bryman, 2008). In this context, the collection of additional text from each participant may have been beneficial. However, similar sized extracts of participant text have been analysed in previous work which extracted data from internet message boards (Brewer et al., 2007; Coulson, 2005; Im et al., 2009). O’Cathain and Thomas (2004) also argue that such an approach (i.e. utilising an open survey question) is entirely valid in the context of carrying out survey research to add a degree of validation to the findings of a ‘main’ quantitative study being conducted (Casebeer & Verhoef, 1997). Therefore these findings add corroboration and provide triangulation to quantitative findings presented in the thesis.

Secondly, there may have been some loss in potential richness of data by using a deductive top-down approach (e.g. Boyatzis, 1998) to analysis rather than examining themes that emerged from the data in an inductive manner. It is possible interesting or insightful themes in participant data may have been ignored by utilising the top-down approach. This potential limitation however can be aligned to the context of the aims of the study, in that the study set out to examine evidence of illness perceptions in participants’ open responses at the end of the survey.

Moreover, with respect to the top-down strategy to analysis (Braun & Clarke, 2006) and the fact that the open responses were recorded at the end of the survey may have resulted in a degree of priming. In this context, answering questions about illness perceptions from the IPQ-R could have effectively primed participants to thinking about their IBS in a structured way. However, any priming was hopefully minimised by the wording of the open question at the end of the survey which allowed participants to give both free and open responses about anything related

to their IBS. Furthermore, previous work (e.g. Amouretti et al., 2006; Chang, 2004; Dancey & Backhouse, 1993) has identified similar issues such as consequences of IBS, without the possibility of priming with the IPQ or IPQ-R. Inter-rater agreement on the themes was also strong, which indicated both researchers did detect evidence of illness perceptions in participant text.

Finally, as highlighted in previous chapters, participants were largely recruited from a self-help website at one time point making it potentially more difficult to generalise these findings to the wider population affected by IBS. There were obviously variations in times of diagnosis and differences in the duration in which participants had been affected by their IBS which may have affected how people expressed feelings about their IBS. Participants may be asked to consider their beliefs about treatment, as the original intention of the research in this thesis was to explore an extended CSM (Horne & Weinman, 2002). It appears that treatment beliefs are less important influences on participants' quality of life judgements and it was noted that any reference to harm or overuse of treatment in responses was confined to a small number of participants.

Furthermore, findings presented in chapter six, suggest the quantitative changes in many IPQ-R scores over two time points are minimal, a finding consistent with previous work in IBS utilising the IPQ (Rutter & Rutter, 2007). Further qualitative investigation may be conducted over several time points to follow up how illness perceptions change over time. The relationships between illness perceptions and coping strategies could also be explored by conducting future qualitative study over several time points.

Many of these limitations may be addressed by conducting a full qualitative, possibly interview or focus group based study. Such an approach may be beneficial to assess components of illness perceptions by asking specific questions based on each component (Goodman et al., 2005; Meyer et al., 1985). A full qualitative study may also offer

additional insights as to which illness and treatment perceptions could be subject to intervention to improve self-management of IBS.

### ***Conclusions and implications***

This write up has reported findings from participants' text responses to an open question included in the cross-sectional study reported in chapters four and five. This approach was justified as several existing studies have conducted similar top-down analysis using postings from internet message boards. The findings presented here offer a degree of triangulation to add support that illness perceptions are important factors in IBS as has been found in previous work (Oerlemans et al., 2010; Rutter & Rutter, 2002; 2007; van Dulmen et al., 1997; 1998). The text analysed demonstrated that illness perceptions appear to be prominent in participants' thoughts when asked if there was anything they would like to express about their IBS. This appeared to be regardless of whether participants used CAM or not to relieve their IBS. Although each component of illness perceptions was encountered in participant text, it is possible that this could be primed by previous questions in the survey or by making participants think in a more focused manner about their IBS.

The unique aspect of this study in including an open question at the end of a quantitative survey has also given some further insight as to where intervention could be targeted to assist with management of IBS. Specifically, interventions could help to facilitate control and coherence. Higher scores on these components (chapter five), were associated with greater reported quality of life. The majority of respondents however, seemed to express that their IBS was not under control and they would like greater education and information from the medical profession about how best to manage their IBS. Intervention could therefore be targeted to improve participant feelings of control and understanding of their IBS. This could extend as far as providing information for employers and business, as in expressing consequences of IBS, many participants referred to occupational issues and a lack of understanding from their employers regarding their IBS.



From an employers perspective reduced productivity due to IBS is problematic (Dean et al., 2005), so attempts to address this problem could have significant economic benefits. One such intervention focused on IBD where employees valued the information provided for employers and thought it had greater impact if delivered by health care professionals or self help groups (Mayberry & Mayberry, 1993). Cash, Sullivan and Barghout (2005) suggest any such workplace intervention focusing on IBS should be based on information provision for both employers and employees, providing incentives to adhere to treatment, and progress of any intervention is monitored at regular points in time.

Emotional representations were also found to be important aspects of illness perceptions. This again concurs with findings in chapter five, but which have been omitted from previous CSM research with IBS samples (Rutter & Rutter, 2002; 2007). Addressing emotional representations with reassurance and information offers an opportunity to potentially reduce emotional distress related to IBS.

The apparent prominence of illness perceptions when individuals were asked about their IBS shows the likelihood that these perceptions have the potential to influence the type of behaviours or strategies that will help them to cope with IBS. From a theoretical perspective, many of the responses also show evidence of external influences on perceptions and how such influences may relate to illness perceptions, a factor that the CSM acknowledges (Leventhal et al., 1998). The findings presented here highlight the importance of illness perceptions by demonstrating their importance in the thoughts of those affected by IBS and has added support to findings presented in previous chapters. Illness perceptions may also represent target points for intervention to decrease use of health care services via improved management (e.g. van Dulmen et al., 1996; 1997).

## Appendix XVI: Participant text from open survey question

[This is raw data, uncorrected and as provided in survey responses]

(Participant 1, P1)

I treat my IBS attacks with Gravol. I stay in bed and sleep as much as possible until the attack is over.

P2

I feel I've wasted about 15 years forever waiting to see Specialists and, because of Cancer, these are now speeded up somewhat but ever-changing Doctors and no suggestions as to do to alleviate symptoms have brought me to research on the internet where I found this survey. Also very angry wasting 6 years mis-diagnosed as a Coeliac - it ruined a lot of occasions. Symptoms seem to be getting worse as I get older and make me feel very unwell for a lot of the time but I keep giving up hoping to find some way to lead a normally active life.

P3

long waiting lists for referrals.doctors not understanding. no support

P4

I'm often told my condition isn't life threatening so just get on with it, but whilst non life threatening it is, it's life limiting and ruins everything

P5

I feel that it is due to lack of exercise.Something which is hard for me to address,due to family commitments. Its down to me to deal with it, feel helpless at times to change the lifestyle. There never seems to be the right time.

P6

lack of social groups to relate + empathise with where i live

P7

The symptoms increase with the stress of work and decrease when away from work for holidays - my case work related

P8

the significance of brain cells-wide current research in that field.contribution of social interaction

P9

it is a dreadful condition which tries to rule your life and makes all aspects difficult and sometimes embarrassing. Life has to be mind over matter with a determination not to give in to it.

P10

I feel my IBS affected me for a term of 3-4 months, since then I have been almost satisfactory all but the bouts of annoying constipation, even though I do stick to pretty much the 5 a day and drink around 3 pints a water a day.

P11

I'm Dutch (European) and living in the Netherlands. I have a very healthy diet, but still get IBS a few times a year :-)

P12

I would be interested in understanding the link between the brain and IBS.

P13

I have been in pain since having a tcre operation to reduce my periods 14 months ago. I was diagnosed with IBS when I had a scan the long probe like camera caused me pain on removal. I saw a gastroenterologist after who asked me about my symptoms. I cut out wheat since I met with her but my pain still exists. I have since paid for an intolerance test which showed I am wheat and lactose intolerant and a few other things but I am still in pain more often than not. I really have to think about what I am eating. I suffer with pain mainly with occasional bouts of constipation. I can't see an end to it nothing seems to give any relief.

P14

I have only just been diagnosed with IBS 3 days ago, I have tried to answer the questions as best I can, I am researching myself to see if I can make it any better, I feel my doctor wanted to do what he wanted rather than what I wanted, he only prescribed me Fibogel and when I asked him what I could take for the pain he suggested I take paracetamol (which I have tried and fails to work) I knew that I could not get an antispasmodic he wouldn't prescribe it to me, so instead I have had to go out and buy some (at a fiver a pack it's not really cheap, especially when I am entitled to free prescriptions) I really do hope I have helped but as I say it's only been a matter of days since my diagnosis, I do hope you do well in your research

P15

How many people have chronic back pain and IC as well as IBS. Wondering if there is a link. Or perhaps with food intolerance

P16

I feel as if all the help and focus is on the people who suffer with the constant need for the toilet rather than those of us who have the chronic constipation side which and most of the medications just make the pain and cramps worse

P17

People without IBS don't have a clue how horrible it is. I would rather have cancer, there is a cure, you either beat it, or you die. Living with IBS is waking up every day fighting a losing battle. You can't beat it.

P18

I was found to have a gluten intolerance some seven years ago along with collagenous colitis, but a recent examination did show that the colitis was not present anymore. Following an accident in 1989 I injured my spine which resulted in me having several spinal discs removed and having a spinal fusion. I was a heavy drinker since my teenage years but have not drunk alcohol for some six years

P19

I was diagnosed with two parasitic infections (Entamoebae histolytica and Giardia lamblia) while living in Africa in January 2001. Was recently diagnosed with Grave's disease (autoimmune hyperthyroidism) in March 2007. Severe, watery diarrhea up to 20x/day when symptoms at worst. Current medical student - feel free to contact me with any questions!

P20

Although I have only recently been told that I may have IBS I have suffered for quite a few years with stomach/bowel disorders

P21

My IBS began after I had a severe bout of gastro-enteritis. I was well up to that point. I then contracted glandular fever resulting in M.E (PVFS). I do not believe that my IBS is caused by stress but has a physiological cause which is not yet fully understood.

P22

i am considering a food intolerance test to see if that can help

P23

After not being able to consume the herbal remedies that i was using; due to not being able to buy it in the UK. i haven't had my period in 2 months and i'm not pregnant.

P24

Very much food related

P25

i have just done an exclusion diet through my diabetic consultant, not from my doctors, i feel that they never see me when i am bad i have in the past resulted to taking photos, so they could see how large my stomach gets through eating. i am a 32 year old woman who is a size 10 2 12 and for the past 3-4 years has worn control pants, i must be the only person who loves winter for the fact that you wear more clothes so people cant see how fat you look,its not good at any age but worse when in summer your fella looks a girls wearing skimpy clothes and not you sat there with a maternity top on .

P26

i sometimes think excitement makes it worse as well as stress

P27

There is a lack of understanding of IBS. Too often it is proclaimed as a "stress related illness". As a result, sufferers often find that they are not taken seriously with their health issues and the impacts on their mental and social well being.

P28

I feel I've managed to control my ibs fairly successfully without the continual use of conventional drugs for the past 15 years(-mainly through the use of diet and herbal medicine) until very recently when it has become more erratic. I've just recently seen my gp about this.

P29

Recovered alcoholic- sober 20yrs.Never used illicit drugs.Semi-addicted to prescribed Codeine phosphate 120mg/day-great for IBS,so need laxatives and Lepicol too,and colonic irrigation/mnth

P30

i decided to go down the herbal route, instead of chemicals like spasm control tablets as i personally believe it inbalances the human body, and to many toxics bad for the body. aloe vera, peppermint oil tea, chinese herbs, ginger, i take everyday and find very helpful

P31

I would be more than happy providing information to help the development of a effective treatment for IBS! I just had an attack and now that tomorrow is going to be another painful day...

P32

i was diagnosed at the age of 16 with what was then called spastic bowel and now called ibs. so i have actually had the condition for over 30 years, some times it is very aggressive others mild but the only time i did not have any symptoms for a noticable length of time was when i was pregnant.

P33

VSL#3 Is very helpfull in reducing urgency and Diarohea

P34

My IBS symptoms may have large gaps inbetween flare ups. I just had one 3 weeks ago; my last incident was a year and a half previously. I feel "normal" when not having an incident, and so far my flare ups have passed quickly with use of anti-spasmodic meds. My biggest mystery and concern is trying to figure out what causes it to start & stop.

P35

I feel that I had symptoms of IBS since early on in childhood.

P36

lists of medication people use

P37

I am surprised the survey did not ask questions about what medication I am using on GP's advice. I would like to know how successful my medication is compared to other peoples experiences.

P38

Doctors tend to put everything down to my IBS..I have now been told I also have a peptic ulcer and for months was told "it's just your IBS"

P39

The most annoying is the constipation (sometimes a week) then diarrhoea (sometimes 6 times in a day) and the wind

P40

i do have 1-2 accidents during the night and cannot control them and the amount of underwear i have thrown away is unbelievable, and when it does happen it causes me embarrassment, and also i don't go out at all unless i know whether there is a toilet nearby. i live like this everyday and feel like my IBS is controlling ME all the time.

P41

Nothing (other than immodium has any effect on my symptoms. I never leave the house without it!

P42

The most annoying thing about being diagnosed as having IBS, is the lack of advice in trying to help make the problem more manageable. Apart from the advice of 'taking the odd peppermint capsule' (which does nothing for me!). Sometimes I wonder if I actually do have IBS and it wasn't just an easy answer to my problem...In other words, more advice and help is needed from doctors etc.

P43

I have the runs all the time and the pain is awful i have not eaten for 4 days now it just will not stop even with my medication i get from the doctor if i move about i have to run to the toilet its bad

P44

I feel that I have had little/no formal education on diet. I am concerned that others will not think to complete their own research to alleviate their symptoms.

P45

diet changes have made a big difference

P46

My symptoms include frequent visits to the toilet, ie. three or four times a day

P47

Doctors don't seem very interested in trying to alleviate IBS. There are so many 'alternative remedies' apparently available but no reliable guide on what does and doesn't work and what is safe. I have tried umpteen recommended supplements only to find that they are then withdrawn as potentially dangerous.

P48

I think it would be interesting and helpful to ask about different triggers for men and women.

P49

I feel GPs need to be better advised of treatment. Some treatments only work for a short time. There should be IBS Clinics with diet plans etc. I also believe food intolerances play a part and all IBS sufferers should be tested.

P50

Was brought about by a very stressful job and overreliance on dairy. Can no longer tolerate dairy for the most part.

P51

I feel there is no definitive way in diagnosing ibs  
no effective conventional medication for bloating swelling change of diet helps  
but does not completely cure

P52

I believe that you should have asked questions about working life as one of the biggest causes of my anxiety is my job & the amount of sickness my IBS causes, leading to my employer taking disciplinary action against me

P53

My life changed following the 3 in 1 treatment for stomach ulcer 10 years ago. I was left with bloating, really loud stomach noises etc - I'd much rather still have the ulcer!

P54

Watery stools cannot be controlled and cause embarrassing events. You didn't ask about accidents. I am also curious that I do not have abd pain and/or cramps like most, just diarrhea. I had a 24HR urine test showing a lack of enzymes to digest carbohydrates. I take Pancreatic enzymes but it doesn't make any difference in diarrhea. An integrative MD says I need to balance my body back out. As a RN, I wonder if it's a nerve pathway that got turned on and now won't turn off, like in RSD. Also wonder if epigenetics plays a role, which would include environmental contaminants like pesticides, ATB, hormones, etc. Just a thought.

P55

I find having ibs very embarrassing even with my closest friends

P56

I strongly believe that the physical symptoms are caused by worry. I do feel that my constant anxiety about the fact that I may need the toilet in a hurry when out shopping, with clients or whatever is what maintains the problem. I have travelled extensively and have enjoyed holidays. I am now dreading my next trip due to the flight - should the seatbelt light come on and I need the toilet, waiting at the airport, getting a cab from the airport to the hotel - how long is the journey, what if I need the toilet en-route. What about walking around a strange city or getting on a tube. This is absolutely destroying my ability to enjoy any normal activity. A drive to the country with friends and my dogs was my favourite pastime; now it is my hell.

P57

I couldn't work, or lead a semi-normal life without loperamide

P58

I have had IBS since I was 15, I am now 39, and very fed up with it.

P59

It completely affects my quality of life. I sit and think about all the missed opportunities and things I could have done if I didn't suffer with this disease. I worry about the future. I worry I won't ever be able to have proper relationships because people will get frustrated with me and I worry I will be too ill to get a job. At 20 years old I hate the fact I have already given up on life.

P60

My diagnosis until a week ago was confused as being IBS and endometriosis, so the emphasis of treatment was put on the endometriosis. I now have re-evaluated all my treatments.

P61

Several years ago I had a colonoscopy which suggested that my IBS could be connected with my monthly cycle. As the symptoms seemed a lot worse they have not got any better even though I am now going through the menopause. I have tried the Activia yogurts advertised to help with digestive problems but they seem to have made mine worse. Horrendous wind and the need to go to the loo very quickly and with very little warning leaving me very bloated and uncomfortable.

P62

I do feel as though things started to go wrong when on holiday, when I ignored the urge to defecate for 4-5 days. As a result of this belief I largely blame myself for the condition. However, I also believe that all my health problems (IBS, Depression, postural problems) are related in some way and that the solutions to all lie in a holistic approach, rather than just treating them in isolation.

P63

First heard of IBS when diagnosed in 2003 but have had the symptoms since my mid-teens (1950's)

P64

I am awaiting to see a gastroenterologist but my referral letter was lost en route to the hospital which was in July 07. Have since contacted doctor's surgery and they've resent letter which the hospital have now received and are putting me on waiting list even though original letter was in July and it's now Nov. Symptoms have been ongoing for over a year without a proper diagnosis and am considering getting a Food sensitivity test done to help with diet. Having a site like Gut Trust has been most helpful as I can relate to many of the symptoms.

P65

My IBS started while I was working away from home on nights and I got food poisoning from reheated fish



P66

It is very difficult to define IBS and I am sure my symptoms are relatively mild, so I don't really talk about it with anybody. I spend quite a lot of time in the toilet compare with my partner and he jokes about it sometime, even I call myself "wee wee girl". But I don't think he knows about my bowel problem and the things happen in the toilet is just not something you would like to talk about even with your partner. I don't think I would bring it up with my GP but I will try to find some remedies and alternative methods to help me.

I think it is a dilemma. If the symptoms are more serious maybe people will realise it is a kind of illness and there's something wrong, and it would be easier to bring it up with others. People would understand why you need to go to toilet so often or so. But if it is mild and not as obvious, just like being constant bloated and having excessive wind, people won't understand that you are in pain or how uncomfortable it could be.

P67

It is a very upsetting illness which I feel health professionals brush under the carpet and refuse to do extensive tests to ensure it is IBS and not another disease such as cancer. The symptoms as well do take over your life but you do try and control it as best as you can so you don't have to worry when you go out where the toilets are all the time just in case but also being a sufferer of IBS you have to learn to change your mind's behaviour as well as to not to constantly think about it so you can have less episodes because to certain extent it also becomes a habit which you need to learn to break.

P68

I need to know good foods and bad foods. Food to avoid that could make things worse for example!

P69

I feel that businesses and organisations I have been with since having IBS do not understand IBS and the effect it has on staff. They offer little or no support to staff regarding this illness and something needs to be done to make business aware that this is a real illness and that people can get ill from it

P70

I feel I have not been provided with enough information on IBS or Tests to see what I am intolerant too.

P71

Fed up with it straight into the loo as soon as I stand upright in the morning sometimes as many as 4 times before I leave for work I have done a physically demanding job for the last 28 years and this lot is not helping me at all braced off

P72

I have been in and out of hospital over the last 3 years with very bad upper abdominal pain and nausea and vomiting ... I've been told it isn't linked to my IBS but I am not convinced I have omeprazole to stop acid reflux as this is something I suffer with the vomiting.

P73

I think it may now be related to toilet phobia - I had an accident in town when I was very unwell a few months ago and have been phobic of not being able to get to a toilet ever since. This has exacerbated my IBS in a vicious cycle.

P74

I have suffered with IBS for 22 years, over the years I have tried to manage my symptoms with little success. I have approached several GP's over the years and discussed how a lot of my symptoms seem to be food related with regard to tolerance for some foods. As these foods or ingredients are difficult to identify without knowing which you cannot tolerate I have requested tests to identify these, I have always been refused and feel my symptoms are dismissed I am currently looking to have these tests carried out by myself. This will hopefully help!?

P75

My IBS first occurred after I suffered from a spastic duodenum for three months. This altered my eating and bowel habits until it was diagnosed and treated. I believe this started the IBS which has been with me since.

P76

My doctor has decided to refer me to a consultant. This is over 3 months ago. He is not suggesting or wanting to talk about treatments.

P77

What I feel frustrated about is how my IBS comes in different forms. I hate that on a daily basis I have to worry about constipation but then during a really bad bout of IBS it is bloating and diarrhea. I hate the fact that even though I don't feel any mental stress at all (I am a very laid back person) during busy work times I get a really bad bout of IBS. I also hate the fact that I feel like I will have to live with this forever - when I don't want to.

P78

Yes, it's constant, it's painful, and I feel like I don't want to go anywhere or do anything, because I feel uncomfortable, my doctor doesn't seem interested, I'm not even sure he's written it in my notes, I've diagnosed myself and told him, he just accepts it, but doesn't offer any assistance, tests etc, 20 years I've been like this and it's affecting my work!

P79

I am 16 weeks pregnant and my symptoms have got worse it makes me worry as to the safety of my baby.

P80

I feel the anxiety, nausea and panic attacks and extreme fatigue have changed my life and disabled me and are by far the worse part of this condition.

P81

would like something to relax me in mornings when I get up, I think it is a lot to do with being nervous

P82

The general consensus on IBS tends to focus on food problems. I think there should be more focus on stress-related causes. Mine started when I was 14 and was being bullied at school. Each morning I'd suffer from cramps and need to go to the toilet. I know associate this (I think) with anxiety. It's a vicious cycle and one that I've not been able to deal with for 20 years.

P83

My IBS started after spending three months travelling around Europe. I experienced a stomach virus while travelling and my stomach just never came back to normal health. I believe I have the Post-Viral IBS.

Most doctors here in the USA are more concerned about just covering up the symptoms of IBS with drugs that have tons of side effects instead of trying to find a cure.

I can understand GP and family doctors not knowing a cure about IBS. But what I can not understand is in the year of 2007 how GI doctors who spealize in the digestive system not only do not know a cure for IBS, colitis, and Chrons but they don't even know the cuase or how to prevent such digestive upsets.

I like the idea of natural cures but it's hard for someone to find the right combination to actually cure something.

Holistic doctors I don't really trust because most of them turn into salesmen. But even though holistic doctors are salemen, people start trusting them because those doctors are more focused on searching for a cure rather than just a band-aid drug.

GP doctors sometimes seem like nothing more than drug pushers who are controlled by drug compaines. And the drugs they give out are only band-aids that had bad side effects because they are not natural they alter the human body too much. Sure doctors of the world can't find a cure things like AIDS or cancer. But in the year 2007, you would think that a GI stomach-doctor would at least have a cure for each case of IBS.

I believe IBS is only "mental" when the adult IBS patient has been suffering since childhood or teenage times. Sometimes like that is cause by young mental trauma and these people need to retrain themselves, both in the mind and body in order to overcome the original tragic events.

Other cases of IBS-A, IBS-C, IBS-D, and PI-IBS that were brought suddently in adult life, are due to overuse of aspirin and other OTC medication, food additives destroyed good bacteria, and hidden travel parasites which unbalance the gut.

GI doctors need to start to study each case of the patients that visit them and see if the IBS was adult onset or from childhood trauma.

Regular GP doctors, especially in the USA, need to start spending more time

with each patient and let them ask more question. And they really need to stop spending their time being slaves to drug compaines and spend more time really reseaching for a cause and cure.

If you read vintage books about IBS from the 1980s and even the late 1990s, many of these books (which were written by GI doctors) on talk about this mental stuff and they were only dealing with the people who had childhood trauma.

The books that came after 2005 about IBS are a little bit better because some GI doctors finally started to figure out that each case of IBS is sort of individual. The GI docotr **SHOULD ASK WHEN** the IBS problems actually started.

The books that came after 2005 are better also because finally they started to talk about probiotics and real natural things that can put the stomach back into balaence.

IBS-childhood-trauma cases are the people who need anti-depression medicine and to spend time meditating. Other IBS cases not caused by childhood trauma need the gut balanece corrected and the hidden parasites knocked out. The depression and anixety that these IBS cases expereince was onset because of the fraustration of having no cure.

The IBS-childhood-trauma cases have been experience on and off depression and anixety since they experience the childhood or youthful trauma.

Maybe one day, I hope, GI doctors will actually find a for something. I don't know how these stomach-doctors get paid for not being able to cure anything! How do they feel each time when they tell someone with IBS or an IBD that there is no cause and no cure? Do they feel bad, or is it just another day of the job?

P84

my ibs affects me in the mornings mainly , i feel as if i dont stop going and for a while i feel as if i need to go even if i dont . i do tend to panick if i cant get to a loo in time which makes going out quite a misery.

P85

explain why ?? with an ablation of colon I **STILL** have IBS symptoms ? although I have a cool and relaxed mind and am pleased with my quality of life. I am french,(no problem) ?

P86

Had radical hysteretomy 4 months ago for gyne problems. I feel that my recent hysterectomy and my problem scoliosis is the cause of my bowel problems and loss of bowel control and back and tummy pain. symptoms appeared 3 weeks after hysterectomy, possibly not helped by my doing too much physical activity within 2 weeks of my hysterectomy and my using herbal laxetives to purge.

P87

Re the follow-up survey I'd be willing to take part but I'm not a UK resident so possibly I filled in teh wrong box for ethnicity...I am white Irish but not from the UK.

P88

Your survey is very thorough and answering the questions makes some things seem more clear (such as the poor manner in which my consultant deals with me). Thanks and all the best

P89

I have numerous day off from work because of IBS . which of course is a problem & have lost more than one job because of IBS.

P90

Currently I have been in contant abdominal pain for nearly four years and am at the point of trying to harm myself again as i see no end to this horriffic and dibilitating condition. I would also like to point out that anti depressants do not help the IBS and actally cause more contipation and pain as my doctor sugested. I managed to get off the mirtzapine for a while and felt much better which is further proof of this but then had to go back on it again due to poor sleeping so the vicious cicle of never being pain free continues.

P91

where can i get help with my IBS please ?

P92

it is very,very painful

P93

It really does control my life

P94

Most people assume IBS is only about diarrhoea and don't realise that painful constipation is also a symptom.

P95

I have suffered from this condition for 23 years. Now in the menopause and have put on about a stone in weight during the past two years.During my last pregnancy {aged 35}my symptoms went. after the birth they began again. It is a miserable contition and I am currently excluding wheat from my diet as a trial.

P96

My IBS is seriously affecting my career, due to the time off I have had due to my IBS.

P97

I only go out to work IBS has ruined my life and I am very often in tears over it, my relationship is suffering and at present no one understands and after 4 years I have had enough

P98

Thank-you for the chance for having my voice heard, as a Psychology student I understand the importance of people participating in studies. I hope you find the answers you are looking for. Good Luck

P99

I feel contributory factors of the onset of IBS are stress related combined with poor diet and general quality of life.

P100

i feel that ibs may mask other health problems, and that worries me, other symptoms don't seem to fit the box.

P101

The symptoms and pain connected with IBS especially at night is very debilitating

P102

Late onset IBS symptoms (at age 57) started c10 months after cholecystectomy. GP is not at all convinced that this is the cause. He would prefer me to try a course of anti-depressants as he feels my 'social circumstances' (eg disabled 35 year old daughter - living in special unit, elderly disabled mother - receiving domicillary care) mean that excessive stress is the cause. Whilst I acknowledge the stress, I am reluctant to take anti-depressants as the potential side effects could make me feel worse! I feel that my theory that the IBS is as a result of the operation should be given some consideration, but he would prefer me to try the anti-depressants route. I fear we are at an impasse!

P103

There seems to be an attitude of very much giving up among doctors. They send you to see a specialist and you try a couple of prescribed medicines but if they don't work then it's just "oh well, you just have to live with it then".

P104

My IBS is completely random in its frequency. I can have it badly every day for weeks and then it will stop apart from the usual menstrual cycle attack. No matter how much I analyse what I have eaten, been stressed by or any other factor in my life, the attacks of IBS appear to be random and impossible to predict ( other than the once a month ones and if a really major event happens to stress or upset me, eg: my mother and fathers deaths)

P105

ibs runs and ruins your life!

P106

I couldn't answer any question concerning hereditary as I was adopted

P107

Doctors dont listen when I try to explain. They dont know the effect that this illness has on people. They dont even understand the cause. This has ruined my life and I feel as if there is no help available to me.

P108

it is extremly painful without treatment i would not wish it on anyone!

P109

Very little advice or direction was provided by NHS, I was basically told I had IBS, live with it. Don't eat things that upset it and avoid stress. I was offered no treatment and was told that I couldn't see a nutricianist as the waiting list was too long. When I have approached my doctor in the past I have found no help what so ever. I insisted that the tests where carried out to confirm IBS as my family has a history of coeliac disease. It has been through my own hit and miss trails of food and emotion diary entries that I have found (some) of the triggers. People think your being fussy or awkard when you decline food or try and explain you feel unwell. Even close family members sometimes look at you as though your making a mountain out of a mole hill. I have to carry spare clothes and toiletries with me because you never know when an attack may occur. Numerous times I have messed myself while shopping, it is extremley embrassing as well as inconvienent, especially trying to find a toilet to sort yourself out. Sorry! No-one else to rant to!

P110

urinary urgency plays a big part in my symptoms particularly when constipated. diareah often at the begining of period. worry sets me off

P111

I dont feel that the questions had much relevance to my condition.This occurs three/four times a year.The severe and almost like childbirthpain is unbearable and lasts always 12 hours and the last time 17 hours.The Buscupan did not help at all this last time. I dont know what starts it and I feel unwell for up to a week afterwards.

P112

I was told my the top professionals in my state that I had one the hardest to diagnose and most severe cases of IBS they had ever seen. I was also told frequently by many of the different healthcare professionals that it was all in my head and that I was crazy until I finally saw a specialist that recognized the symptoms.

P113

I undertook a 8 week course of Hypnosis recently and my symptoms of IBS have all but disappeared. I costantly used to take Peppermint oil, charcoal tablets and always have Imodium and Mortilium tablets handy just in case of flare ups.

I still get the odd flare up but it passes as quickly as it arrives. Hypnosis is (hopefully) the best thing I could have done as I have more energy and am enjoying life a lot more after the treatment.

P114

I find the website [www.helpforibs.com](http://www.helpforibs.com) useful for support and understanding.

P115

i am currently self managing, using stress management and relaxation exercises.

P116

My IBS is pain predominant. Every 3 months or so its so bad the only thing to ease the pain is morphine so i have my own supply from doctors. It effects every single area of my life and I hate it. Im off with it nearly a month every year so it effects my employment opportunities and i have to rely on my parents often to care for me. I suffer everyday and yet most people regard IBS as nothing, its nothing to me, its very severe and serious.

P117

feel doctors in this country are very reluctant to examine patients properly with IBS diagnosis. In the US they do colonoscopies etc, here they prod your stomach and say it's 'probably ibs'. had to fight to get referred to a gastroenterologist. (and still they only did 1 blood test) surely it's important to rule out coeliac, cancer and all other gut complaints before starting a course of treatment?

P118

I generally feel as though I am wasting the doctors time. In fact, one doctor actually counted out the number of times that I had been to visit the surgery in one year, in front of me, and told me this was unacceptable! As a result I felt ashamed, worthless and severely depressed (no surprises there then!) It has been a while since I suffered this bad with the symptoms, hence spending a Saturday night searching the web for help. (I am so relieved to have found this site...thank you). In fact, I have completed this questionnaire in tears! I have a stressful job managing a small but fantastic charity. Stress triggers my IBS which I find incredibly frustrating. I am currently in physical pain, I feel unattractive, unsociable and completely misunderstood! My partner is fed up with me 'always being ill' (he has now gone to the pub!). I now feel isolated and utterly fed up. I find myself becoming increasingly self-pitying and dramatic about it all ... 'When will I finally learn to be a 'better' person and be able to control my IBS and live a normal life!' (Actually, writing this is making me laugh!) Deep down I know that I've just got to get on with it. Thank you for this opportunity to get my frustrations off my chest. I've stopped crying now. :)

P119

I truly wish they could find a cure or medication that will help as I don't believe that they realize how much it effects your quality of life!

P120



My I.B.S has taken my life away. I now have verry little quality of life. I now can only leave the house rarely, due to pain, wind, mucus, diharear, & constipation

P121

I feel my Dr is not interested and I'm nnot sure where to go for help or what else to try

P122

I think when doctors first diagnose the person with ibs, they should provide support. All I got was one meeting with a dietician.

P123

Is IBS life htreatening or can it lead to more serious illnesses

P124

food intolerance plays a 99% role in my ibs

P125

Currently looking into having further tests done as pattern and severity has increased and to rule out ovarian cancer or hormone problems (monthly probs that mirror ibs symptoms but may not be and i always blame ibs for everything)

P126

Very little support is provided to determine the triggers of IBS to assist in self management. Only offered by Docs after several years of complaints and trial of various drugs!

P127

I find in general that GPs and Consultants just shrug their shoulders and you are told to "get on with it"

P128

i do not no a lot about it and it would be nice to lern more about it and what you can eat and what not.

P129

I have suffered an anal fistula and another abcess in the past year. The fistula requiring surgery.

P130

I have found out that certain foods eg bananas brown bread and some cheeses effect my condition so I avoid these at all costs.

P131

Recently my IBS has been extremely bad. I have a possible duodenal ulcer which has made me want to eat more which has an effect on my IBS. Also I had an exam so my stress levels were higher. I have recently undergone a blood test for food intolerance which was positive. I am waiting for the results of an in depth blood test to find out which foods I am intolerant to and will eliminate

these from my diet to see if that will alleviate my IBS and asthma. My doctor hasn't been much help with this.

P132

my ibs ruins my life at times i seem to be free of it and the moment i plan to do anything eg go on holiday go out ,along it comes again, sometimes are worse than others

P133

That the most annoying thing is that it seems to be my emotions that control it, like excitement or worry. If it was triggered by food I would just avoid the food that caused it, but emotions such as worry are hard to control at the best of times; even more so when you feel cramps and you are on a bus half way towards your destination.

P134

I would like to understand more about IBS i dont understand why I have the illness and I don't understand if it will get better or not. My IBS totally affects my life I never know how I'm going to feel, some days I am fine but others I feel extremely. i have had 11 weeks off sick in the past year.

P135

I think the hardest part is when your consultant cannot find any REAL problems and sends you away to get on with it!

P136

I had an operation at 3 weeks of age called pylorus stenosis (my feeding tube was squashed?) My mother also died from pancreatic cancer but was originally diagnosed with gall stones

I have never been allergic to anything and am really baffled as to why this condition rears its ugly head randomly and so severely.

P137

Because the pain can be so intense it is difficult to accept there is not a more serious condition underlying. It seems you get tested for everything possible, and when there are no positive results for any other condition it is declared you have IBS.

P138

suffered from chronic fungal infections for over 30 years (skin and thrush) given penicillin daily for over a year as a child for 'glandular fever' and tonsillitis

P139

Main feeling when I saw my GP after diagnosis was that as I don't have the 'more serious' inflammatory bowel diseases I should go away and get on with it.

P140

I have noticed my IBS symptoms are worse in the days before my period starts. I suffer badly from fatigue

P141

had a nervous breakdown because of my IBS

P142

to date I have both received & read conflicting advice & so don't know whether I'm doing right for doing wrong!

P143

Tried all 3 prescribed medicines for IBS and none of them worked, tried several free-from diets and herbal remedies and none seem to have worked so far.

P144

I feel a bit annoyed about the information available. For example some alternative treatments and IgG tests promise a cure. I can possibly believe one would offer a cure or some understanding, but not all of them. Hence there should be some control over claims people can make.

P145

There is nothing that triggers IBS for me

P146

Felt fobbed off by first doctor, only seeing another doctor I was referred for tests to rule out other things that could cause symptoms.

P147

My IBS starts as soon as I wake up in the morning, so any appointments I may have to make, have to be after midday. Some days I feel so weak that I have to spend the day in bed. It means that I miss out on a lot of LIFE.

P148

Have had it since 1974. Have learned to live with it.

P149

I think people's perception of IBS is a contributing factor. If IBS comes from stress then making people feel nervous and anxious about their problems heightens stress levels. (Excuse any poor spelling English was not my best subject!)

P150

most of the women on my mum's side of the family have IBS

P151

I have felt more comfortable about my IBS since joining THE Gut Trust the national Charity for Irritable Bowel Syndrome in the UK. [www.theguttrust.org](http://www.theguttrust.org)

P152

significantly worse in the last 2 years

P153

I dont think GPs understand the level and intensity of the pain suffered on a daily basis by many IBS sufferers like myself - they never believe how bad the pain is or the level of bloating that occurs - i was told it was my imagination

P154

Tendency to faint due to pain

P155

It would be really helpful if IBS sufferers were allowed to use disabled toilets!

P156

The best way I have found to control all the symptoms is regular ibuprophen

P157

I often feel very specific lower left pain (which has been investigated), which feels as if I've pulled a muscle on the inside.

P158

I feel that IBS is a misunderstood illness that people do not understand unless they live with it. It is not just the bowel problem it causes various other problems such as depression etc. It is about time that it is recognised for what it is. It is a disability. Thank you.

P159

IBS attacks are totally unpredictable and cause me a great deal of depression as I've suffered from it for 33 years.

P160

Do people with IBS have a increased chance/risk of developing bowel cancer?

P161

We need stronger pain killers and to be taken seriously

P162

antibiotics!!!!!!!!!!!!!!

P163

diet controlled

P164

do you feel ibs is related to candida ?

P165

When I was diagnosed as having IBS I was not convinced. However as IBS is such a vague description I have had to accept this. I have not had a normal bowel movement since having surgery two and a half years ago for a bladder

condition and removal of ovaries. I have never felt constipated but do suffer from severe bloating, unpleasant wind and chronic diarrhoea. Bowel movements are always extremely loose and can occur any time during the day or night. I do not like to leave the house or where I have eaten, eg. restaurant etc. for at least an hour after. Prior to surgery I did not have a bowel problem. I was as "regular as clockwork" every morning after breakfast. Occasionally if I was going on holiday or some other important event was imminent I could dash to the loo on the morning of the holiday/event but that was it for the day. Normal service was quickly resumed! Various treatments were suggested but these did not make any difference. Nor does what I eat, I have used processes of elimination without effect. One day a certain food may cause a great upset when it has not done so before. The specialist I saw said the IBS could be due to various factors, i.e. stress after the operation, physical and psychological. However, I have had operations in the past and this problem did not occur then. I have always been pleased that operations have been successful so I could get on with my life. This is all a complete mystery to me as well as being a great inconvenience. I hope your survey will assist in the search for treatments for IBS.

P166

I found taking pre-bio 7 tablets very useful, and I have been able to manage my IBS allot better since taking them.

P167

my psychologist first pointed out the link between my starting on antidepressants and the first major flare up of my IBS, i found colpermin really helped with the pain, but not much helps with the diarrhoea

P168

IBS affects my life a great deal. I can no longer happily or confidently go to restaurants as I always need to urgently need toilet soon afterwards and sometimes even mid-courses.

P169

I eliminated foods to help with my symptoms and now eat them in moderation

P170

the symptoms seem to follow a cycle, and it always gets into a vicious circle of anxiety that triggers it then it gets worse from the symptoms, and it always of course happen at the most inconvenient time. Staying at home with regular diet exercise and no stress would cure it, but for the boredom it would not be worth it. Imodium has made the single biggest improvement, taking it as a preventative measure when needed has restored a lot of my confidence and made the condition manageable to a certain extent. P

P171

Hi, i just wanted to clarify that i dont think my GP is rubbish or anything, Ive heard them say there isn't a lot out there for IBS except the couple of anti spasmodic drugs that i have tried. By far, the most successful IBS remedy i have tried has been natual Aloe Vera juice by a company called Forever Living. The stuff tastes awful but it really helped eliminate the bloating and that "urgent"

feeling. Im still trying to find something to control the really sharp cramps i get in the mornings.

P172

I had bowel cancer about 10 years ago.

P173

Had IBS since childhood

P174

Good luck with your research

P175

It is an extremely painful existance on a day to day basis yet no specialist can tell you much about it, there's no known cause and no known cure, basically you are sent away and told to live with it, basically live in missery!!! I am so ill and exhausted with it and have no live!!