



**SCHOOL OF PSYCHOLOGY
DOCTORATE IN CLINICAL PSYCHOLOGY**

MAJOR RESEARCH PROJECT

LITERATURE REVIEW: Illness representations and associated coping responses in adults experiencing multimorbidity: A systematic review and narrative synthesis.

EMPIRICAL PAPER: Understanding illness representations and coping responses for common mental health symptoms in adults experiencing multimorbidity: A thematic analysis.

Submitted by **Charlotte Donegan**, to the University of Exeter
as a thesis for the degree of **Doctor of Clinical Psychology**, October 2019

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Signature:

Table of Contents

Table of Contents	2
List of Tables	5
List of Figures	6
LITERATURE REVIEW	7
Abstract	8
Introduction	10
Aims of the Review	13
Method	14
Eligibility Criteria	14
Search	16
Study Selection	16
Evaluation Criteria	17
Data Extraction	17
Results	18
Study Selection and Characteristics	18
Qualitative Studies	20
Quantitative Studies	26
Summary of Evidence	36
Discussion	38
Bias and Limitations of Included Studies	41
Bias and Limitations of this Review	43
Clinical Implications	44
Areas for Future Research	45
Conclusion	46
References	48
Appendix A: Database Search	60

Appendix B: CASP Checklist	62
Appendix C: Quality Appraisal Scores and Ratings	63
Appendix D: Data Extraction Form	64
Appendix E: Nominated Journal Guidelines	75
EMPIRICAL PAPER	71
Abstract	72
Introduction	74
Aim of the Study	78
Method	79
Participants	79
Measures and Materials	83
Procedure	83
Method of Analysis	84
Results	87
Theme 1: Interconnected conditions	90
Theme 2: Methods of responding to mental health difficulties	91
Theme 3: Relationships; the importance of connection and understanding	95
Theme 4: Narrow treatment options	97
Discussion	100
Limitations of the Study	105
Clinical Implications	106
Areas for Future Research	108
Researcher Reflexivity	108
Conclusion	109
References	111
Appendix A: Illness Representation Example	124

Appendix B: Ethical Approval	125
Appendix C: List of Chronic Conditions	126
Appendix D: Participants' Health Information	128
Appendix E: Participant Information Sheet	129
Appendix F: Consent Form	133
Appendix G: Questionnaire	134
Appendix H: Interview Schedule	136
Appendix I: Debrief	137
Appendix J: Method of Analysis	139
Appendix K: Use of the CASP and COREQ	144
Appendix L: Dissemination Statement	146
Appendix M: Nominated Journal Guidelines	147

List of Tables

Literature Review

Table 1.	Inclusion and exclusion criteria for identifying studies for the systematic literature review.	15
Table 2.	Search terms for the literature review.	16
Table 3.	Summary of the qualitative studies included in the review.	21
Table 4.	Summary of the quantitative studies included in the review.	27
Table 5.	Database search details and results.	60
Table 6.	Items in the CASP (2018) quality appraisal tool for qualitative studies.	62
Table 7.	Quality assessment ratings for quantitative studies included within the review using the EPHPP Tool (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012).	63
Table 8.	Quality assessment ratings of qualitative studies included within the review using the CASP (2018) tool.	63

Empirical Paper

Table 1.	Inclusion and exclusion criteria for recruiting participants for the research.	80
Table 2.	Participants' pseudonyms and demographics.	82
Table 3.	Description of key themes and sub themes with deviant cases.	88
Table 4.	Participants' health information.	138
Table 5.	Data analysis process illustrated within Braun and Clarke's (2006) six phases of analysis.	139
Table 6.	The use of quality appraisal tools and guidelines at key phases within the research.	144

List of Figures

Literature Review

- Figure 1. The Common-Sense Model of Self-Regulation (Leventhal et al., 1980) adapted from Hagger and Orbell (2003). 12
- Figure 2. Flow diagram illustrating the process of selecting papers for inclusion. 19
- Figure 3. Ideas webbing conceptualising and exploring connections among the main findings of both qualitative and quantitative studies included in the review. 36

Empirical Paper

- Figure 1. The Common-Sense Model of Self-Regulation (Leventhal et al., 1980) adapted from Hagger and Orbell (2003). 76
- Figure 2. Study recruitment flowchart. 81
- Figure 3. Visual model of a key theme identified by the thematic analysis. 141



SCHOOL OF PSYCHOLOGY

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LITERATURE REVIEW

**Illness representations and associated coping responses in adults
experiencing multimorbidity: A systematic review and narrative synthesis.**

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Target Journal: **Psychology and Health**

Word Count: 6,699 words (excluding abstract, table of contents, list of tables, list of figures, tables, references, appendices)

**Submitted in partial fulfilment of requirements for the Doctorate Degree in
Clinical Psychology, University of Exeter**

Abstract

Objectives: Research indicates that illness representations are associated with the management of health conditions. They are therefore important to understand when supporting people to best cope with their illnesses. This systematic review aims to summarise and synthesise the literature exploring illness representations and associated coping responses in people experiencing more than one chronic condition.

Methods: A systematic review of literature published prior to November 2018 on MEDLINE, Embase, CINAHL, Web of Science and PsycINFO databases. Search terms included three broad areas; multimorbidity, health and illness representations. Results are synthesised using a narrative approach.

Results: Eight papers are included in the review and comprise qualitative and quantitative research designs. Findings indicate that illness representations in those with multimorbidity vary across conditions and individuals, while people hold representations relating to both individual conditions and multimorbidity. These representations have been associated with medication adherence and self-management behaviours.

Conclusions: This narrative synthesis highlights that representations have a role in coping. There is a need to consider illness representations in clinical consultations and in the delivery of care to improve condition management. Further research is needed to establish how this may be best achieved and to consider other variables which may influence representations and coping. Developing a theoretical framework which may account for both single and multimorbid representations will be important for such future research.

Keywords: Multimorbidity, chronic condition, common-sense model, illness representation, systematic review, narrative synthesis.

Introduction

Defining Multimorbidity. The occurrence of multiple chronic health conditions, termed multimorbidity, is now becoming the norm and is considered an overriding challenge currently facing healthcare systems (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005; World Health Organization, 2016). Multimorbidity is defined as the presence of two or more concurrent chronic health conditions (Johnston, Crilly, Black, Prescott, & Mercer, 2018; Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009), differing from comorbidity where an index disease and co-dependence is present (Meghani et al., 2013). Both comorbidity and multimorbidity refer to the occurrence of multiple chronic conditions within an individual. However, comorbidity refers to the combined effects of additional conditions related to an index condition, whilst multimorbidity indicates that no single condition takes priority over other conditions (Tugwell & Knottnerus, 2019). Multimorbidity is conceptually new and therefore its definition continues to be debated and a lack of consensus remains (Almirall & Fortin, 2013; Nicholson et al., 2019; Valderas, 2015). Consequently, comorbidity and multimorbidity are terms that continue to be used interchangeably, the misuse of these terms may have adverse implications for both research and clinical practice (Nicholson et al., 2019). For the purpose of this review we are referring to multimorbidity as the presence of two or more concurrent chronic physical or mental health conditions.

The Challenges of Multimorbidity. Multimorbidity poses many challenges to both individuals and healthcare systems (Aiden, 2018; Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007; Ording & Sørensen, 2013). Multimorbidity significantly impacts on the person, reducing quality of life, whilst increasing psychological distress and the risk of mortality (Fortin et al., 2004;

Fortin et al., 2006; Nunes, Flores, Mielke, Thume, & Facchini, 2016). The challenges facing healthcare systems often arise from the single disease organisation of healthcare which can lead to fragmented and inconsistent care (Harris, Dennis, & Pillay, 2013). Additionally, the management of multimorbidity is made more complex as a result of interactions between multiple conditions and treatments (Bramley & Moody, 2016). Consequently, effective and appropriate coping responses by the person experiencing multimorbidity is key to managing the challenges it poses (Lorig et al., 2001). However, poor self-management has been observed in those experiencing multimorbidity (Gallagher, Donoghue, Chenoweth, & Stein-Parbury, 2008). Such poor coping responses have been associated with worse health outcomes and increased healthcare use in those experiencing a chronic condition (Barker, Steventon, Williamson, & Deeny, 2018; Marti et al., 2013). Developing an understanding of the processes guiding coping responses may be key in meeting the needs of this growing population (Conner & Norman, 2005). One construct which has been studied due to its association with coping responses in those with single conditions and potential amenability to change is illness representations (Conner & Norman, 1998; Hagger & Orbell, 2003).

Illness Representations. Illness representations are defined as a person's own implicit beliefs and expectations about their illness or a health threat (Morrison & Bennett, 2017). These mental representations feature in many health models (Johnston & Johnston, 1998), yet the Common-Sense Model (CSM) of Self-Regulation has provided extensive work on this topic (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Phillips, & Burns, 2016). The CSM differs from other health models in that it is grounded in a general theory of cognition, considers both emotional and cognitive representations and places

focus on patient generated representations (Edgar & Skinner, 2003; Newman, Steed, & Mulligan, 2009). For these reasons this theoretical model will be considered within this literature review.

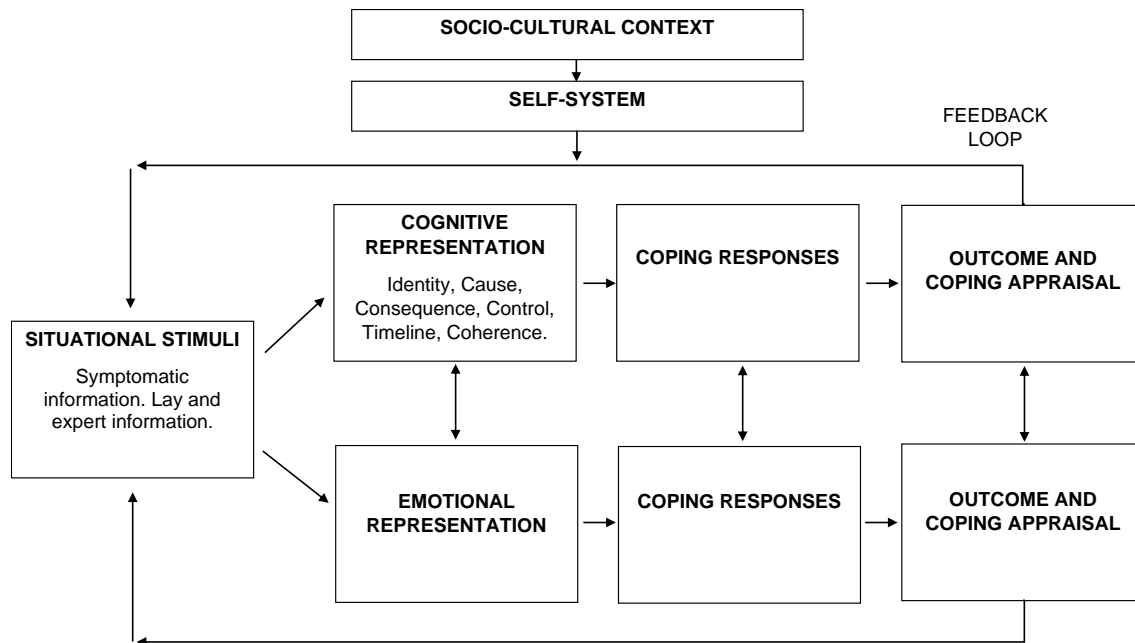


Figure 1: The Common-Sense Model of Self-Regulation (Leventhal et al., 1980) adapted from Hagger and Orbell (2003).

The development of illness representations are based on people's knowledge and experiences and inform the management of a health threat (O'Mahen, Flynn, Chermack, & Marcus, 2009). The cognitive and emotional illness representations held by people experiencing single conditions have been associated with coping, help-seeking and health outcomes (Hagger & Orbell, 2003; Hale, Treharne, & Kitas, 2007; Petrie & Weinman, 2006). If inaccurate or negative representations are developed, this can result in difficulties relating to coping efforts (Cameron & Moss-Morris, 2010). Therefore, it is suggested that illness representations are an important construct to understand and influence people's responses to their health conditions. Much of the research exploring illness representations has been undertaken with people who have a single

health condition (Gibbons et al., 2013). As multimorbidity is conceptually new, few studies have been conducted in this area (Academy of Medical Sciences, 2018; Smith et al., 2012). However, due to the growing multimorbidity population and its common occurrence in clinical practice, some research has been conducted exploring illness representations within the context of multimorbidity. These studies will be the focus of this review.

Summary. Multimorbidity has many adverse consequences for both people and healthcare systems. Poor coping responses may contribute to this adversity by increasing healthcare use and lead to poorer health outcomes (Barker et al., 2018; Marti et al., 2013). To understand individual's responses to their health conditions the CSM, a well-established and researched theoretical model, proposes that illness representations, which are amenable to change, are a key factor guiding coping responses. Illness representations have shown to be associated with coping responses and have demonstrated their utility as a useful construct to consider in the design and delivery of interventions and services for those experiencing single conditions (Sararoudi, Motmaen, Maracy, Pishghadam, & Kheirabadi, 2016). Therefore, exploring illness representations and their association with coping responses in those with multimorbidity may inform policy and practice, allowing the needs of this growing population to be met.

Aims of the Review

This systematic review aims to offer an objective account of the research exploring illness representations and their association with coping responses in those experiencing multimorbidity. Therefore, the focus of this review is on the following research question: What are the illness representations held by those

experiencing multimorbidity and how are these associated with coping responses?

This question will be addressed by identifying relevant papers and critically evaluating and integrating findings using a narrative synthesis approach (Popay et al., 2006). This review will aim to summarise and synthesise the topic area whilst identifying any gaps and contradictions within the research.

Method

An initial scoping review of the literature in relation to multimorbidity and illness representations was carried out on the Cochrane Database of Systematic Reviews and the Evidence for Policy and Practice Information Centre. This indicated that a review in the area had not been previously conducted and informed the need for the current systematic review. To inform the review the Preferred Reporting Items for Systematic review and Meta-Analyses (PRISMA) checklist was followed to report results (Moher, Liberati, Tetzlaff, & Altman, 2009). This was to ensure a transparent and standardised approach during the systematic review of the literature.

Eligibility Criteria

Eligibility criteria was based on the Sample, Phenomena of Interest, Design, Evaluation, Research type (SPIDER), search strategy tool and was informed by published research within the topic area (Table 1; Cooke, Smith, & Booth, 2012). This criterion informed the search strategy and was utilised in the study selection process. The inclusion criteria for this review encompassed all research designs and peer reviewed published literature. Studies included within the review explored illness representations and associated coping

responses in adults experiencing two or more chronic health conditions (Jabine, 1987).

Table 1

Inclusion and exclusion criteria for identifying studies for the systematic literature review.

Inclusion	Exclusion
<i>Sample</i>	
<ul style="list-style-type: none"> • Adults aged 18 and over. • Individuals with two or more chronic concurrent health conditions and therefore considered multimorbid. 	<ul style="list-style-type: none"> • Children, adolescents or non-human subjects. • Individuals who do not have two or more chronic health conditions, are experiencing substance misuse or “dual diagnosis” or a severe and enduring mental illness (e.g. psychosis, bipolar, personality disorders and eating disorders). • Studies that specifically focus on individuals’ experience of cancer and/or end of life.
<i>Phenomenon of Interest</i>	
<ul style="list-style-type: none"> • Illness representations of health conditions in those experiencing multimorbidity. • Consideration of the association or influence of illness representations on coping responses in those experiencing multimorbidity. 	<ul style="list-style-type: none"> • Studies that only focus on illness representations in those experiencing a single condition. • Any observations or interventions that are not based around reporting patients’ perspectives on their health conditions and its association with coping responses in the context of multimorbidity. • Studies that focus on health care professionals, family or carer perspective, decision making, or management of multimorbidity. • Studies that focus on comorbidity as this is a conceptually different category of phenomena.
<i>Design</i>	
<ul style="list-style-type: none"> • All research designs. 	
<i>Evaluation</i>	
<ul style="list-style-type: none"> • How individuals represent their illness whilst experiencing multimorbidity, and how this is associated with coping responses. 	
<i>Research Type</i>	
<ul style="list-style-type: none"> • Any qualitative, quantitative or mixed methods research. • Peer reviewed published papers. • Published in the English language. 	<ul style="list-style-type: none"> • Non-peer reviewed articles. • Unpublished papers, book chapters, conference papers or dissertations. • Papers not published in the English language.

Search

A search was carried out in November 2018 on five databases; PubMed (MEDLINE), Embase, CINAHL, Web of Science, PsychINFO (see Appendix A for results). Search terms (Table 2) varied slightly between databases as proximity searching was only available on some of the databases searched, all searches included title, abstract and keyword fields (Northcentral University Library, n.d.).

Table 2

Search terms for the literature review.

Construct	Search Terms
Multimorbidity	multimorbid* (to include multimorbidity, multimorbidities, multimorbid) or “multi-morbid*” or “multiple morbidity” or comorbid* or “chronic condition*” or “chronic disease*” or “long term condition*” or “multiple illnesses”
Physical Health or Mental Health	illness or condition or “physical health” or “physical illness” or “mental health” or “mental illness” or “mental wellbeing”
Illness Representation	(illness adj2 representation*) or (illness adj2 perception*) or (illness adj2 belief*) or (illness adj2 expectation*) or (cognitive adj2 representation*) or (patient adj2 belief*)

Study Selection

The search strategy and study selection procedure were informed by the four-phase flow diagram included within the PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) and other published guidance (Bramer, de

Jonge, Rethlefsen, Mast, & Kleijnen, 2018). Results produced from database searching were exported to a reference management programme. Following the removal of duplicates, papers titles and abstracts were screened against the inclusion and exclusion criteria. Papers were then screened by the full-text and a reason for exclusion was clearly documented. At the full-text stage six articles were reviewed by an independent-rater to ensure rigour within the process. Inter-rater reliability ($\kappa = 1$) indicated excellent agreement (Landis & Koch, 1977).

Evaluation Criteria

Identified qualitative studies were evaluated according to the Critical Appraisal Skills Program (CASP; 2018) research evaluation tool. The ten-item checklist was utilised (Appendix B) and a score was awarded for each fully met criterion. The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool (QAT) was used to evaluate quantitative studies included in the review (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012). A second-rater reviewed the quality of three studies, selected at random, included in the review to determine if these were reliably graded, the inter-rater reliability again indicated excellent agreement ($\kappa = 1$). The evaluation tools utilised measured risk of bias at the study level (Appendix C), whilst the quality ratings produced were used to inform the narrative synthesis.

Data Extraction

Data from the identified studies was extracted using a standard data extraction form recommended by the Cochrane Collaboration (Munro et al., 2007; Noyes & Lewin, 2011; Appendix D). This allowed key information –aims, methods, results, implications, limitations– to be extracted and summarised.

Results

Study Selection and Characteristics

The initial search of five databases produced 1494 results, 935 remained following duplicates being removed (Figure 2). Further reference searching, which involved reading around the topic area and forwards and backwards citation chaining, revealed a further 13 potentially relevant papers (Australian College of Applied Psychology Library, n.d.). However, all 13 papers identified through reference searching were excluded following being reviewed by title and abstract. After reviewing all 948 articles by title and abstract, 108 papers were included in the full-text review stage.

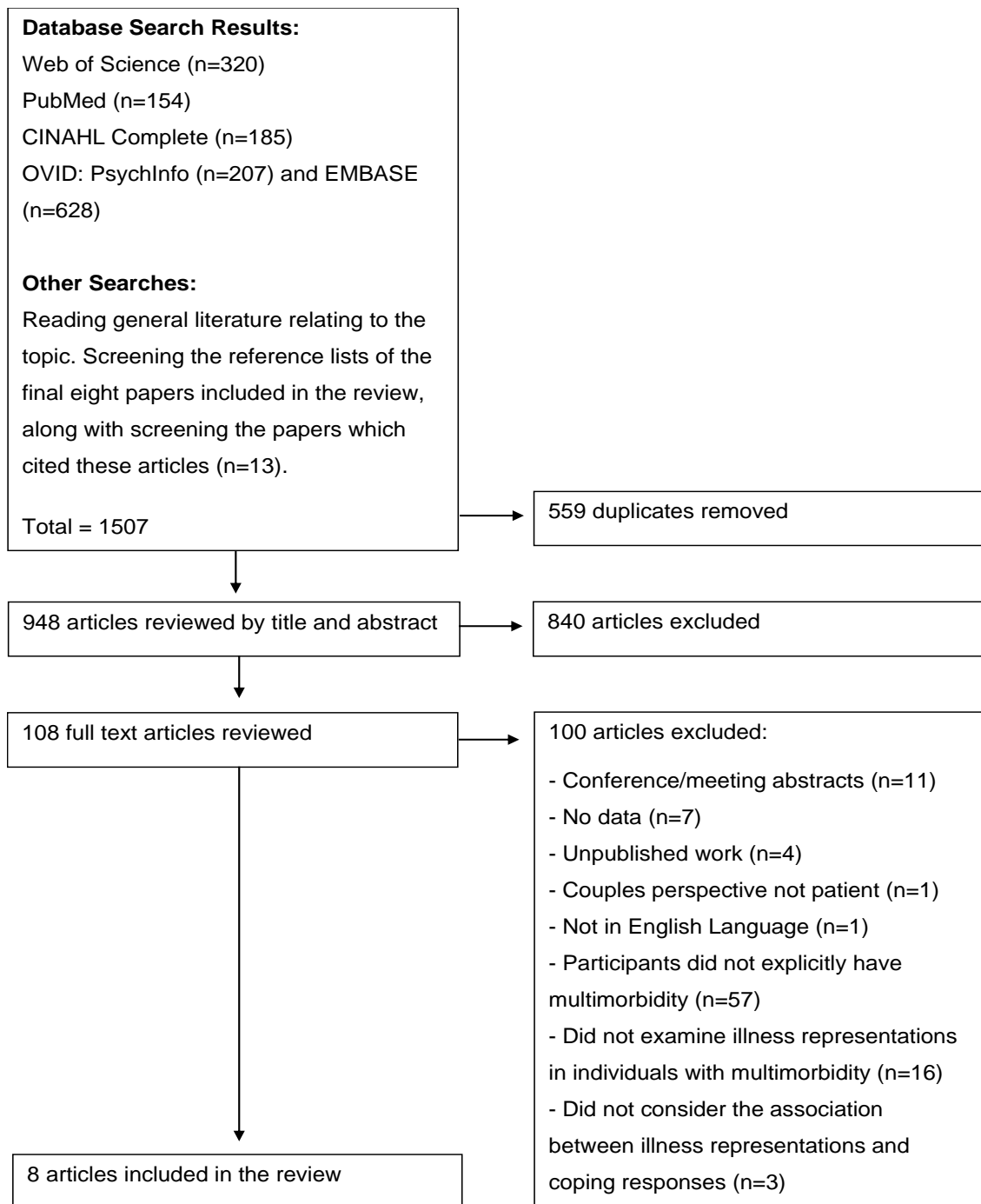


Figure 2. Flow diagram illustrating the process of selecting papers for inclusion.

Only eight studies prior to November 2018 explored illness representations and considered their association with coping responses in adults experiencing multimorbidity. As recommended by Cochrane guidelines (Ryan & Cochrane Consumers and Communication Review Group, 2013), studies were considered separately within the preliminary synthesis in

accordance to their research design. The relationships between research findings were then explored across all studies included in the review.

Qualitative Studies

Three qualitative studies met the inclusion criteria and have been included in this review. Study characteristics have been outlined below (Table 3).

Table 3

Summary of the qualitative studies included in the review.

Authors, Year and Country	Quality Score	Aim	Method / Data	Risk of Bias / Limitations	Main Findings
2. Boeckxstaens et al. (2012) Belgium	CASP: 8/10	Explore the perspectives of patients with Chronic Obstructive Pulmonary Disease (COPD) and comorbidities in primary care.	<ul style="list-style-type: none"> - Exploratory qualitative study. - Face-to-face, open interviews. - Participants (n=7) with COPD and an additional chronic condition interviewed. - Analysed using inductive thematic analysis. 	<ul style="list-style-type: none"> - No information provided regarding the researcher-participant relationship. - Despite qualitative approach, the study had a small sample size. 	<ul style="list-style-type: none"> - Participants integrated their illness into their lives which was discussed alongside positive coping responses such as planning, resting and pacing. - Illness representations of COPD were identified in relation to functional status (consequences), anxiety (emotional representation) and limited knowledge of the condition (cause and coherence). - A high internal locus of control (cause and control) was observed alongside limited self-management skills and reliance on medical assistance. - Polypharmacy, a representation relating to multimorbidity was discussed as a factor influencing medication non-adherence. - General coping strategies were adopted over disease specific approaches.
3. Bower et al. (2012) United Kingdom	CASP: 8/10	Examine the impact of multimorbidity on illness representations and explore how individuals represent multimorbid conditions.	<ul style="list-style-type: none"> - Exploratory qualitative study. - Face-to-face, semi-structured interviews lasting one to two hours. - Participants (n=28) with two chronic conditions interviewed. - Analysed using framework analysis. 	<ul style="list-style-type: none"> - Limited participants to those who experienced two of five chronic conditions. - Unclear if the researcher-participant relationship had been adequately considered. 	<ul style="list-style-type: none"> - Illness representations in relation to identity, cause, consequence, coherence and emotional representations were influenced by the presence of multimorbidity. - Participants had difficulty linking symptoms to particular conditions (cause and coherence), and discussed anxiety and frustration (emotional representation) in relation to their experience of multimorbidity. - Representations relating to multimorbidity itself were identified; related or unrelated conditions, condition combination and polypharmacy. These were associated with coping responses such as condition and medication

					prioritisation, medication nonadherence, and the synergies and antagonisms in condition management.
6. Mc Sharry et al. (2013)	CASP: 8/10	Exploration of cognitive representations and self-management in multimorbid individuals.	<ul style="list-style-type: none"> - Exploratory qualitative study. - Semi-structured, face-to-face interviews. - Participants (n=17) diagnosed with both diabetes and depression were interviewed. - Inductive thematic analysis and elements of grounded theory were used to analyse the data. 	<ul style="list-style-type: none"> - Unclear if consideration had been given to the researcher-participant relationship. - Comprehensive grounded theory analysis was not undertaken. - Additional multimorbid conditions were not considered. 	<ul style="list-style-type: none"> - Individuals hold illness representations regarding multimorbidity; related or unrelated conditions and polypharmacy. - Dimensions relating to cause, coherence and control were influenced by the representation of related or unrelated conditions. - Participants differed in the confidence in which they described representations, those who had poor confidence in their representations looked to others for information, whilst those who had successes in self-management and perceived control over their condition had increased confidence in their representations. - Others poor understanding of participants conditions created challenges to positive self-management. - Multimorbid illness representations appeared to guide coping responses in relation to separate management, management integration and management conflicts. - Polypharmacy influenced medication adherence.

Synthesis of Qualitative Studies. All three qualitative studies conducted face-to-face interviews with participants using an open (Boeckxstaens et al., 2012), or semi-structured approach (Bower et al., 2012; Mc Sharry et al., 2013) to gather data on illness representations and coping responses. Boeckxstaens et al. (2012) and Mc Sharry et al. (2013) analysed the data utilising an inductive approach to thematic analysis, elements of grounded theory were also utilised by Mc Sharry et al. (2013). Bower et al. (2012) also focused on emerging themes, data were analysed using framework analysis drawing on the CSM as the theoretical framework (Leventhal et al., 1980). Key findings identified by qualitative studies have been described below within two clusters; the presence of multimorbidity influences illness representations and representations guide coping responses.

The presence of multimorbidity influences illness representations.

Illness representations relating to identity, cause, consequence, control, coherence and emotion were reflected within participants' accounts in the included qualitative studies. Experiencing multimorbidity often influenced representations; causing anxiety and frustration (Boeckxstaens et al., 2012; Bower et al., 2012), having a greater functional impact and decreasing coherence in relation to linking symptoms to conditions (Bower et al., 2012). Qualitative studies also identified that participants not only hold representations relating to single conditions in the context of multimorbidity, but also develop illness representations relating to multimorbidity (Boeckxstaens et al., 2012; Bower et al., 2012; Mc Sharry et al., 2013). Studies noted that in an attempt to make sense of multiple illnesses and treatments participants developed new multimorbid representations. These were; related or unrelated conditions, condition combination and polypharmacy. Multimorbid representations illustrate

different dimensions to those outlined in the CSM and are unique to those experiencing multiple conditions (Leventhal et al., 1980).

The representation of related or unrelated conditions referred to participants viewing their multiple chronic conditions as connected and interacting or separate and discreet (Bower et al., 2012; Mc Sharry et al., 2013). These representations were divided in participant's accounts with some viewing their conditions as related and others viewing them as unrelated, illustrating that variance in representations exists between individuals (Bower et al., 2012; Mc Sharry et al., 2013). Mc Sharry et al. (2013) hypothesised that the observed variability between participants may have been due to some individuals focusing on more dominant conditions or alternative causes to conditions. This suggests that those who focused on all their conditions equally and identified complex causal relationships may have been more likely to develop the related conditions representation. Condition combination was a representation which illustrated the collective impact of experiencing multiple illnesses in terms of consequences and control (Bower et al., 2012). This representation was only identified by Bower et al. (2012) and illustrated the greater functional impact and increased treatment risk and consequences that experiencing multiple conditions presented. Polypharmacy was highlighted as a representation relating to multimorbidity within all three qualitative studies (Boeckxstaens et al., 2012; Bower et al., 2012; Mc Sharry et al., 2013). Within the polypharmacy representation participants often discussed the concerns, coherence, necessity and burden of taking multiple medications.

Representations guide coping responses. Representations relating to single illnesses held by participants within these studies were associated with coping responses. Low perceived personal control and limited knowledge of a

condition was associated with limited self-management skills and a reliance on medical assistance (Boeckxstaens et al., 2012). Condition consequences in relation to their potential severity and impact on functioning also guided coping responses in relation to condition prioritisation (Bower et al., 2012).

Representations relating to multimorbidity also appeared to have a role in guiding coping responses (Boeckxstaens et al., 2012; Bower et al., 2012; Mc Sharry et al., 2013). Condition combination and polypharmacy led participants to make judgements and decisions in relation to condition and treatment prioritisation (Boeckxstaens et al., 2012; Bower et al., 2012). Polypharmacy was also associated with medication taking, with participants' discussing non-adherence to medication when highlighting concerns relating to multiple medication use, its efficacy, necessity, limited understanding and negative side effects (Boeckxstaens et al., 2012; Bower et al., 2012; Mc Sharry et al., 2013). The representation of related conditions identified by both Bower et al. (2012) and Mc Sharry et al. (2013) lead participants to identify, consider and address antagonisms and synergies between conditions and their treatments. However, the joint management and management conflicts of conditions was only discussed by participants who viewed their health conditions as related (Mc Sharry et al., 2013). Those who held the unrelated conditions representation discussed managing their conditions separately.

Quality Appraisal. Qualitative studies were quality appraised utilising the CASP tool (2018; Appendix C). All studies scored 8/10 on the CASP with risk of bias predominantly relating to the researcher-participant relationship and ethical issues as it was unclear if these had been sufficiently considered. In qualitative data analysis it is important to consider and account for researcher bias and influence (Mehra, 2002). However, studies included within this review

did not adequately consider or clearly report the researcher's relationship with participants. This raises questions regarding methodological rigour and the trustworthiness of study findings (Noble & Smith, 2015).

Quantitative Studies

Five quantitative studies met the inclusion criteria and have been included in this review. Study characteristics have been outlined below (Table 4).

Table 4

Summary of the quantitative studies included in the review.

Authors, Year and Country	Quality Score	Aim	Method / Data	Risk of Bias / Limitations	Main Findings
1. Batchelder, Gonzalez and Berg (2014) United States of America	QAT: Weak	Explore medication nonadherence and compare illness and treatment representations in people with type 2 diabetes and HIV.	<ul style="list-style-type: none"> - Cross-sectional design. - Self-report questionnaires administered within an interview setting. - Participants (n=62) with HIV and type 2 diabetes. - Self-reported adherence, illness representations, medication beliefs, side-effects and symptoms. - T-tests and logistic regression analyses explored the relationship between representations and medication taking. 	<ul style="list-style-type: none"> - Additional illnesses were not considered. - Complete IPQ-R not administered. - Considered chronic conditions as comorbid. 	<ul style="list-style-type: none"> - Variance in representations was observed for both chronic conditions experienced in relation to particular dimensions. - HIV was discussed as having greater negative consequences than diabetes, while more personal control was reported for diabetes. - Treatment control, coherence and emotional representations were consistent across conditions. - The emotional representation of diabetes was associated with nonadherence to diabetes medication. - Symptom burden, medication concerns and symptoms of depression were also associated with medication taking.
4. Heid, Pruchno and Wilson-Genderson (2018) United States of America	QAT: Weak	Explore illness representations in multimorbid individuals and their association with self-management.	<ul style="list-style-type: none"> - Exploratory quantitative research design. - Pilot study utilising interviews and self-report measures. - Participants aged 64 and over (n=25) experiencing two or more chronic conditions. 	<ul style="list-style-type: none"> - Small select sample. - Only considered representations at one time point and in two conditions. - Only four subscales from 	<ul style="list-style-type: none"> - Illness representations in relation to the timeline, timeline-cyclical, consequences and personal control dimensions demonstrated variability and consistency within participants. - Timeline and timeline-cyclical representations were more consistent within persons. Whilst personal control and consequences were more illness dependant.

			- Descriptive statistics and interclass correlations were examined.	the IPQ-R administered.	- Illness representations were associated with the self-management behaviours for hypertension but not arthritis. - Perceiving hypertension as cyclical was associated with poor adherence to a healthy diet and less sleep, whilst more personal control was associated with adherence to a healthy diet and more sleep. Greater negative consequences were associated with less exercise.
5. Kenning et al. (2015)	QAT: Weak	Exploration of factors which predict self-management and health outcomes in those with multimorbidity.	- Longitudinal prospective quantitative study. - Participants (n=499) experiencing multimorbidity completed a range of self-report measures. - Correlational and multivariate linear regression analyses to determine factors that predict self-management and health outcomes.	- Limited to those experiencing a combination of five particular conditions. - Recruitment method and response rate weakened the external validity. - Examined three representation dimensions in the condition with the greatest personal impact.	- The chronic condition with the greatest personal impact had, on average, moderate scores for condition consequences and personal control, while high scores for treatment control were observed. - Condition consequences were negatively correlated with self-management behaviours at 4 months. - Illness consequences, experiences of healthcare and the experience of multimorbidity all predicted self-management or health status.
United Kingdom					
7. Schüz et al. (2014)	QAT: Moderate	Examine three competing operationalisations of multimorbid illness representations in predicting	- Longitudinal study. - Participants (n=215) aged 65 and over with two or more chronic health conditions completed questionnaires measuring illness representations,	- Focused only on the two most severe conditions identified by participants.	- The B-IPQ reflect a three-factor model; consequences, control and timeline. - Illness representations relating to both single conditions and multimorbidity are held by participants. - Participants hold combined overall representations of their multiple illnesses,
Germany					

		medication adherence and physical functioning.	physical functioning and medication adherence. - Outcome measures were completed at two time points over six months. - Exploratory factor analysis and multiple regression analyses.		suggesting a multimorbid-specific representation. - Medication adherence was predicted by greater negative consequences, illness timeline and perceived personal control. - Physical functioning was predicted by control and consequence representations.
8(a&b). Weiss et al. (2016)	QAT: Weak	Examine the relationship between illness representations, medication beliefs and medication adherence in individuals experiencing multimorbidity.	- Longitudinal design. - Participants (n=151) had HIV and another chronic condition. - Two cohorts were included: HIV and hypertension (8a) and HIV and chronic kidney disease (8b). - Electronically monitored medication adherence and self-reported measures of illness representations and medication beliefs. - Descriptive statistics, t-tests, ANOVA and correlational analyses.	- Study participation criteria may have biased the sample, particularly in relation to medication adherence. - Small sample size (n=37) within one cohort (8b).	- Some illness representations for single conditions; coherence, timeline, identity, consequences and emotional representations, varied between the different chronic conditions experienced (8a). - Dimensions relating to treatment and personal control did not differ across conditions (8a). - Illness representations were consistent between chronic conditions (8b). - Medication adherence for HIV was associated with good condition coherence and perceiving the condition as less controllable by treatments (8a).

Synthesis of Quantitative Studies. All five quantitative studies included in this review used standardised questionnaires to measure illness representations. Questionnaires were developed based on the CSM framework (Leventhal et al., 1980). Coping responses, such as medication taking and self-management behaviours were captured by self-report measures or electronic devices.

Three longitudinal studies administered illness representation measures at a single timepoint and explored their association with self-management, health outcomes, physical functioning, medication adherence or healthcare service delivery (Kenning et al., 2015; Schüz et al., 2014; Weiss et al., 2016). Studies utilised a variety of statistical analyses to measure the association between variables. Two other quantitative studies adopted a cross-sectional (Batchelder et al., 2014) and exploratory (Heid et al., 2018) research design, where variables were measured at a single timepoint. A variety of statistical analyses examined associations between illness representations, mental health conditions, medication beliefs, medication adherence and self-management behaviours. Key findings from quantitative studies reflect three clusters; variability and consistency in illness representations, the representation of multimorbidity and illness representations association with coping responses.

Variability and consistency in illness representations. Findings suggest that moderate to high scores were largely noted for coherence, timeline, personal and treatment control dimensions (Batchelder et al., 2014; Heid et al., 2018; Kenning et al., 2015; Weiss et al., 2016), whilst low to moderate scores were observed for identity and emotional representation dimensions (Weiss et al., 2016). This illustrates that representations demonstrate some commonality across participant's accounts, although these

were not observed for all conditions or within all studies included in the review. Three quantitative studies found that dimensions of illness representations demonstrated variability and consistency between individuals and chronic conditions experienced (Batchelder et al., 2014; Heid et al., 2018; Weiss et al., 2016). Some dimensions of illness representations demonstrated variability between conditions and were considered illness dependent, while other dimensions were consistent between conditions and within persons.

The consequence representation dimension varied between chronic conditions experienced and was identified as illness dependent in three studies (Batchelder et al., 2014; Heid et al., 2018; Weiss et al., 2016), whilst personal control was also identified by two studies as illness dependent (Batchelder et al., 2014; Heid et al., 2018). This suggests that representations relating to illness consequences and personal control are guided by the chronic condition experienced. However, Weiss et al. (2016) found the personal control dimension to be consistent between conditions. Treatment control, coherence, timeline and emotional representation dimensions also demonstrated consistency between conditions or within persons in three studies (Batchelder et al., 2014; Heid et al., 2018; Weiss et al., 2016). This suggests that these dimensions are not driven by illness differences and are possibly influenced by personal outlooks. Other dimensions of illness representations were also identified as demonstrating consistency or variability within studies. However, there was a lack of consensus regarding the dimensions of illness representations considered more illness or person dependent between studies, illustrating outcome variability between studies included within this review.

Two studies that identified variability in illness representations offered some explanation to account for the discrepancy (Batchelder et al., 2014; Heid

et al., 2018). Batchelder et al. (2014) suggested that cultural influences and treatment regimens may have had a role in the representation variability observed between HIV and diabetes. Many participants had been diagnosed with HIV at a time of high social stigma alongside an increase in treatment availability. It was hypothesised that this may have influenced perceptions of illness consequences. The difference in treatment for HIV and diabetes may also account for the variability observed in the personal control representation. Condition management for HIV may only involve medication adherence, whereas diabetes management may involve multicomponent self-care requiring complex and challenging behavioural and lifestyle changes (Batchelder et al., 2014). Alongside this, person-level characteristics such as personality may also have had a role in accounting for some of the variability observed in illness representations (Heid et al., 2018).

The representation of multimorbidity. Schüz et al. (2014) explored competing models of illness representations in multimorbidity and identified that while individuals hold representations relating to single conditions, they also combine their multiple illness representations for single conditions into an overall representation of multimorbidity. The dimensions of illness representations overlap to form an overall representation of multimorbidity rather than participants only focusing on their most prominent condition.

Illness representations association with coping responses. All quantitative studies included in the review identified an association between illness representations and medication-taking or self-management behaviours. Medication adherence was associated with many illness representations for individual conditions. Those who perceived their illness to have many negative consequences, had a good understanding of their illness and viewed their

illness as chronic were more likely to adhere to medication taking (Schüz et al., 2014; Weiss et al., 2016). High personal control and low treatment control were also associated with medication adherence, suggesting that participants who viewed their condition as being controllable by themselves but not the prescribed treatment were more likely to take their medication (Schüz et al., 2014; Weiss et al., 2016). Adherence to medication was also associated with the emotional representation of an illness, with increased distress associated with medication non-adherence (Batchelder et al., 2014).

Studies found that limited or poor self-management behaviours were associated with conditions which were perceived to have many negative consequences and were cyclical in nature (Heid et al., 2018; Kenning et al., 2015), whilst high personal control was associated with positive self-management (Heid et al., 2018). These findings suggest that particular dimensions of illness representations, such as control, consequence and timeline, were associated with condition self-management. For example, Heid et al. (2018) found that people with hypertension who viewed their condition as having negative consequences were less likely to engage in exercise. Viewing hypertension as cyclical in nature resulted in less sleep and poorer adherence to a reduced fat diet, while those who believed they had more personal control over their condition adhered to a reduced fat diet and had more sleep.

Although all five quantitative studies showed that illness representations were associated with coping responses, some found that this was condition dependent (Heid et al., 2018; Weiss et al., 2016). Heid et al. (2018) found an association between representations and self-management behaviours in those with hypertension, but did not for those experiencing arthritis. Equally, findings from the study conducted by Weiss et al. (2016) illustrated an association

between representations and medication adherence in the HIV and hypertension cohort, but not the HIV and chronic kidney disease cohort. These findings suggest that the type and combination of conditions experienced may have a role in coping. Studies also identified other variables that were associated with coping responses (Batchelder et al., 2014; Kenning et al., 2015). Concerns regarding medication were associated with medication non-adherence (Batchelder et al, 2014), while ease in healthcare utilisation was associated with improved self-monitoring and insights (Kenning et al., 2015). Findings from the quantitative studies included in this review suggests that representations are associated with coping, however, this varied within and between studies, with condition type and other variables appearing to play a role.

Quality Appraisal. Quantitative studies were quality appraised utilising the QAT tool, this highlighted that all studies were weak in quality, with the exception of one study graded as moderate (Armijo-Olivo et al., 2012; Appendix C). A variety of methodological issues were identified across quantitative studies included in this review. The precision and interpretation of results may have been influenced by the small sample sizes observed in some studies (Heid et al., 2018; Weiss et al., 2016). This limitation, alongside poor response rates and recruitment strategies decreases the external validity and generalisability of such studies (Kenning et al., 2015). Only the study completed by Schüz et al. (2014) was assessed as very likely to be representative of the target population. Nevertheless, there were some criteria on the QAT that may have been less important for the studies within this review to adhere to, for example item four, 'blinding'. Within the quantitative studies it was unclear if participants were aware of the research question, and although blinding may

not have been a particularly important factor in the studies reviewed, a knowledge of this information may have been important when considering respondent bias. Although, it is not important and not appropriate for researchers to be unaware of participants "interventions status" as no interventions were delivered within these studies. Considering this the 'blinding' criteria for all studies were rated as weak, influencing their overall quality rating in relation to this tool.

All quantitative studies included within the review utilised self-report approaches to measure illness representations, four of these studies also used self-report measures to gather information on coping responses. A strength of these measures is that they allow data to be easily obtained, however, they do pose a risk of bias. Factors such as response bias, a lack of introspective ability or poor understanding and interpretation of questions, particularly in relation to an abstract concept such as illness representations, may have influenced responses recorded by participants. Therefore, there is a need to question the validity and reliability of the illness representations and coping responses reported by studies (Demetriou, Ozer, & Essau, 2015). Although the standardised questionnaires utilised by studies measuring illness representations within this review have shown to be valid and reliable (Hagger & Orbell, 2005), four studies only used or reported on some subscales of these measures (Batchelder et al., 2014; Heid et al., 2018; Kenning et al., 2015; Schuz et al., 2014). The validity and reliability of the brief-Illness Perception Questionnaire (IPQ) utilised by two studies (Kenning et al., 2015; Schüz et al., 2014) has also been debated (Broadbent, Petrie, Main, & Weinman, 2006; Van Oort, Schröder, & French, 2011). Despite the IPQ being the most established measure of illness representations, these were designed for those experiencing

single not multiple conditions (Moss-Morris et al., 2002; Weinman, Petrie, Moss-Morris, & Horne, 1996).

Summary of the Evidence

The main findings identified by this review are captured within the ideas webbing (Figure 3) below. Key concepts and their relationships between all studies included in the review are illustrated (Clinkenbeard, 1991). Numbers shown within figure 3 correspond to the study reference (see Table 3 & 4).

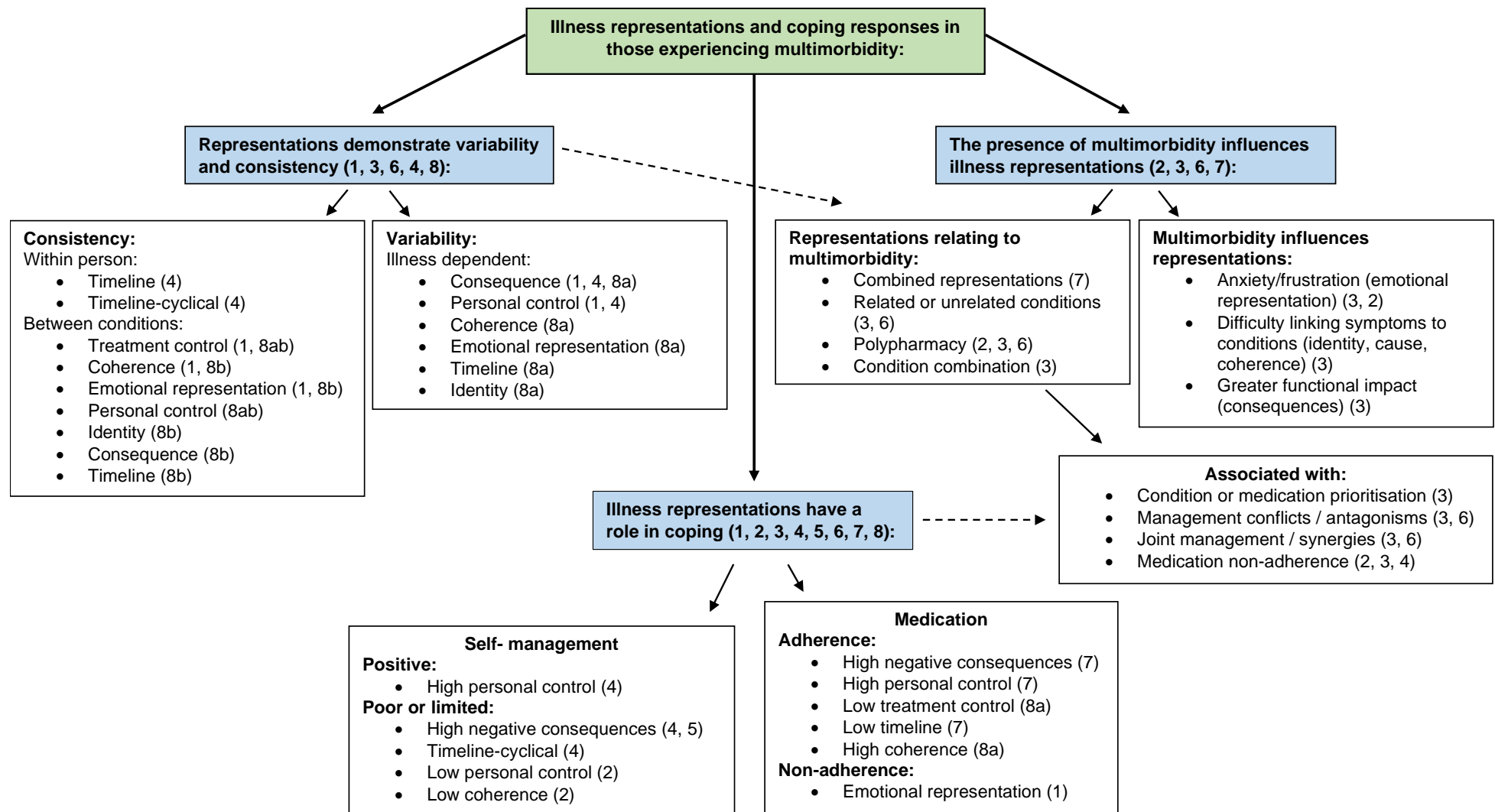


Figure 3: Ideas webbing conceptualising and exploring connections among the main findings of both qualitative and quantitative studies included in the review.

Three key findings have been identified across all eight studies included in the review. These include; 1) representations demonstrate variability and consistency, 2) the presence of multimorbidity influences illness representations, and 3) illness representations have a role in coping. As illustrated within figure 3, findings from this review have highlighted that illness representations relate to both individual chronic conditions and multimorbidity. Five studies, of varying design, identified that representations vary, often guided by individual or condition factors. Four studies, three of which were qualitative studies, identified that the presence of multimorbidity influences representations with some individuals developing multimorbid representations. All studies included within the review identified that representations have a key role in coping responses such as self-management or medication adherence. The representations associated with these coping responses somewhat varied between studies. Studies which identified multimorbid representations also highlighted an association with responses related specifically to multimorbidity, such as joint management and condition prioritisation.

Discussion

This systematic review aimed to answer the question: What are the illness representations held by those experiencing multimorbidity and how are these associated with coping responses? Illness representations held by those experiencing multimorbidity relate to both single and multiple illnesses, these demonstrate variability in relation to individuals and conditions. Representations are associated with self-management behaviours and medication taking, as well as multimorbid specific coping such as condition prioritisation and joint management. This section discusses the key matters arising from the main

findings of this review, the bias and limitations both at the study and review level and the clinical and research implications.

Holding single and multimorbid representations. This review illustrates that illness representations are held in relation to both single conditions and multimorbidity. These representations vary between conditions and individuals, consistent with previous research (Rozema, Völlink, & Lechner, 2009). This variability may be exacerbated given the variety of complex conditions and symptoms experienced by those with multimorbidity (Marengoni et al., 2011), and the different participant characteristics and study heterogeneity in this review. Alongside this, many factors such as self-efficacy, functional limitations, primary care accessibility, culture and exposure to health information, have been shown to influence the way people think about and experience their conditions (Benyamini, 2011; Peltzer, Mmusi, Phaswana, & Misi, 2006; Schüz et al., 2012; Schüz et al., 2015). The variability observed in this review illustrates the distinctiveness of representations and the need to give careful consideration to each person and condition, and to the variables which may influence such representations.

The CSM (Leventhal et al., 1980) had provided a useful framework to formulate the research question and consider the concept of illness representations and their association with coping responses in those experiencing multimorbidity. Although it has allowed for the findings of this review to be considered in the broader context and field of knowledge, it appears insufficient to comprehend all the review findings. As identified in figure 3 the findings of this review reflect many of the key concepts proposed by the CSM, such as individuals holding representations relating to a variety of dimensions and these representations having an association with participants

copied responses. However, this model was originally developed considering individuals' representations and responses to single, not multiple, conditions. The multimorbid representations identified by studies within this review are not able to be considered within the clear and concrete dimensions outlined within the CSM. Therefore, despite these dimensions showing construct and discriminant validity across a variety of single illnesses (Hagger & Orbell, 2003), these dimensions do not appear to coherently capture all the representations held by those experiencing multimorbidity. The CSM may therefore need to be reconceptualised with the addition of further dimensions considering both single and multimorbid representations. The findings of this review suggest that although elements of the CSM have potential utility, further research of this model in those with multimorbidity is needed to extend the model so that it may capture both single and multimorbid representations and address the unique features of multimorbidity.

The role of personal control and coherence in effective coping.

Many dimensions of illness representations within this review appear to be associated with coping. However, high personal control and good condition coherence appear to play a key role in positive coping, these findings are consistent with previous research in those with single conditions (Fok, Chair, & Lopez, 2005; Gallagher, Donoghue, Chenoweth, & Stein-Parbury, 2008; Kemp Morley, & Anderson, 1999; Moss-Morris, Petrie, & Weinman, 1996). Coherence also appeared to be reflected in participants multimorbid representations and associated coping responses. Those who hold multimorbid illness representations such as related conditions and condition combination may have more understanding of how their conditions overlap and interact. This understanding may allow them to utilise self-management strategies to benefit

more than one condition or prioritise conditions appropriately (Mc Sharry et al., 2013), leading to more effective management of their multiple conditions.

Nevertheless, control and coherence dimensions were not observed to be associated with coping responses within all studies or for all chronic conditions. Although illness representations are the most consistent variable influencing coping, they do not account for all the variance (Fortune, Richards, Griffiths, & Main; 2002; Leysen et al., 2018). Difficulties in healthcare encounters, poor mental health and treatment beliefs have been associated with coping by studies within this review (Batchelder et al., 2014; Kenning et al., 2015). Other research has also recognised a variety of other factors guiding condition management in those with multimorbidity (Bayliss, Ellis, & Steiner, 2007; Chilcot, Wellsted, Davenport, & Farrington, 2011). This highlights a need to consider the degree to which illness representations are associated with coping and the role other variables may have. Many studies in this review only explored associations between representations and coping responses, therefore there may be a need to explore causality between these variables.

Bias and Limitations of Included Studies

The key issues in relation to bias and limitations that have been identified at the study level are the concept of multimorbidity and the measuring and reporting of illness representations.

Concept of multimorbidity. Although most studies identified their participants as experiencing multimorbidity, two studies included in the review referred to participants as experiencing comorbidity (Batchelder et al., 2014; Weiss et al., 2016). Although the sample within these studies included participants who met the criteria for multimorbidity, differences in terminology

may have led to differing interpretations by researchers and therefore needs consideration.

Several studies included in the review limited the sample to those experiencing particular types of chronic conditions, whereas multimorbidity encompasses all chronic health conditions. Conditions with often well-defined diagnoses have been included, potentially considering a narrow and less complex multimorbid population (Bower et al., 2012; Heid et al., 2018; Kenning et al., 2015). Some studies only focused on illness representations in one or two of the conditions experienced, or the condition perceived to be most severe by participants (Kenning et al., 2015; Mc Sharry et al., 2013; Schüz et al., 2014). Focusing on only one condition fails to consider other co-existing health conditions and their association or influence on illness representations and coping responses. This issue potentially oversimplifies a complex area.

Measuring and reporting illness representations. The method adopted to measure illness representations differed between studies depending on the research design. Qualitative studies utilised individual interviews and quantitative studies utilised self-report standardised questionnaires designed for those experiencing single conditions. Representations relating to multimorbidity are also more frequently identified in qualitative studies. Therefore, there is a need to consider the role that research design has had in shaping the understanding of the illness representations held by those with multimorbidity. Those using standardised measures are limited in the representations they may identify while qualitative studies have allowed for novel representations to be identified.

Although all studies included within this review explored illness representations in those experiencing multimorbidity, some quantitative studies focused more on their association with coping responses (Heid et al., 2018; Kenning et al., 2015; Schüz et al., 2014). Therefore, the reporting of the illness representations held by participants has not always been coherently and comprehensively conveyed. This may have shaped the understanding of illness representations within this review.

Bias and Limitations of this Review

Several limitations have been identified at the review level and therefore caution is needed before generalising the review findings. A key issue, also identified as a limitation at the study level is the lack of consensus regarding the concept of multimorbidity (Almirall & Fortin, 2013). This may have influenced the studies included within the review (Smith et al., 2012). Studies limiting the sample to those experiencing particular types of chronic conditions may have excluded relevant individuals with undiagnosed conditions or more complex presentations. The review therefore may not accurately represent the multimorbid population.

Consideration needs to be given to the heterogeneity of the studies included in this review in relation to the health conditions experienced by participants. It is important to acknowledge that not all chronic conditions are experienced, represented and responded to equally. Consideration of this limitation is needed given that such variability was observed in relation to the representations and associated coping responses held by participants.

The inclusion of grey literature may have broadened the scope of the search and reduced publication bias (Dalton, Bolen, & Mascha, 2016).

However, searching grey literature was beyond the scope of this review. Additionally, only studies published in the English language were included which presents a potential selection bias. Despite measures being taken to increase rigour it was not feasible to have more than one researcher involved at all stages of the review as is recommended (Centre for Reviews and Dissemination, 2008).

The overall quality of quantitative studies included in this review were on average rated as 'weak'. As aforementioned, this overall quality rating may have been influenced by the criteria included in the QAT, a tool developed to evaluate a variety of study designs (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012). Nevertheless, quality ratings suggest that the quantitative studies included in this review are of low quality, suggesting that caution is needed when considering the findings of this review and the application of its recommendations (Khan, Kunz, Kleijnen, & Antes, 2003). However, the rigorous appraisal of study quality and acknowledgment of study limitations will allow the findings and conclusions of this review to be considered in light of these.

Clinical Implications

Personalised and person-focused care needs to be fundamental to clinical consultations with those experiencing multimorbidity, as suggested in previous research (Barnett et al., 2012; Starfield, 2011). Clinicians need to explore and understand the illness representations and coping responses for each single condition and multimorbidity. This will be important in patient-provider interactions as people's needs will differ according to the representations they hold (Mc Sharry et al., 2013). For example, individuals who hold multimorbid representations concerning related conditions or combined conditions may

benefit from discussing management antagonisms and synergies to improve self-management. However, those who discuss poor coherence regarding a dominant condition may benefit from receiving health information in relation to that condition. Different coping strategies, treatments and discussions with clinicians may therefore benefit different people depending on what illness representations they hold. Considering representations in consultations with those experiencing multimorbidity holds promise given that exploring representations in consultations with those experiencing single conditions has shown to have a positive impact on patient-practitioner communication (de Ridder, Theunissen, & van Dulmen, 2007).

Exploring illness representations will not only allow clinicians to provide the best treatment options and advice to individuals, but also provides opportunity to challenge and change representations. Targeting inaccurate illness representations and increasing peoples understanding and perceived personal control of their condition will be important in improving coping responses in this population (Batchelder et al., 2014; Boeckxstaens et al., 2012; Heid et al., 2018; Schüz et al., 2014). Nevertheless, there is a need to consider how representations may be best explored in consultations with those experiencing multimorbidity and the additional training clinicians may need to deliver such care.

Areas for Future Research

This review highlights many potential avenues for future research. This includes; 1) considering how to best explore and change illness representations in those with multimorbidity, 2) considering the factors that have a role in determining illness representations, 3) developing an understanding of causality

in the relationship between illness representations and coping responses, 4) developing and adapting a theoretical framework which may capture single and multimorbid illness representations.

These explorations may provide a better account of the variability observed for illness representations and coping response between and within studies included in this review. An increased knowledge and understanding of these variables may support interventions targeting the development of positive representations and improving coping responses (Rijken et al., 2014). Revisions to the CSM may be key in allowing such research to be collected, understood and utilised in the design and delivery of interventions for this population (Alderson, 1998; Anderson, 2008; Leventhal et al., 1980). Nonetheless, any future research in this area should include a clear conceptual definition of multimorbidity, high quality and rigorous research and standardised measures of illness representations. This may ensure the generalisability and applicability of such research (Smith et al., 2012). Although advancements have been made in the development of a standardised measure for multimorbid representations, the scale neglects to consider representations of single conditions or those who develop weak representations of multimorbidity (Gibbons et al., 2013).

Conclusion

Overall, this review looked at the existing research examining illness representations and associated coping responses in those experiencing multimorbidity. This systematic review in an area of growing interest, identifies a small but emerging body of literature. Illness representations relate to both single and multiple conditions, and are altered by the presence of multimorbidity. Coping responses are dynamic and can differ for each chronic

condition experienced, they are often guided by the specific illness representations held, consistent with previous research and the CSM (Hagger & Orbell, 2003; Leventhal et al., 1980). However, the research to date is limited by the approaches adopted to measure illness representations, the low quality of some studies and an over-reliance on individuals with well-defined chronic health conditions.

Findings suggest that person-focused care is needed when supporting those experiencing multimorbidity. Illness representations should be explored in clinical consultations with clients through discussion in order to inform the information and intervention provided, increasing the possibility of successful coping. Developing and amending the existing theoretical framework to capture novel multimorbid representations will be important for future research and clinical practice. Implementing these clinical and research implications may allow us to improve outcomes for this growing population, which remains an important goal for healthcare providers worldwide.

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Appendix A: Database Search

Table 5

Database search details and results.

	Key Terms
<p><u>Web of Science</u></p> <p>1900 to 28/11/2018</p> <p>Searched by 'Topic' – title, abstract and keywords.</p> <p>Results: 320</p>	<p>multimorbid* OR multi-morbid* OR "multiple morbidity" OR comorbid* OR "chronic condition*" OR "chronic disease*" OR "long term condition*" OR "multiple illnesses"</p> <p>AND</p> <p>illness OR condition OR "physical health" OR "physical illness" OR "mental health" OR "mental illness" OR "mental wellbeing"</p> <p>AND</p> <p>"illness representation*" OR "illness perception*" OR "illness belief*" OR "illness expectation*" OR "cognitive representation*" OR "patient belief*"</p>
<p><u>PubMed</u></p> <p>1966 to 28/11/2018</p> <p>Searched by 'Text Words' – title, abstract, MeSH Headings & Subheadings etc.</p> <p>Results: 154</p>	<p>multimorbid* OR multi-morbid* OR "multiple morbidity" OR comorbid* OR "chronic condition*" OR "chronic disease*" OR "long term condition*" OR "multiple illnesses"</p> <p>AND</p> <p>illness OR condition OR "physical health" OR "physical illness" OR "mental health" OR "mental illness" OR "mental wellbeing"</p> <p>AND</p> <p>"illness representation*" OR "illness perception*" OR "illness belief*" OR "illness expectation*" OR "cognitive representation*" OR "patient belief*"</p>
<p><u>CINAHL Complete</u></p> <p>1992 to 28/11/2018</p> <p>Searched by 'Select at Fields Option'- Title, abstract and subject fields.</p> <p>Results: 185</p>	<p>multimorbid* OR multi-morbid* OR "multiple morbidity" OR comorbid* OR "chronic condition*" OR "chronic disease*" OR "long term condition*" OR "multiple illnesses"</p> <p>AND</p> <p>illness OR condition OR "physical health" OR "physical illness" OR "mental health" OR "mental illness" OR "mental wellbeing"</p> <p>AND</p> <p>"illness representation*" OR "illness perception*" OR "illness belief*" OR "illness expectation*" OR "cognitive representation*" OR "patient belief*"</p>
<p><u>PsychInfo</u> (OVID)</p> <p>1806 to November Week 3, 2018</p> <p>Searched by mp. (multi-purpose) - Title, Original Title,</p>	<p>multimorbid* or "multi-morbid*" or "multiple morbidity" or "comorbid*" or "chronic condition*" or "chronic disease*" or "long term condition*" or "multiple illnesses"</p> <p>AND</p> <p>"illness" or "condition" or "physical health" or "physical illness" or "mental health" or "mental illness" or "mental wellbeing"</p> <p>AND</p>

<p>Abstract, and Subject Heading.</p> <p>Results: 207</p>	<p>(illness adj2 representation*) or (illness adj2 perception*) or (illness adj2 belief*) or (illness adj2 expectation*) or (cognitive adj2 representation*) or (patient adj2 belief*)</p>
<p>EMBASE (OVID)</p> <p>1974 to 28/11/2018</p> <p>Searched by mp. (multi-purpose) - Title, Original Title, Abstract, and Subject Heading.</p> <p>Results: 628</p>	<p>multimorbid* or "multi-morbid*" or "multiple morbidity" or "comorbid*" or "chronic condition*" or "chronic disease*" or "long term condition*" or "multiple illnesses"</p> <p>AND</p> <p>"illness" or "condition" or "physical health" or "physical illness" or "mental health" or "mental illness" or "mental wellbeing"</p> <p>AND</p> <p>(illness adj2 representation*) or (illness adj2 perception*) or (illness adj2 belief*) or (illness adj2 expectation*) or (cognitive adj2 representation*) or (patient adj2 belief*)</p>

Appendix B: CASP Checklist

Table 6

Items in the CASP (2018) quality appraisal tool for qualitative studies.

Item	Question
1	Was there a clear statement of the aims of the research?
2	Is a qualitative methodology appropriate?
3	Was the research design appropriate to address the aims of the research?
4	Was the recruitment strategy appropriate to the aims of the research?
5	Was the data collected in a way that addressed the research issue?
6	Has the relationship between researcher and participants been adequately considered?
7	Have ethical issues been taken into consideration?
8	Was the data analysis sufficiently rigorous?
9	Is there a clear statement of findings?
10	How valuable is the research?

Appendix C: Quality Appraisal Scores and Ratings

Table 7

Quality assessment ratings for quantitative studies included within the review using the EPHPP Tool (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012).

	Selection Bias	Study Design	Confounders	Blinding	Data Collection Methods	Withdrawals and Drop-outs	Global Rating
Batchelder et al. (2014)	Moderate	Weak	Strong	Weak	Strong	Not Applicable	Weak
Heid et al. (2018)	Moderate	Weak	Strong	Weak	Strong	Not Applicable	Weak
Kenning et al. (2015)	Weak	Moderate	Strong	Weak	Strong	Moderate	Weak
Schüz et al. (2014)	Moderate	Moderate	Strong	Weak	Strong	Moderate	Moderate
Weiss el al. (2016)	Moderate	Moderate	Strong	Weak	Strong	Weak	Weak

Table 8

Quality assessment ratings of qualitative studies included within the review using the CASP (2018) tool.

	CASP Items										Overall Score
	1	2	3	4	5	6	7	8	9	10	
	Aims	Appropriate methodology	Appropriate design	Recruitment strategy	Data collection	Researcher participant relationship	Ethical issues	Rigorous data analysis	Statement of findings	Valuable	
Boeckxstaens et al. (2012)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes	Yes	8/10
Bower et al. (2012)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes	Yes	8/10
Mc Sharry et al. (2013)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Yes	Yes	8/10

Appendix D: Data Extraction Form**Standard data extraction form** (Munro et al., 2007)

1. Country
2. Aims of study
3. Ethics – how ethical issues were addressed
4. Study setting
5. Theoretical background of study
6. Sampling approach
7. Participant characteristics
8. Data collection methods
9. Data analysis approach
10. Key themes identified in the study (1st order interpretations)
11. Data extracts related to the key themes
12. Author explanations of the key themes (2nd order interpretations)
13. Recommendations made by authors
14. Assessment of study quality

Appendix E: Nominated Journal Guidelines

Authors Guidelines for the Nominated Journal, Psychology and Health

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SCHOOL OF PSYCHOLOGY
DOCTORATE IN CLINICAL PSYCHOLOGY

EMPIRICAL PAPER

**Understanding illness representations and coping responses for common
mental health symptoms in adults experiencing multimorbidity: A
thematic analysis.**

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Target Journal: **Psychology and Health**

Word Count: **8,475 words (excluding abstract, table of
contents, list of tables, list of figures,
references, appendices)**

**Submitted in partial fulfilment of requirements for the Doctorate Degree in
Clinical Psychology, University of Exeter**

Abstract

Objectives: Research has highlighted an association between illness representations and coping responses, such as self-management, medication taking and treatment-seeking. However, illness representations for common mental health symptoms when experienced alongside multimorbidity are poorly understood. The current study aims to understand how people experiencing multimorbidity represent and respond to their common mental health symptoms.

Methods: Semi-structured interviews were conducted with thirteen participants experiencing mild to moderate symptoms of anxiety and/or depression alongside physical multimorbidity. Thematic analysis combined with deviant case analysis was used to analyse the data.

Results: The results provide an understanding of illness representations and coping responses for common mental health symptoms in those experiencing multimorbidity. Four key themes were identified; 1) interconnected conditions, 2) methods of responding to mental health difficulties, 3) relationships: the importance of connection and understanding, and 4) narrow treatment options.

Conclusions: Illness representations for common mental health symptoms appear to have a role in guiding coping responses, including treatment-seeking. Having an awareness of people's illness representations will be useful in clinical practice to guide consultations and interventions. By understanding and working with illness representations and increasing primary care accessibility we may begin to improve coping and treatment-seeking within this population. The implications of this research will be useful in allowing health services to meet the needs of the growing multimorbidity population and close the mental health treatment gap.

Keywords: Multimorbidity, chronic conditions, mental health, illness representations, coping responses, treatment-seeking, qualitative research.

Introduction

Advances in medicine, combined with an aging population, is resulting in a growing number of people experiencing multimorbidity (Ording & Sørensen, 2013); the presence of two or more concurrent chronic health conditions (Johnston, Crilly, Black, Prescott, & Mercer, 2018; Meghani et al., 2013; Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009). Multimorbidity has a significant impact on the person and represents a leading challenge facing healthcare systems (World Health Organization, 2016). This represents a need for policy and practice to adapt given this shift from single and comorbid conditions (Prince et al., 2015).

Physical and Mental Multimorbidity. Common mental health conditions such as anxiety and depression frequently occur in those with physical health conditions (Naylor et al., 2012). Furthermore, the prevalence of these common mental health difficulties increases with the number of physical health conditions experienced (Gunn et al., 2012). Experiencing both physical and mental multimorbidity poses competing demands and conflicting management on the person (Detweiler-Bedell, Friedman, Leventhal, Miller, & Leventhal, 2008; Mc Sharry, Bishop, Moss-Morris, & Kendrick, 2013). The presence of common mental health symptoms negatively impacts self-management and treatment adherence for chronic physical health conditions, leading to worse health outcomes and increased healthcare costs (Bayliss, Ellis, & Steiner, 2007; Ciechanowski, Katon, & Russo, 2000). Several studies have recognised the negative consequences that untreated mental health difficulties can have in those with physical conditions (Prince et al., 2007). However, poor treatment-seeking for mental health conditions are observed in people experiencing a physical health condition (Andrews, Issakidis, & Carter, 2001; Demyttenaere et

al., 2006). Physical health conditions experienced alongside common mental health symptoms have the potential to serve as an additional barrier contributing to the mental health treatment gap (Kohn, Saxena, Levav, & Saraceno, 2004).

Current research has predominantly stressed the need for person-centred treatment approaches and more integrated models of care to meet the needs of those with mental and physical multimorbidity (Mercer, Gunn, Bower, Wyke, & Guthrie, 2012; Sampalli, Fox, Dickson, & Fox, 2012). Although changes to service provision are important to consider, the management of multimorbidity requires patient involvement. This promotes a need to understand the processes guiding health behaviour to ensure care can be best organised for those with multimorbidity (Conner & Norman, 2005).

Illness Cognition and Behaviour. Many models have been developed to understand, predict and modify health behaviour (Conner & Norman, 1998). Many models have identified that people develop cognitive and affective mental representations of a health threat (Johnston & Johnston, 1998). It is suggested that such mental representations, or beliefs and expectations of an illness, guide coping responses. One model which has provided the most extensive work on this topic and has attempted to characterise illness representations is the Common-Sense Model (CSM) of Self-Regulation (Leventhal, Meyer, & Nerenz, 1980).

The Common-Sense Model. The CSM (Figure 1) provides a framework to explain how people understand and manage their health conditions (Leventhal et al., 1980; Leventhal, Phillips, & Burns, 2016). Illness representations are the construct considered key within the model and are influenced by people's knowledge and experiences (see Appendix A). Cognitive

Illness Representations of Common Mental Health Conditions.

Illness representations have most commonly been explored in those experiencing physical health conditions (Petire, Broadbent, & Kydd, 2008). However, research has increasingly explored illness representations of mental health conditions. The literature suggests that representations of common mental health difficulties are often negatively influenced by social stigma (Memon et al., 2016). When common mental health difficulties are experienced in the context of physical health conditions, they are often normalised (Coventry et al., 2011). The causal attributions and beliefs regarding the controllability of common mental health conditions often varies between individuals (Oexle et al., 2015). These representations have been associated with people's ability to return to work, condition management and treatment-seeking (Løvvik, Øverland, Hysing, Broadbent, & Reme, 2014).

Illness Representations and Coping Responses in Multimorbidity.

Despite the apparent association between representations, coping and health outcomes in those with single conditions, little research has explored this in those experiencing multimorbidity (Gibbons et al., 2013). Recent studies have begun to make explorations in this area and have suggested that representations relate to both single and multiple conditions (Schüz et al., 2014). In an attempt to make sense of their multiple conditions, people may develop novel representations relating to multimorbidity (Boeckxstaens et al., 2012; Bower et al., 2012; Mc Sharry et al., 2013). These multimorbid representations are not able to be captured within the clear and concrete dimensions of the CSM, a model initially developed considering single not multiple conditions (Leventhal et al., 1980). Findings suggest that the CSM in its current format may not be able to capture the complexity of multimorbidity (Mc

Sharry et al., 2013). Both single and multimorbid representations within these studies were shown to be associated with condition management (Batchelder, Gonzalez, & Berg, 2014; Heid, Pruchno, & Wilson-Genderson, 2018; Kenning et al., 2015; Weiss et al., 2016).

Summary. There is a clear gap in the literature exploring mental and physical multimorbidity. Filling this gap has the potential to address two major public health challenges. Specifically, meeting the needs of a growing multimorbidity population and closing the mental health treatment gap. Illness representations have been associated with coping responses within the multimorbidity population, and treatment-seeking and health outcomes across a variety of conditions, including mental illness (Oexle et al., 2015; Petrie & Weinman, 2006). Therefore, research in this area would make a valuable contribution to the literature. Developing a clearer understanding of common mental health symptoms in those experiencing multimorbidity, with a particular focus on treatment-seeking, may inform recommendations regarding policy and practice to meet the needs of a growing population.

Aim of the Study

This study explores illness representations and coping responses for common mental health difficulties in adults experiencing multimorbidity. A particular focus in relation to coping responses will be on treatment-seeking given the mental health treatment gap (Kohn, Saxena, Levav, & Saraceno, 2004) and poor treatment-seeking observed for mental health difficulties in those with physical conditions (Andrews, Issakidis, & Carter, 2001). This study is guided by the following question: What are the illness representations and coping responses for common mental health symptoms in adults experiencing multimorbidity?

Method

A qualitative research design, utilising thematic analysis as a method to analyse individual interview data and address the research aims was adopted. This design facilitates an understanding of people's views which was appropriate to answer the research question posed (Creswell, 2013). Ethical approval was obtained from the University of Exeter Psychology Ethics Board (project 2018/547 – see Appendix B).

Participants

Participants were recruited through organisations with community groups in the South West of England for those with physical health conditions or the older adult population. Six organisations identified via an online search – Arthritis Care, British Heart Foundation, Diabetes UK, Motor Neurone Disease Association, Stroke Association, University of the Third Age– agreed to support recruitment. Community groups associated with organisations interested in the research were visited and given a brief overview of the study (Figure 2). Other organisations disseminated information via posters, website, social media and magazine advertisements. Willing participants were asked to contact the researcher directly.

Potential participants were screened against study inclusion and exclusion criteria (Table 1) to ensure eligibility. Verbal consent was requested for the pre-interview telephone screen to take place. Figure two outlines the recruitment procedure.

Table 1

Inclusion and exclusion criteria for recruiting participants for the research.

Inclusion	Exclusion
<ul style="list-style-type: none"> • Two or more chronic physical health conditions (these are conditions that require ongoing management over a period of years). A list of chronic conditions has been established by Jabine (1987), this will be utilised as a guideline to ensure participants have a chronic condition (Appendix C). • Co-existing self-reported or diagnosed anxiety and/or depression, (mild to moderate) experienced for at least one month. 	<ul style="list-style-type: none"> • End-stage terminally ill individuals receiving palliative care. • Acute or severe and enduring mental health conditions. • Significant risk to self or others identified. • Significant cognitive impairments that may impact ability to provide informed consent and engage in the research.

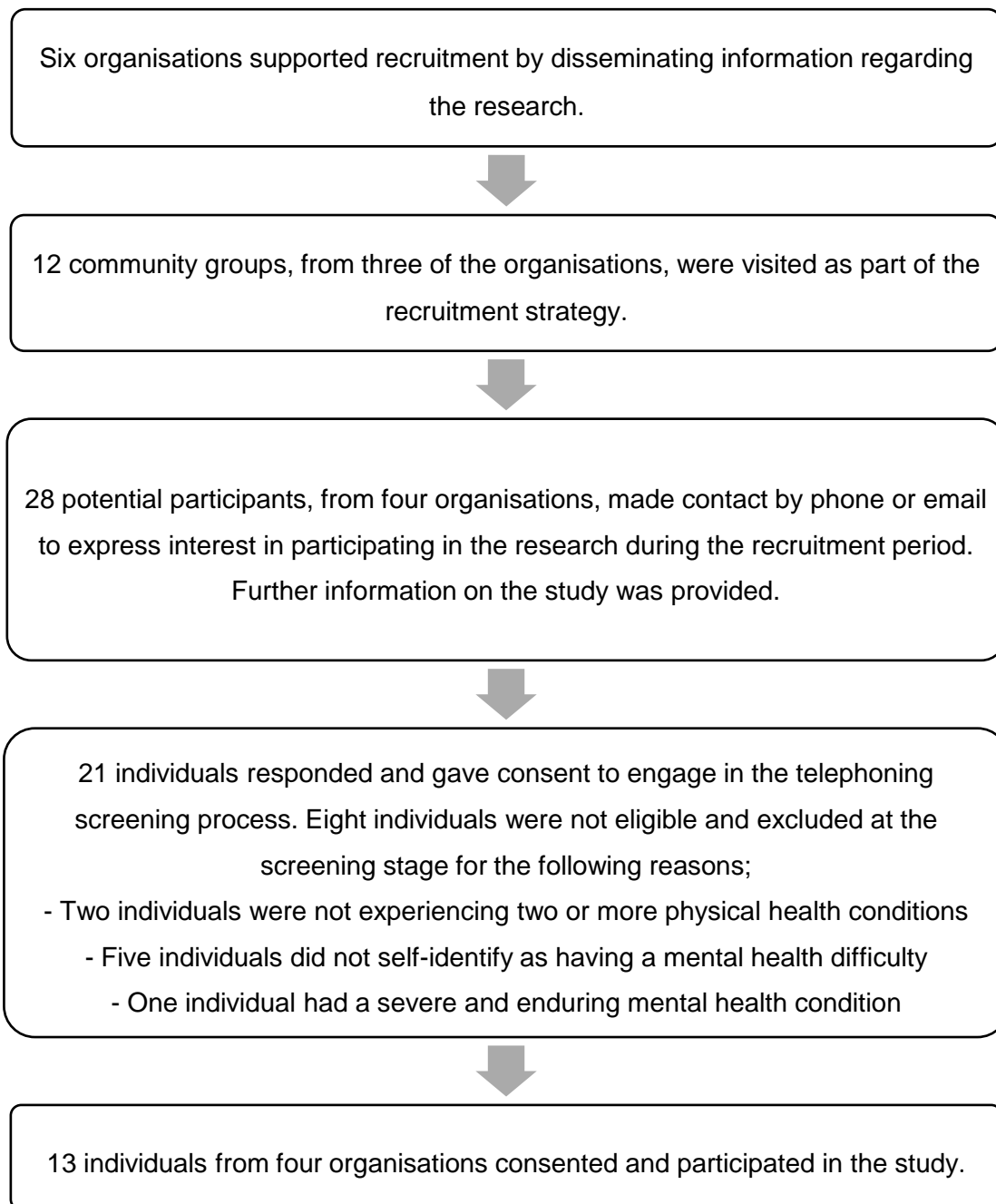


Figure 2: Study recruitment flowchart.

Thirteen adults (seven women, six men) with a mean age of 71.77 years (SD=10.31, range=48-89), were recruited into the study (Table 2). All participants were white British, twelve were retired (92.3%) and one reported being unemployed and seeking work; eleven married (84.6%) and two widowed.

Table 2

Participants' pseudonyms and demographics.

Pseudonyms	Gender	Age	Physical Health Conditions	GAD-7 Score	PHQ-8 Score
Ashley	M	75-84	Cardiovascular disease, cancer, type 2 diabetes, atrial fibrillation, asthma, trichiasis, Fuchs' endothelial dystrophy.	5 (mild)	13 (moderate)
Alison	F	65-74	Cardiovascular disease, osteoarthritis, irritable bowel syndrome.	5 (mild)	8 (mild)
Freya	F	45-54	Arthritis, asthma, type 2 diabetes, myotonic dystrophy, epilepsy.	6 (mild)	8 (mild)
Dilys	F	75-84	Cardiovascular disease, asthma, bladder prolapse, osteoarthritis.	13 (moderate)	12 (moderate)
Maureen	F	75-84	Cancer, rheumatism, pulmonary embolism.	3 (no significant symptoms)	8 (mild)
Lorraine	F	75-84	Hypertension, type 2 diabetes, underactive thyroid, liver cirrhosis, deafness, rheumatism.	5 (mild)	4 (no significant symptoms)
Natalie	F	85-94	Cardiovascular disease, arthritis, underactive thyroid, stress incontinence.	3 (no significant symptoms)	5 (mild)
William	M	65-74	Cardiovascular disease, skin condition, arthritis, transient ischemic attack, urinary frequency.	4 (no significant symptoms)	9 (mild)
Mark	M	65-74	Arthritis, atrial fibrillation.	7 (mild)	4 (no significant symptoms)
Anita	F	55-64	Psoriatic arthritis, psoriasis, migraine, underactive thyroid.	5 (mild)	6 (mild)
Fynlee	M	55-64	Eczema, anosmia, allergies.	2 (no significant symptoms)	11 (moderate)
Liam	M	75-84	Cardiovascular disease, type 1 diabetes, retinal condition.	3 (no significant symptoms)	14 (moderate)
Stephen	M	75-84	Cardiovascular disease, cancer, carpal tunnel syndrome, trichiasis.	2 (no significant symptoms)	8 (mild)

Participants were required to score between five and 14 on the PHQ-8 (Kroenke et al., 2009) or GAD-7 (Spitzer et al., 2006), and not 15 or above on either measure to take part in the study. Screening measures indicated that mild to moderate symptoms were observed for depression (n=6), depression and anxiety (n=5), and anxiety alone (n=2). Four participants scored above the cut-off of 10 for a self-reported diagnosis of anxiety or depression, these scores have been highlighted in bold in table 2. None of the participants were currently receiving any psychological intervention for their mental health symptoms. Many participants had discussed their mental health difficulties with a healthcare practitioner or received specialist mental health support in the past (n=9). A summary of the health and treatment information collected from participants is presented in Appendix D.

Measures and Materials

During the screening procedure the PHQ-8 (Kroenke et al., 2009) and GAD-7 (Spitzer et al., 2006), were administered to ensure participants met the inclusion criteria of experiencing mild to moderate symptoms of anxiety and/or depression. On both measures scores of 0 to 4 represents no significant symptoms; 5 to 9 represents mild symptoms; 10 to 14 moderate symptoms and a score above 15 represents moderately severe/severe symptoms. A score equal to or higher than 10 represents clinical caseness. Both scales have demonstrated validity and reliability (Naeinian, Shairi, Sharifi, & Hadian, 2011; Pressler et al., 2011).

Procedure

Following recruitment, participants were invited to take part in an individual interview. Prior to the interview commencing, participants were given an overview of the purpose and procedure of the study and were provided with

a participant information sheet (Appendix E). Signed consent was obtained from all individuals prior to their participation in the research (Appendix F), they were made aware that they could leave the study or withdraw their data at any time. Participants completed a brief questionnaire (Appendix G) which gathered information regarding participant demographics, health conditions and treatments. An audio-recorded semi-structured interview (Appendix H) was undertaken. The interview schedule was informed by the available literature, appropriately justifying the areas being explored and was piloted prior to its use within the study. Individual interviews were conducted with participants face-to-face in an interview room (n=11) or over the telephone (n=2). Interviews ranged in length from 18 to 86 minutes, the average was 42 minutes. The heterogeneity of the length of interviews appeared to be associated with the number of multimorbid conditions experienced by participants. Interview length did not reflect the approach adopted, telephone or face-to-face interviews, to collect data. Once the study had finished, participants were provided with a debrief form (Appendix I) and given an option to receive a summary of the research findings.

The researcher is a trainee clinical psychologist with experience in conducting interviews in clinical practice and conducting research in clinical settings. The researcher had attended community groups as part of the recruitment procedure, therefore several participants had briefly met the researcher prior to taking part in the research.

Method of Analysis

Interviews were transcribed by a professional transcription service and checked against audio recordings for accuracy. Transcripts were analysed using thematic analysis, a theoretically flexible approach for identifying,

analysing and reporting themes within qualitative data (Braun & Clarke, 2006; Braun & Clarke, 2013). Although other approaches were considered, thematic analysis was chosen as the most suitable method to address the research aims due to its theoretical flexibility and the well-established guidelines. This approach was also well suited to a pragmatic stance; whereby the method adopted is one that effectively helps to answer the research question (Fishman, 1999; Morgan, 2007).

Given that there is little research exploring illness representations and coping responses in those with multimorbidity, a semantic and inductive approach to analysis was adopted. This approach meant that the codes and themes developed were directed by the content of the data. Nevertheless, the researcher had an awareness of the literature that may be relevant to this study and whilst being mindful of this tried to remain open to data that was contradictory and unique.

Each phase of the Braun and Clarke (2006) guidelines were carried out as part of the analysis to ensure rigour and provide clarity around process and method. The recursive process began with *familiarisation with the data*, involving repeated reading and noting ideas observed in the data. *Initial codes* were developed identifying features of the data relevant to answering the research question. Codes were developed reflecting the semantic content of the data employing a complete coding approach (Braun & Clarke, 2013). Codes were then utilised to identify broader patterns within the data; organising codes into groups allowed for the *searching for themes* phase to commence. Codes were sorted into different themes using visual representations. The following phase involved *reviewing the themes* to ensure that there was sufficient data to establish a theme and developing a candidate thematic map. Themes were

then *defined and named*; this involved identifying a themes central organising concept and writing a detailed analysis. The final phase was *producing the report* where extracts capturing the essence of themes were chosen and included within the write-up of the analysis.

Measures were taken to ensure rigour and increase trustworthiness in the analysis (Barbour, 2001). A second coder, who was also a trainee clinical psychologist, coded one complete transcript to ensure consistency in the codes and subsequent themes identified. Similar codes were identified by both first and second coder with minor differences discussed and resolved. The preliminary themes identified were refined through discussion with the second coder. Extracts from two other transcripts were also coded by other researchers and discussed in small groups. Contradictory positions within and across participants narratives representing deviant case analysis was also employed (Booth, Carroll, Ilott, Low, & Cooper, 2013). This enabled themes to be further considered and refined. The Critical Appraisal Skills Programme (CASP; 2018) and *COnsolidated criteria for REporting Qualitative research* (COREQ; Tong, Sainsbury, & Craig, 2007) checklists were consulted throughout each phase of the study to ensure all relevant aspects of the research were sufficiently considered and reported.

To increase reflexivity, the researcher regularly recorded details of their experience in a reflective log (Koch & Harrington, 1998). The aim of this was to increase their awareness of their influence, this was considered and reflected upon during the analysis and write-up. During the development of the log it had been reflected that some of the views expressed by participants regarding mental health differed from the researchers. Factors such as clinical experience and age were considered as variables influencing these views. The

consideration of age difference was particularly important given that societal views and the clinical treatment of mental health had changed so considerably over time (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014).

Results

Data analysis revealed four main themes comprising eight sub-themes (Table 3). Using an illustrative approach these themes are described further with quotes below (Braun & Clarke, 2013).

Table 3

Description of key themes and sub-themes with deviant cases.

Key Themes	Sub-themes (if applicable)	Deviant Cases (if applicable)
<p>Theme 1 Interconnected conditions: Mental and physical health conditions were connected; this posed challenges to condition regulation.</p>		<p>Lorraine did not view a connection between her health conditions.</p> <p><i>Interviewer: Do you ever feel like your mental health impacts your physical health at all?</i> <i>Lorraine: No. No.</i> <i>Interviewer: Do you feel that they are quite separate things?</i> <i>Lorraine: Yes.</i></p>
<p>Theme 2 Methods of responding to mental health difficulties: Concealing, normalising, avoiding and controlling are all methods of managing and responding to mental health difficulties.</p>	<p>Concealing: Withholding and hiding the experience of mental health difficulties from others in an active or passive manner.</p>	<p>Both Natalie and Fynlee discussed how they would be happy to share their experiences of mental health symptoms if they felt this would be beneficial to others:</p> <p><i>Fynlee: If there's anything I can share that might be helpful I have no problem. So I'm quite happy. I'm sort of, I don't really hold back in terms of what I... I will say if I think it's useful.</i></p>
	<p>Normalising: Normalising the experience of mental health symptoms and distancing from abnormality by rejecting clinical labels and preferring to use non-clinical terminology.</p>	<p>According to Natalie having a diagnosis of depression is important to be understood by others and to receive the correct support. Below Natalie discusses her experience of trying to set-up and access a support group for those with clinical depression, she discusses an encounter with a nurse in setting-up the group:</p> <p><i>Natalie: I've found the important thing is only people who are suffering from clinical depression are suitable for the group". "Oh no," she [nurse] said, "we are taking anybody who is suffering from depression". I said, "Well, because they are gambling or they are a shopaholic or something like that, umm an alcoholic, they need different um help, um and they won't understand people with clinical depression.</i></p>
	<p>Avoiding: A desire to disengage from and avoid thinking about mental health difficulties; which can often be fulfilled by using active coping strategies.</p>	

Controlling: Having a sense of personal responsibility and determination to control mental health difficulties was discussed. This was often enacted by learning coping strategies to aid personal control of mental health difficulties.

Theme 3

Relationships; the importance of connection and understanding:

Relationships play a key role in helping or causing mental health difficulties. Both connection and disconnection, often influenced by others understanding, were associated with mental health difficulties.

Social connectedness and support: Feeling close, connected, understood and supported by others helps alleviate and manage mental health symptoms.

Isolation: Loss of close relationships, social circumstances and poor understanding can lead to isolation; a key causal and exacerbating factor for mental health symptoms.

Theme 4

Narrow treatment options: Formal treatment options for managing mental health difficulties were either poorly understood, unwanted and perceived or experienced as inaccessible or ineffective.

Unknown or unwanted treatments: Having a limited understanding of the variety of treatments available for mental health difficulties, and a reluctance to engage in the treatments there was an awareness of.

Poor treatment provision and efficacy: Managing mental health difficulties through formal means is perceived or experienced as inaccessible or ineffective.

Anita discussed her experiences of having to wait a long time to discuss her mental health difficulties with her GP, consistent with the notion that treatments were often inaccessible. However, Anita also discussed her experience of easily accessing primary care mental health services through a self-referral pathway:

Anita: ...because it was self-referral it was, it was very easy.

Both Dilys and Natalie discussed helpful experiences of accessing formal treatments, although these were both discussed in the context of other fruitless treatment experiences:

Natalie: I'd been to a very expensive clinic which was just near to where I lived in [town] and they were helpful.

Theme 1: Interconnected conditions

Many participants discussed the relationship between their physical health and mental health symptoms. Physical health conditions and mental health symptoms were discussed as interconnected, often in relation to causal attributions and exacerbating factors. As shown in the below extract, many participants like Mark discussed physical health conditions as causing or exacerbating mental health difficulties, reflecting a sense of co-dependence between conditions.

Mark: The low mood, it does coincide with these conditions [physical health] and I suppose as they become a little bit more dominant in my life it's become more. But like I say, it can drag me down.

Around half of participants also discussed the opposite relationship; their mental health influencing their physical health. Yet mental health symptoms were only discussed by participants as an exacerbating factor not a causal attribution or source of physical health conditions.

Alison: Yeah, it can set off the angina but that's extreme anxiety, but I can get chest pain if I'm really anxious. Umm, the IBS is one that it sets off more than anything.

Some participants viewed their conditions as connected; discussing symptoms and conditions as closely related or overlapping. This occasionally made them hard to separate, posing a challenge to distinguishing between different conditions and recognising the cause and effect of symptoms. Such entanglement appears to influence the coherence individuals had regarding their condition.

Anita: ...with both my mental and my physical health, one of the things with my mental health is going downhill is that my sleep pattern breaks up and I find that quite difficult because my physical health sometimes breaks my sleep pattern up and it's working out what's caused and what's not sort of thing and if I get very overtired I then have a migraine.

Entanglement also posed challenges to the management of interconnected conditions for participants. Many discussed the need to find a balance of managing both physical health conditions and mental health symptoms. The dynamic nature of health conditions was often discussed as leading to changing management priorities. The below comment from Dilys illustrates this concept; attempting to manage her mental health by going outside, yet the effect this may have on her asthma requires her to change priorities and balance the regulation of both her physical and mental health.

Dilys: I do tend to prioritise the mental health but if it's a really bad day outside, if there's a lot of wind or umm very, very... you know, there's a lot of sort of rain and stuff, I know I shall be crippled if I go outside the door, I won't be able to walk far because I shall get an asthma attack and this has happened a few times now. I know that I've got to be very, very careful.

Theme 2: Methods of responding to mental health difficulties

Concealing. Several participants described themselves and others as hiding or withholding experiences of mental health symptoms. Concealment appeared to be both an active and passive process from participants' accounts.

Withholding and not discussing mental health difficulties appeared to be a more passive process and was most frequently reflected in participants accounts.

Withholding was discussed mostly in relation to social relationships. However, three participants also discussed withholding their experience of mental health difficulties from healthcare professionals.

Freya: People don't like to talk about their mental health. They don't like to say that they've got difficulties with their mental health.

Some participants discussed actively concealing their mental health difficulty from others. The driving factor for hiding their condition for three participants was the fear of stigma and discrimination. The notion of both actively and passively concealing mental health difficulties is captured in the following comment by Dilys:

Dilys: Always felt embarrassed by it, ashamed of it. I'd never ever tell people I had a mental health problem. At school, never tell anybody umm. The headmaster wouldn't have known. [...] but umm you never let on that you had a mental health issue, you'd be scared of the consequences. I think I would. I would always be scared of the consequences. I wouldn't like people to know. Nowadays we laugh and joke about it because when you get to a certain age, you don't care, you know, you laugh and joke, say low mood, because a lot of us have low mood at the heart place, a lot of us do and they all say, "Well you don't," but they don't understand, you know, they don't understand, because

there's always this veneer. I always cover it. Always.

Normalising. Some participants normalised the mental health symptoms experienced, discussing their symptoms as typical and commonplace. Some suggested that symptoms were not at the level of being considered a clinical condition. Participants' discussions regarding their mental health difficulties reflected a sense that the symptoms and level of distress experienced were normal.

William: Well, low mood, I don't think I, I don't think you could clinically say that I am depressed. I don't think you could say that. In all honesty, I think you'll find that if you took this interview to anybody you would detect most of us human beings have a low mood.

Normalising mental health difficulties also involved participants distancing themselves from abnormality. Some discussed their reluctance and uncertainty about using clinical terminology to label their difficulty. Participants often actively choose to reject clinical labels and use non-clinical language such as 'low mood' and 'down' to discuss their condition.

Stephen: Well, no, I don't like the word depressed. I wouldn't use the word depressed. I'd say, like you say, I'm a bit low sometimes, quite often I'm low.

Avoiding. Avoiding thinking about mental health difficulties was often desired and endeavoured by participants. Distracting themselves from thoughts and feelings attached to their mental health symptoms appeared to allow them to disengage from the difficulty, which participants felt aided coping.

Ashley: You want to just forget it. I'll sit and go into a bit of a fantasy, sit in the chair and in no time, I'll be asleep and it's all forgotten.

The use of active coping strategies, such as keeping busy and engaging in activities, often facilitated this disengagement. Being task orientated allowed participants to distance themselves from thoughts and symptoms of their mental health difficulty in an active way. Engaging in activities was discussed as a frequently utilised and effective coping method to manage mental health difficulties.

William: So, you know, it's all about keeping yourself active. Keep yourself active then thinking of being depressed goes away. It's all up here, all in the mind, that's the thing.

Controlling. Some participants expressed a sense of personal responsibility over the management of their mental health symptoms. A duty and determination to independently control and persevere with their mental health difficulty was reflected in participants' accounts. The need to "get on with it" (Maureen, Lorraine) and be self-reliant was often discussed by participants.

Fynlee: ...ultimately, it's down to what's within you to sort the, you've got to sort things out yourself.

Some participants discussed the process of taking responsibility and demonstrating their determination through learning how to best manage their condition. Developing strategies and insights into their difficulties over time was frequently discussed as a coping response. Such learned coping responses, which had a focus on individuality, allowed participants to control their

symptoms. This control appears to have enabled self-reliance and a sense of coherence regarding symptom management.

Natalie: I have found to be uh, the best way of dealing with my problem and I've had a lot of years to practice and experiment, you can't automatically say that somebody else could do the same thing.

Theme 3: Relationships; the importance of connection and understanding

Social connectedness and support. Feeling connected, understood and supported by others was discussed as a key factor helping to alleviate mental health symptoms. Most participants discussed the practical support relationships offered them. The detection and management of mental health difficulties, and the facilitation of treatment-seeking was often aided by interpersonal relationships. This notion that interpersonal relationships had a key role in improving mental health is illustrated in the below comment from Natalie who described improvements to her mental health through the development of a relationship with her neighbour.

Interviewer: What do you think would help alleviate your mental health difficulty?

Natalie: Well, it already has, my neighbour, a person. Someone who is supportive, someone I can feel comfortable with and trust, someone who is loyal and someone who doesn't take me over but is always there for me, someone with similar ideas and interests to myself.

Participants often discussed close relations such as their spouse and friends as having an important role in alleviating and managing their mental

health symptoms, while generally connecting with people was also considered beneficial and important. Participants discussed the value of talking, meeting and interacting with people more generally. Seeking out such social connection represented an active coping response in the management of mental health difficulties.

Maureen: It is really to get out into the air, get out and talk to people, it's the best medicine there is really.

Isolation. Connection in relationships was discussed as positively influencing mental well-being and condition management, while social disconnection was often discussed as a factor adversely influencing mental health. Interpersonal disconnection was often discussed by participants as arising from the loss of close relationships or social circumstances. The loneliness and isolation experienced from such disconnection was often discussed as a causal attribution or exacerbating factor of mental health difficulties.

Ashley: Nobody comes around to see us. My daughter lives 120 miles away and very rarely rings up. And it makes me feel very low.

The experience of mental health difficulties and not feeling understood also appeared to exacerbate this feeling of isolation. This is captured in the below comment from Anita as she reflects on her experience of being at university, feeling misunderstood and alone with her mental health.

Anita: I can quite understand why university people kill themselves, you know that isolation, that nobody understands how bad this is.

Social disconnection, isolation and a lack of understanding appeared to be associated with mental health difficulties from participants accounts. Some participants perceived others; such as healthcare practitioners, family, and the public, as having a poor understanding of their mental health symptoms or of mental health more generally. For some this appeared to leave them feeling misunderstood or isolated with their condition. The perceived poor knowledge of healthcare practitioners, and its influence on feelings of isolation and treatment-seeking is captured in the following comment by Ashley:

Ashley: I don't know whether they [GP's] get any mental training. Do they? I shouldn't think so. No. I can't see that happening. You're on your own. When you've got a mental problem, you're on your own. I don't know because I've never tested the system. I've never been that bad. Not recently. No, no I wouldn't ever go, I don't think. I don't think I would think it worth the bother.

Theme 4: Narrow treatment options

Unknown or unwanted treatments. Many participants discussed their lack of awareness of the variety of interventions available to treat mental health symptoms. Reflected in participants accounts was their limited knowledge of both the treatments available and how to access these, posing a barrier to treatment-seeking.

Ashley: ...I don't know what help is on the market.

Freya: I don't know really. I don't know what's out there that I can do.

Although many participants discussed medication as a treatment option to manage mental health symptoms, there was often a reluctance to take medication for mental health symptoms.

Stephen: No, I'm not aware of any, any treatments. I certainly don't want to take pills.

This reluctance to take medication and its acceptability as a viable treatment option may have stemmed from the negative views held by some participants regarding medication. Medication was perceived by some as ineffective or as the incorrect way to manage mental health difficulties.

Liam: I didn't want to take tablets or anything like that, I felt that was a false way of going about sorting it out.

Being unaware and uncertain regarding the treatment options available for mental health conditions appeared to shape participants expectations of treatment-seeking. The limited awareness and acceptability of treatments posed barriers to seeking out formal support, narrowing options for condition regulation.

Freya: ...the only thing they are going to give you if you go and say, "I'm depressed," is antidepressants and that's not any good, that doesn't help all the time.

Poor treatment provision and efficacy. Some participants discussed how formal treatment options for managing mental health symptoms were difficult to access or unavailable. Perceived or experienced long waiting times, limited GP availability, time constrained services and poor availability of

specialist mental health services were discussed. These were discussed as barriers for participants in seeking mental health support and sharing their difficulties.

Interviewer: Do you think there are any barriers in you seeking support now?

Lorraine: Oh there's a lot of barriers.

Interviewer: Okay. So what would they be now?

Lorraine: The first one, you can't get an appointment with the doctor to talk about things. You have a 10-minute slot and that's it. You can discuss one thing and one thing only. Since I've lived here, you are the only person I've spoken to about it.

Many participants discussed successfully accessing treatment or support for their mental health difficulty. Participants who discussed accessing such treatment and support in the past described these as fruitless. Experiences of receiving treatment for mental health difficulties was often discussed by participants as unhelpful or limited in its gains.

Fynlee: ...when I went to the doctor, she decided to refer me for CBT umm, which I did a four-week or six-week, six-week course I think. Umm. If I'm being quite honest, it wasn't terribly constructive, I didn't find it particularly helpful. It didn't work for me.

The perceived and experienced poor efficacy and availability of formal treatment options appeared to be a barrier for participants to access support and seek treatment for their mental health symptoms.

Discussion

This study aimed to develop an understanding of illness representations and coping responses for mental health symptoms in people experiencing multimorbidity. The results of this study provide insight into how individuals with multimorbidity represent, experience and respond to their mental health symptoms. Four key themes were identified: 1) interconnected conditions, 2) methods of responding to mental health difficulties, 3) relationships: the importance of connection and understanding, and 4) narrow treatment options. This section discusses the key matters arising from the identified themes, the strengths and limitations of this study, researcher reflexivity, clinical implications and recommendations for future research.

The interface between mental and physical health. In this study physical health conditions are often discussed as causing or exacerbating common mental health symptoms, consistent with other research exploring illness representations in those experiencing depression (Brown et al., 2001). Many participants discussed their physical and mental health as related, also identified in previous research with those experiencing multimorbidity and comorbidity (Bower et al., 2012; Mc Sharry et al., 2013; Richardson, Scott, Schüz, Sanderson, & Schüz, 2017). Consistent with this previous research, interconnected conditions and the entangled relationship between mental and physical health described by some participants may characterise an illness representation relating to multimorbidity.

Interconnected conditions and the changeable nature of illnesses pose challenges to symptom identification and self-regulation (Bayliss, Steiner, Fernald, Crane, & Main, 2003; Morris, Sanders, Kennedy, & Rogers, 2011). These narratives mirror the challenges facing healthcare systems and practitioners attempting to assess and manage physical and mental multimorbidity (Mercer et al., 2012; Naylor et al., 2016). These complexities highlight the importance of considering the interface between different health conditions both at the organisational level and within individual consultations.

Rejecting the condition. In this study, participants discussed the process of concealing, normalising and avoiding their mental health difficulty. These methods of responding appeared to convey rejection and evasion of their condition, this may reflect participants belief that the condition is unacceptable to their self-concept (Van Bulck et al., 2018). Such coping responses may also exacerbate people's difficulties in the long term. For example, concealing may involve some degree of social withdrawal and isolation, identified by participants as a key causal factor for mental health difficulties (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001). Normalising or concealing difficulties may also pose additional barriers and complexity in the detection and treatment of mental health symptoms (Batten, 2019; Hagger & Orbell, 2003; McCabe, Davison, Mellor, & George, 2009). The process of normalising mental health difficulties when experienced alongside chronic physical health conditions has been previously observed in the literature within both patients and practitioners accounts (Coventry et al., 2011). Individuals may be more likely to normalise and distance themselves from mental health symptoms when experienced in the context of physical multimorbidity. This warrants consideration given that normalising symptoms, distancing from clinical labels and concealing mental

health difficulties have been associated with poor help-seeking and self-management in those with single conditions (Sarkisian, Lee-Henderson, & Mangione, 2003; Van Bulck et al., 2018).

In this study it is unclear what underlying factors motivated participants to distance themselves from their mental health symptoms and the condition identity. However, there are some accounts from participants suggesting that stigma and discrimination may have played a role in this. Although these accounts did not form a coherent theme, they may have influenced these processes as highlighted within other research (Thoits, 2016). Participants may have attempted to distance themselves from cultural stereotypes associated with mental illness by utilising mechanisms such as concealing, normalising and avoiding in order to protect the threat to their self-identity and self-esteem, (Major & Schmader, 2017). Nevertheless, normalising and avoiding thinking about mental health symptoms may also represent adaptive responses by participants in managing their symptoms. This may be particularly important given that the majority of individuals included within this study reported mild symptoms and are unlikely to represent a clinical population.

Understanding and connection. Participants' narratives highlighted the importance of connection and understanding in social relationships. Consistent with the literature, social isolation was discussed as a key causal attribution of mental health difficulties (Pettigrew, Donovan, Boldy, & Newton, 2014). Some participants discussed that feeling isolated was caused or exacerbated by others' limited understanding of their difficulties and mental health more generally. Participants' accounts reflected their belief that healthcare practitioners do not understand mental health, and whilst the research literature suggests the contrary, this is an issue with important implications (Morgan,

Jorm, & Reavley, 2013). Understanding and connection in the practitioner-patient relationship has been an important factor influencing self-management and health outcomes (Sultan, Attali, Gilberg, Zenasni, & Hartemann, 2011). Therefore, a good working relationship and connection in clinical consultations may be facilitated by practitioners developing their understanding and knowledge of an individual's condition. This has also been considered key when managing the complexities of mental and physical multimorbidity (Roland & Paddison, 2013).

The preference for self-reliance is fixed through treatment knowledge and appraisal. Participants expressed a preference for personal control over their mental health symptoms, as highlighted in theme two. In the sub-theme 'controlling' participants discussed their sense of personal responsibility and determination to independently manage their mental health difficulty. This preference for self-reliance to control their mental health symptoms may have been fixed given their limited understanding and negative appraisal of other treatment options. This is reflected in theme four, narrow treatment options. This may suggest that the limited treatment opinions available to participants may have resulted in an enduring need for self-reliance to control their mental health symptoms. Formal options for controlling mental health difficulties are also discussed as either poorly understood, unwanted, inaccessible or ineffective, conceivably increasing feelings of isolation, discussed as a key causal attribution of mental health difficulties.

Consistent with previous research, the lack of knowledge and understanding expressed by participants in relation to the treatments available for mental health difficulties appeared to limit their options for managing their symptoms (Alderson, Foy, Glidewell, McLintock, & House, 2012). Such poor

mental health literacy has been recognised in the literature as a factor contributing to poor help-seeking and health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Henderson, Evans-Lacko, & Thornicroft, 2013; Jorm, 2000).

Participants discussed poor health service availability as a barrier to treatment-seeking, this has also been recognised in other research exploring the barriers to treatment-seeking for mental health symptoms (Erler et al., 2011). Nevertheless, there is a deviant case in relation to poor service accessibility where the self-referral pathway to primary care services was discussed as easily accessible. This may reflect the lack of knowledge participants have in relation to the available treatments for mental health conditions and how to access these, not necessarily the reality of service availability and accessibility.

Summary. In this study participants experiencing mental and physical multimorbidity discussed their representations and coping responses for mental health symptoms. Participants often focused on conditions being closely tied with their physical health and social relationships. These variables are discussed as shaping mental health representations, often in relation to control, coherence and cause dimensions. Participants often made associations between illness representations and coping responses. The analysis identified that participants may distance themselves from their condition and have a preference for self-reliance in its management. This preference for self-reliance appeared to be fixed through limited treatment knowledge and negative treatment appraisal.

The illness representations identified in this study appear to reflect some of the dimensions within the CSM (Leventhal et al., 1980). Some dimensions

appear to be more salient than others when considering the data, such as personal and treatment control, identity, coherence and cause. Consistent with the model, illness representations appear to guide coping responses and treatment-seeking within this study. The CSM helps to inform our understanding of illness representations for common mental health symptoms in those experiencing multimorbidity. However, there is a theme identified which is not able to be captured within the dimensions characterised within the model; interconnected conditions. The interconnection of health conditions suggests that participants developed a representation in relation to multimorbidity. This does not relate to the concrete dimensions of illness representations outlined within the CSM and reflects a belief about the interaction of different conditions. Although this may relate to some of the CSM dimensions such as cause, control and coherence, it represents a perception unique to those experiencing multimorbidity and does not fit into any one particular dimension. This indicates that the CSM, a model developed considering single not multiple conditions, may not accurately capture the complexity posed by multimorbidity, as suggested in previous research (Mc Sharry et al., 2013). This illustrates that the results of this study extend beyond what may be captured within the CSM and the need for the model to adapt given the additional dimension captured in participants' accounts.

Limitations of this Study

Due to recruitment predominantly taking place through community groups, those who are not involved in such community groups or who are unable to access these remain unheard. The method of recruitment may have also led to selection bias as those who volunteered to participate may have a greater interest in their health and well-formed illness representations compared

to the more general multimorbidity population (Mc Sharry et al., 2013; Salkind, 2010).

In this study, all but one participant is over the age of 60, representing an older person population. It is likely this occurred due to the method of recruitment and the occurrence of chronic conditions increasing with age (Vogeli et al., 2007). Age may have been a factor influencing people's illness representations and coping responses within this study, as it has been recognised as an important factor in other research (Gump et al., 2001). Having a more representative adult sample may have altered the themes identified within this study.

The sample included within this study reported experiencing mild to moderate symptoms of anxiety and/or depression. Only four participants included within this study fulfilled clinical caseness and therefore the sample does not represent a clinical population. This is important to consider when interpreting the findings of this study and the clinical implications will need to be applied and considered in light of participants' symptom severity.

Although steps have been taken to increase rigour it was beyond the scope of this research to consider 'member checking' which involves the practice of gaining participant feedback regarding the study's results (Braun & Clarke, 2013). This may have allowed for increased understanding and clarification of identified themes (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008).

Clinical Implications

There is a need for holistic care considering biological, psychological and social factors given the importance placed on interconnected conditions and social connectedness and understanding in participants' accounts within this

study (Mercer et al., 2012; Prior & Vestergaard, 2018). A holistic approach in clinical consultations and integrated mental and physical health care may facilitate meaningful discussions, assessments and management of common mental health difficulties in the dynamic context that is multimorbidity (Bower et al., 2012; Langan, Mercer, & Smith, 2013; Roland & Paddison, 2013). Such implications are in line with Ariadne principles considered fundamental to clinical practice with people experiencing multimorbidity (Muth et al., 2014). The Ariadne principles highlight the importance of developing shared and realistic treatment goals with individuals which includes consideration of the interaction of conditions, treatments and context, prioritising individuals' preferences and individualised management. However, implementing these principles into clinical practice is challenging and further exploration around their use would be beneficial (Bower, 2014; Muth et al., 2019).

Clinicians should routinely raise the topic of mental health in consultations with those experiencing multimorbidity. Considering that participants discussed concealing and normalising common mental health symptoms, and also discussed the entanglement of physical and mental health, identifying mental health difficulties may be a challenge. Therefore, utilising mental health screening tools may be beneficial to aid symptom detection within this population (Christensen et al., 2005).

Clinicians should aim to develop an understanding of people's illness representations as this may offer opportunities to challenge and change representations that may be maintaining difficulties or exacerbating other health conditions (Brown et al., 2007; National Institute for Health and Care Excellence, 2016). As illness representations appear to be important in guiding coping responses and treatment-seeking, developing an understanding of these

may allow practitioners to offer and provide individuals with the most appropriate information and treatment options (Hale, Treharne, & Kitas, 2007), whilst also enabling more collaborative and person-centred care (Noël, Frueh, Larme, & Pugh, 2005).

This research also highlights the potential need for service provision to change to meet the needs of those experiencing common mental health symptoms (Coventry et al., 2015). Improving access to primary care, by increased appointment availability may increase treatment-seeking and widen options for coping for this population. Increasing public awareness of self-referral routes to primary care mental health services may also be beneficial in increasing treatment-seeking and decreasing the current pressures on GP's as recognised by participants within this study (Brown, Boardman, Whittinger, & Ashworth, 2010).

Areas for Future Research

Participants' accounts highlight many potential areas for future research. This includes a need to consider; 1) how increasing acceptance and understanding of mental health symptoms and associated treatments in those experiencing multimorbidity may be achieved, 2) explore the use of managing multimorbidity guidelines in clinical practice, 3) develop an enhanced understanding of illness representations and their association with coping responses and outcomes in this population over the age span. These areas for future research may allow for a better understanding of people's experiences of mental and physical multimorbidity and address barriers and challenges to effective condition management. They may also inform theory, policy and practice to meet the needs of this growing population and address the mental health treatment gap.

Researcher Reflexivity

There is an importance placed on the active role of the researcher in qualitative research and particularly within the method of analysis adopted within this study (Braun & Clarke, 2013). It has been important to consider both personal and functional reflexivity whilst undertaking this research. My clinical and academic interests are the reason I choose to explore this area of study, while also having recognised this as a gap within the literature. I have no personal experience of chronic health conditions or physical and mental multimorbidity. I feel that I have an 'outsider status' given that I do not share the same group identity to participants in relation to age and health status (Le Gallais, 2008). Participants are also aware of my professional identity and this may have influenced how they discussed their views on mental health and experiences with services.

Conclusion

This study used thematic analysis to explore adults' illness representations and coping responses for mental health symptoms in the context of multimorbidity. Themes identified indicate that beliefs regarding common mental health symptoms are shaped by social relationships and physical health conditions. The illness representations held by participants in this study reflected both dimensions within the CSM and representations unique to those experiencing multimorbidity (Leventhal et al., 1980). These illness representations appear to have a role in guiding coping responses. Participants often respond by evading and rejecting their mental health symptoms, whilst their preference for self-reliance is likely fixed given the poor accessibility, limited knowledge and negative appraisal of treatments.

This study improves our understanding of illness representations and coping responses, whilst providing valuable recommendations on delivering the most efficacious care to meet the needs of this growing population. Clinicians taking a holistic approach in consultations to understand and respond to illness representations may improve coping responses and consequently health outcomes within this population. Improving primary care accessibility may also aid treatment-seeking for common mental health symptoms. There is a need to further our understanding in this area in order to inform health models and clinical practice to best respond to the challenges presented by multimorbidity.

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Appendix A: Illness Representation Example

Diefenbach (n.d) provides an example of how illness representations may be constructed. The illness threat in this example is of a sore throat.

“An individual might identify the sore throat as the beginning symptoms of a cold (label). The initial cold label determines that it is an acute condition (timeline), with minor consequences, potentially caused by a number of factors. It can usually be cured (control/cure). Taken together, these attributes of the illness representation making up the “cold profile” will lead the individual to engage in common-sense health behaviors, such as drinking lots of fluid, getting some rest, and combating the cold symptoms with over-the-counter remedies. The emotional reactions during these cognitive processes, as conceptualized in the parallel processing model, are likely to be muted, maybe ranging from annoyance about the potential impact on work to worrying that the cold is a precursor to something more serious (illness coherence).”

Appendix B: Ethical Approval

CLES – Psychology
Psychology
College of Life and Environmental Sciences
University of Exeter
Washington Singer Building
Perry Road
Exeter
EX4 4QG
Web: www.exeter.ac.uk

CLES – Psychology Ethics Committee

Dear Charlotte Donegan

Ethics application - eCLESPsy000547

Understanding illness representations in those experiencing multimorbidity and its influence on treatment seeking for anxiety and depress

Your project has been reviewed by the CLES – Psychology Ethics Committee and has received a Favourable opinion.

The Committee has made the following comments about your application:

Paul Farrand commented, Sound proposal that has been discussed.

- Please view your application at <https://eethics.exeter.ac.uk/CLESPsy/> to see comments in full.

If you have received a Favourable with conditions, Provisional or unfavourable outcome you are required to re-submit for full review and/or confirm that committee comments have been addressed before you begin your research.

If you have any further queries, please contact your Ethics Officer.

Yours sincerely

Date: 28/04/2019

CLES – Psychology Ethics Committee

Appendix C: List of Chronic Conditions

The below text has been retrieved from appendix II of Jabine's (1987) publication:

Chronic condition—A condition is considered chronic if (1) the condition is described by the respondent as having been first noticed more than 3 months before the week of the interview, or (2) it is one of the following conditions always classified as chronic regardless of the onset.

- *Absence (loss) of breast, ear, eye, kidney, larynx (voice box), lip, limb(s), lung, nose, or tongue*
- *Alcoholism*
- *Allergy, any, except cases with onset in past 3 months and due to drugs, bee sting, venomous bites (such as snake and spider), chemicals (contactants, including sunburn, substances taken internally, or radiation)*
- *Arteriosclerosis*
- *Arthritis, any type or cause, except when due to current acute injury*
- *Asthma, any type*
- *Bronchiectasis*
- *Calculi (stones), any part of urinary system*
- *Cancer, any type*
- *Cardiac condition, any type*
- *Cataract, any type or origin*
- *Cerebral palsy (and synonyms)*
- *Cerebrovascular disease*
- *Cirrhosis of liver*
- *Clawfoot*
- *Cleft palate*
- *Clubfoot*
- *Color blindness*
- *Congenital condition, any*
- *Coronary condition*
- *Cyst, any site or type*
- *Deafmutism, other total deafness*
- *Detachment of retina*
- *Diabetes, any form*
- *Drug addiction or dependence*
- *Emphysema*
- *Epilepsy, except when due to current acute injury*
- *Flatfoot, fallen arches*
- *Glaucoma, any type or origin*
- *Goiter*
- *Gout, any type or cause*
- *“Growth” (in, on) any site*
- *Harelip*
- *Hay fever (any synonyms)*
- *Heart or cardiac disease, any type or cause*
- *Hemeralopia (day blindness)*

- *Hemorrhoids (piles)*
- *Hernia (or “rupture”)*
- *Hypertension, except that arising in current pregnancy*
- *Mental deficiency, or retardation*
- *Mental disorders.*
- *Mole (pigmented, nonpigmented, benign, malignant)*
- *Mongolism (or synonym)*
- *Multiple sclerosis*
- *Neoplasm*
- *Neuroses*
- *Nyctalopia (night blindness)*
- *Optic nerve disorders*
- *Paralysis agitans (Parkinson’s disease), any cause*
- *Personality disorders*
- *Polyps, any site*
- *Prostate condition, any*
- *Psychosis, any type*
- *Refractive errors*
- *Retardation, mental*
- *Retinal conditions*
- *Retrolental fibroplasia*
- *Rheumatic fever, active or inactive*
- *Rheumatism (muscular) except due to current acute injury*
- *Rupture meaning hernia*
- *Specific learning disturbances*
- *Stones (calculi) any part of urinary system*
- *Stroke or other cerebrovascular disease*
- *Thyroid (gland) condition, any*
- *Trick knee*
- *Tuberculosis, any site or stage*
- *Tumour*
- *Ulcer of stomach, duodenum or jejunum*
- *Varicose veins of any site*

In addition, such terms as atrophy, contracture, deformity, degeneration, dystrophy, fibrosis, sclerosis—of any site—will be coded”1 ,“ regardless of onset and any condition coded to X00-X99(impairments).

Appendix D: Participants' Health Information

Table 4

Participants' health information.

Variable	Total (N = 13)	
PHQ-8	N (%)	
Moderate	4 (30.8)	
Mild	7 (53.9)	
No Depression	2 (15.4)	
All PHQ-8 Score	Mean = 8.46 (3.28)	Range = 4 - 14
GAD-7	N (%)	
Moderate	1 (7.7)	
Mild	6 (46.2)	
No Anxiety	6 (46.2)	
All GAD-7 Scores	Mean = 4.85 (2.88)	Range = 2 - 13
Ongoing Physical Health Treatment Interventions	Mean = 1.62 (0.77)	Range = 1 - 3
Regular Medications	Mean = 5.92 (3.84)	Range = 1 - 17
Frequency of Health Appointments	N (%)	
Once a month	5 (38.5)	
Once every three months	6 (46.2)	
Once every six months	2 (15.4)	
Number of Self-management Procedures	Mean = 2.54 (1.13)	Range 1 - 4

Appendix E: Participant Information Sheet**Participant Information Sheet**

Title of Project: Understanding illness representations in those experiencing multimorbidity and its influence on treatment seeking for anxiety and depression

Researcher name: Charlotte Donegan

Invitation and brief summary:

Thank you for considering taking part in this research. The aim of this project is to develop an understanding of the experiences of people with multiple chronic physical health conditions and a mental health difficulty such as anxiety and/or depression to better understand how this impacts treatment seeking for such conditions.

To participate in this study, you must have two or more chronic physical health conditions, and experience mild to moderate anxiety and/or depression (this does not have to be diagnosed). Unfortunately, you will not be eligible to participate in this study if you have a terminal illness, are receiving palliative care, have a severe and enduring mental health difficulty, pose a significant risk to yourself or others or have received any form of psychological intervention in the last six months.

This study involves a brief 10-minute telephone screening to check suitability for the study against the criteria noted above. If you are eligible and still interested in participating a face-to-face or telephone interview will then be offered which will last approximately 60 minutes. Following the interview, no further involvement is required. Further details about the study and how to participate is noted below.

Purpose of the research:

The main aim of this research is to develop an understanding of individuals experience of managing multiple chronic physical health conditions and a common mental health condition, such as anxiety and/or depression. We aim to address the research question; *How do people experiencing multimorbidity view a common mental health difficulty when experienced alongside physical health conditions and how may this inform ways to improve treatment seeking for anxiety and/or depression?*

Research suggests that people view, prioritise and manage health conditions differently and this may impact upon help seeking for their conditions and engagement with treatment. In conducting this research, we hope to develop a better understanding of the barriers in relation to help seeking for high prevalence mental health conditions in the context of other chronic physical health conditions. Results offer the potential to inform future service developments to help improve the quality of care and treatment given to people experiencing both physical and mental health difficulties.

Why have I been approached?

Adults with two or more chronic physical health conditions experiencing mild to moderate anxiety and/or depression will be recruited for the study in the

South West and South Wales area via community groups for those with physical health conditions. You may have been given this information sheet or seen a poster advertising this study in your community group. However, your participation is purely voluntary, you have no obligation to participate in this research if you do not wish to.

What would taking part involve?

Anyone interested in taking part will be asked to contact the researcher, Charlotte Donegan on the contact details below. Charlotte will be able to provide further information regarding the study. Individuals still interested in participating will then undergo an initial telephone-based screening process that will take approximately 10 minutes. This is to ensure you meet the study inclusion and exclusion criteria. If you are deemed eligible to take part in the study, you will be invited to participate. You can either meet with the researcher at the place of your community group meeting, at the University of Exeter or another mutually agreed public location. However, the study can take place over the phone or skype if this is preferable. During the study which will last approximately 60 minutes, you will be asked to complete a short questionnaire and an interview. The interview will explore your experiences of living with multiple health conditions and depression and/or anxiety. To give us some idea as to the type of people taking part in the study a small number of questions will also be asked about age, gender, physical and mental health conditions being experienced and management and treatments for these. Following completion of the interview, no further participation will be required.

What are the possible benefits of taking part?

This study has the potential to allow us to develop a deeper understanding of individuals experiences living with multiple physical health conditions and a mental health difficulty. This may help inform ways to improve health service provision and delivery. Participating in this research may also provide you with an opportunity to discuss your current difficulties and have information on how you may seek any support needed.

What are the possible disadvantages and risks of taking part?

It is not believed that taking part in the research has any foreseeable risks to participants, although discussing your physical and mental health difficulties is something that people at times can find upsetting. However, you do not have to discuss anything that you do not want to and are free not to answer any questions from the questionnaire or interview if you choose not to without explanation. You are also free to leave the study and withdraw your data at any time. Should you find any aspect of the study upsetting we may direct you to where you can receive support from.

What will happen if I don't want to carry on with the study?

You can stop taking part in this study at any time without having to give a reason. You can also withdraw your data at any time including after participation by contacting the researcher. You do not need to give any reason for this. However, following the data being anonymised it will have no link to the participant that will be identifiable. Therefore, the data will not be able to be destroyed or withdrawn after this point.

How will my information be kept confidential?

The data provided by you will be completely anonymised and held confidentially and only the research team (Charlotte Donegan and Professor Paul Farrand) will have access to the data. The anonymous data will be retained in accordance with the General Data Protection Regulation (GDPR) and stored on a password-protected laptop belonging to the researchers. Should any concerns regarding risk to yourself or others be identified during the interview confidentiality may need to be broken to best support you and ensure yours and others safety. Where possible the research will discuss this with you beforehand.

If you are not eligible to participate in the study any information gathered from you during the screening process will be destroyed, no information will be stored about you if you are not eligible to participate in the study.

Once data has been transcribed from the voice recordings, tapes will be destroyed. A professional transcription service will be used to transcribe the voice recordings. To ensure data anonymity, no person identifiable information will be kept on transcripts.

Following completion of the research, anonymised transcripts and other raw data will be kept on a password protected computer belonging to the researcher and primary supervisor and stored for five years post publication. This will be kept in accordance to the GDPR. The researcher and primary supervisor will have access to the data. Your anonymised data may be used or shared with other researchers in the future to conduct further analyses to be included within other research projects.

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information can be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

Will I receive any payment for taking part?

You will not receive any payment for taking part in the study. However, any travel outside of your normal routine to participate in the study will be reimbursed on the presentation of a receipt/ticket.

What will happen to the results of this study?

Following completion of the research, the study will be written as a final year thesis for the Doctorate in Clinical Psychology programme and submitted to the University of Exeter with consideration for publication in a peer-reviewed journal. Findings may also be disseminated at relevant conferences and to relevant services.

Who has reviewed this study?

This project has been reviewed by the Psychology Research Ethics Committee at the University of Exeter and has received a favourable opinion.

Further information and contact details

This project is being conducted by Charlotte Donegan (Trainee Clinical Psychologist) at the University of Exeter, under the supervision of Professor Paul Farrand, University of Exeter. You may contact Charlotte Donegan to have

more information on this study or express an interest to participate on the below contact details;

Charlotte Donegan

Email: cd510@exeter.ac.uk

Telephone: 07791380462

Should you be unhappy with any aspect of the project and wish to make a complaint but do not wish to contact the above researchers you may contact Gail Seymour, Research Ethics and Governance Manager by email; g.m.seymour@exeter.ac.uk, or by telephone; 01392 726621.

Thank you for your interest in this project.

Appendix F: Consent Form

Consent Form



Participant Identification Number:

Title of Project: **Understanding illness representations in those experiencing multimorbidity and its influence on treatment seeking for anxiety and depression.**

Name of Researcher: **Charlotte Donegan**

Please initial box:

1. I confirm that I have read the information sheet dated 12/06/2018 (version no 1.0) for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.

3. I understand that relevant sections of the data collected during the study may be looked at by members of the research team, individuals from the University of Exeter or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I understand that taking part involves a 60-minute audio recorded interview which will be transcribed by a professional transcription service. Once transcribed the audio tape will be destroyed. I understand that taking part also involves providing demographic data and information regarding my health conditions and treatments. This data and the interview transcript will be stored anonymously and used for the purposes of research. The research project will be submitted to the University of Exeter as a Doctorate in Clinical Psychology Thesis. It may be published in an academic publication, shared with other researchers for use in future research projects, used for training materials and public engagement activities. This data will be archive for a period of up to 5 years.

5. I agree to take part in the above project.

Name of Participant: _____ Date: _____

Signature: _____

Name of researcher taking consent: _____ Date _____

Signature: _____

When completed: 1 copy for participant; 1 copy for researcher/project file.

Appendix G: Questionnaire



Questionnaire

Please complete the below questions to the best of your ability. Please ask the researcher if you need any assistance with reading or answering the questions. Some of the questions you will be asked concern personal topics, such as your health and what treatments you are currently receiving. You are free to omit any questions you do not wish to answer or withdraw from the study at any time by letting the researcher know.

Age: _____

Gender (please circle): Female / Male / Unspecified

Working status / occupation: _____

Marital status: _____

Ethnicity: _____

Please note any physical or mental health conditions you currently have:

Please note any treatments you are currently receiving for your physical and or mental health conditions (e.g., medication, physiotherapy etc):

How many different types of medication do you regularly take?

On average, how frequently do you have health related appointments (visits to the GP, therapist, clinics etc; please tick one option):

- More than once a week**
- Once per week**
- Once per fortnight**
- Once a month**
- Once every 3 months**
- Once every 6 months**
- Once a year**
- Other (please note):** _____

Do you regularly engage in any self-management procedures to manage your health conditions? (Checking blood sugar, mindfulness, Continuous Ambulatory Peritoneal Dialysis (CAPD), physiotherapy exercises etc):

- Yes**
- No**

Please note each self-management routine:

Thank you for completing this questionnaire. Please return this to the researcher.

Appendix H: Interview Schedule

Exploring health conditions generally:

- Can you tell me a bit about your physical and mental health conditions?
- How do they impact your daily life?
- How do you manage these?
- What are the challenges of managing these conditions?
- Are there some conditions that are more or less important than others?
- Do you prioritise any of your conditions? If you do prioritise any of your conditions can you tell me a little about which ones and why?

Exploring the representation and coping response of mental health conditions:

- Can you tell me a bit more about your mental health condition?
- How did it start? What do you believe caused it to develop?
- What impact does it have on your life?
- How do you manage it?
- Does it impact any of your other physical health conditions? (if yes; How? How do you manage this?)
- What do you think will help alleviate this condition?
- What treatments are available to you?
- Have you received any treatment for your mental health condition in the past? (What led you to seek this out? OR, why not?; can you tell me a bit about this?)
- Are there (or was there) any barriers for you in seeking treatment for your (mental health condition; anxiety and/or depression)? (can you tell me a bit about this)
- What would enable you to seek support or treatment for this condition currently?
- Is there anything else you would like to mention that we haven't discussed?

Appendix I: Debrief**Debrief**

Thank you very much for taking part in this research.

The main aim of this research was to develop an understanding of peoples experience of managing multiple chronic physical health conditions alongside a mental health condition. Our aim was to address the research question; *How do people experiencing multimorbidity view a common mental health difficulty when experienced alongside physical health conditions and how may this inform ways to improve treatment seeking for anxiety and/or depression?*

Research suggest that people view and prioritise physical and mental health conditions differently. This can result in a difference between the number of people receiving treatment for a mental health difficulty and those not receiving treatment for it, something called the 'treatment gap'. In conducting this research, we hope to develop a better understanding of the barriers in relation to help seeking for high prevalence mental health conditions in the context of other chronic physical health conditions. Understanding what conditions individuals prioritise and why could be of value when planning and delivering services in the future.

We also asked about the number of health conditions that you have, the frequency of your health appointments and the current treatments you are receiving. This is because much research has suggested that individuals with multiple chronic conditions may experience not only the burden of symptoms but also treatment burden. Understanding if treatment burden is a common factor in your care and if this influences how you view and manage your conditions can help us think about its importance and impact. Considering this factor may influence how care and treatment is delivered and managed in the future so services not only provide the best care, but also in the best and most effective way.

The data you have provided during this study has been fully anonymised and is held confidentially on a password protected computer belonging to the researcher in a manner consistent with the General Data Protection Regulation. You have the right to withdraw your data without explanation at any time by contacting Charlotte Donegan on the contact details below.

If you have any concerns about your physical or mental wellbeing, then please contact your GP to make an appointment. If you would like more information about physical or mental health conditions and how you can receive support, then again please contact your GP, or see the following websites:

Mental Health

<http://www.mind.org.uk/>

<https://www.samaritans.org/how-we-can-help-you>

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/mental-health-helplines.aspx>

Physical Health

<http://www.nhs.uk/Pages/HomePage.aspx>

If you have any further questions about this research, then please contact Charlotte Donegan or Professor Paul Farrand:

Charlotte Donegan
Trainee Clinical Psychologist
University of Exeter

Email: cd510@exeter.ac.uk

Professor Paul Farrand
Washington Singer Laboratories
Psychology
College of Life and Environmental
Sciences
University of Exeter
Exeter, EX4 4QG

Email: P.A.Farrand@exeter.ac.uk

Should you be unhappy with any aspect of the project and wish to make a complaint but do not wish to contact the above researchers you may contact Gail Seymour, Research Ethics and Governance Manager by email; g.m.seymour@exeter.ac.uk, or by telephone; 01392 726621.

Appendix J: Method of Analysis

Analysis process

To illustrate the process of the analysis table 5 below outlines the action taken by the researcher at each phase of the Braun and Clarke (2006) guidelines.

Table 5

Data analysis process illustrated within Braun and Clarke’s (2006) six phases of analysis.

Phase	Description of the process
1. Familiarisation with the data	<ul style="list-style-type: none"> • Checking the transcripts against audio recordings for accuracy. • Repeated reading of the transcripts. • Highlighting and noting ideas observed in the data.
2. Generating initial codes	<ul style="list-style-type: none"> • Adopting a complete coding approach where anything of interest or relevance to answering the research question was identified. • Codes focused on explicit and surface meanings of the data (semantic). • A second coder and small group of researchers coded transcripts and extracts; codes identified were discussed. This allowed the researcher to reflect on the codes developed. • Data relevant to each code was collated.
3. Searching for themes	<ul style="list-style-type: none"> • All codes were noted on index cards and the researcher began to organise them into groups. • Using visual representations allowed the codes to be sorted and re-arranged many times to identify broader patterns within the data. • Potential themes were identified by clustering codes based on related characteristic and constructs. • All data relevant to each potential theme were collated into a document.
4. Reviewing themes	<ul style="list-style-type: none"> • Potential themes identified were reviewed, considering the coded extracts and the overall data set, this ensured that there was sufficient data to establish a theme. • A candidate thematic map was developed at this phase illustrating themes and sub-themes. • The researcher again met with the second coder to discuss the themes identified.

	<ul style="list-style-type: none"> • The researcher began to actively search for deviant cases and contradictory positions within the data at this phase, enabling themes to be further refined. • Reviewing and using the reflective log at this phase allowed the researcher to reflect on the analysis process and their influence.
5. Defining and naming themes	<ul style="list-style-type: none"> • Themes were defined and named at this phase, the names and definitions can be seen in table 3. • The researcher identified each themes' central organising concept, ensuring that all aspects of a theme cohered around a central idea. • The researcher met with the second coder for the final time to further discuss and refine theme names and definitions.
6. Producing the report	<ul style="list-style-type: none"> • The researcher aimed to tell the story of the data when writing the report. • Vivid and compelling extracts were chosen which captured the essence of themes and also reflected a variety of participants perspectives. • Deviant cases were considered and reflected upon within the write-up. • Within the discussion section of the report, key matters arising from the analysis and the findings relevance to the research question and broader literature was discussed.

An example of theme four; 'narrow treatment options', has been outlined below (figure 3), illustrating the sub themes, codes and coded data associated with this key theme.

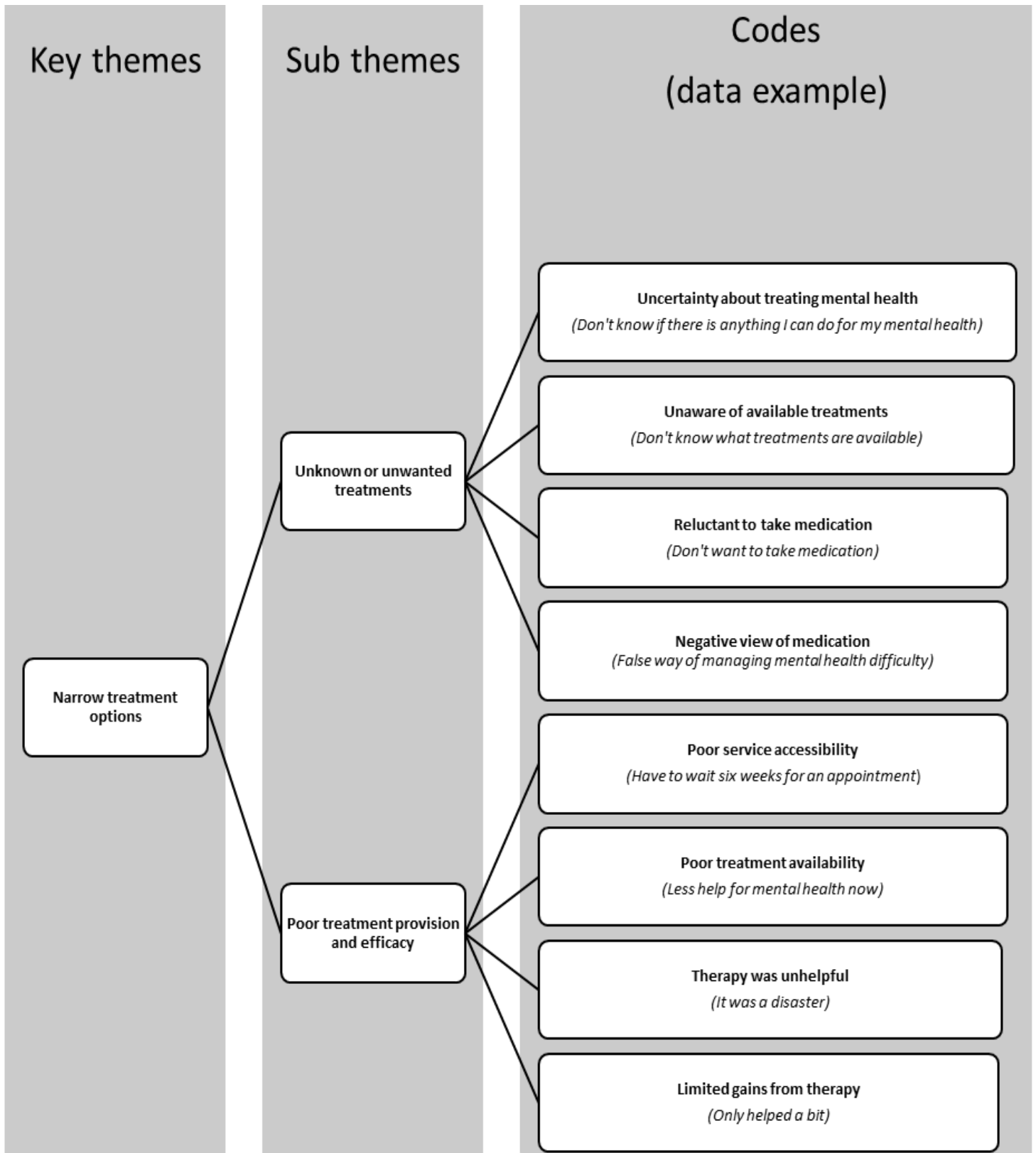


Figure 3: Visual model of a key theme identified by the thematic analysis.

Use of the Reflective Log

During the research process a reflective log was used by the researcher to regularly record details of their experience. The log which was kept over a 12-month period included details of their experience during the recruitment, data collection, data analysis and write-up phases of the research.

In some instances, the researcher used the clinical log to note their experiences of data collection. The log appeared to have allowed the researcher to increase their awareness of issues that may have the potential to influence the data collection process.

It has been a challenge to resist the temptation not to go into ‘therapist mode’ when interviewing participants, to not summarise, or to offer reflection or advice. Yet making space at the end of the interview to facilitate time for some of this thinking and signposting has felt important part of the debrief process. (October 2018).

The log also allowed and promoted the researcher to consider their own beliefs and values. Below is an extract from the reflective log which prompted reflections in relation to differing researcher-participant beliefs and the possible aetiology of these. This was reflected upon in the write up of the report (page 108-109). This extract illustrates the different views and beliefs regarding mental health observed by the researcher. This made the researcher aware of the difference in beliefs and values and how this may influence the analysis process.

As I have noted in previous entries I have been struck by the limited understanding and negative views held by some participants regarding their mental health. I am mindful that this is something that struck me from the very beginning of the research. It is likely that I have failed to consider the knowledge and experience I have of mental health and how this has provided me with a possibly more compassionate understanding of others’ difficulties. Yet I don’t think it is just knowledge which is a factor widening our views but the factor of age. I am mindful that one participant recently interviewed was over 60 years

older than myself. ... I'm left trying to consider how mental health was viewed and treated then and how this shaped individuals' representations, compared to someone with the same conditions but 60 years younger. How would their experiences have been different? So, trying to hold in mind that I am of a younger generation to my participants and of a different occupation and experiences. (December 2018).

Initially the researcher felt that negative views of mental health, stigma and discrimination were key emerging themes from the data. However, this second extract illustrated how the log allowed for reflection in relation to this and influenced the analysis undertaken.

When I initially started this log, I reflected on the possible shame and stigma surrounding mental health difficulties in participants accounts. However, as I have delved deeper into the analysis, I have come to realise that this was something only expressed by a few individuals and that 'concealing' and 'normalising' is more commonplace. I have come to realise that stigma and shame may be something underlying these methods of responding to mental health difficulties but there is not sufficient data to support a coherent theme around shame and discrimination. I have been able to reflect on this in the analysis and discussion, but it has felt difficult to let this potential theme go, maybe because it felt like such a strong possible theme when I first started familiarising myself with the data. Reflecting back on this log it's likely that this felt like such a strong theme as it was such a different belief and experience to my own in relation to mental health. (July 2019).

Reflecting on the use of the log it appears that its main functions for the researcher were to keep thoughts, feeling and experiences visible (Ortlipp, 2008) in relation to both the data analysis collection process.

Appendix K: Use of the CASP and COREQ

The below table illustrates the use of the CASP tool (2018) and COREQ checklist (Tong, Sainsbury, & Craig, 2007) at key phases of the study to ensure study quality.

Table 6

The use of quality appraisal tools and guidelines at key phases within the research.

Study Phase	Use of CASP and COREQ
Designing and planning	<ul style="list-style-type: none"> The CASP criteria stipulates the need to clearly outline study aims and rationale, whilst also ensuring that a qualitative methodology is the most appropriate research design. Finalising and reviewing the research proposal involved reflecting on the CASP criteria, the researcher used the CASP questions to ensure that decisions made were appropriately rationalised.
Data collection and analysis	<ul style="list-style-type: none"> Using the CASP criteria at this stage allowed the researcher to critically evaluate their approach to data collection and analysis. This ensured that the recruitment strategy, method of data collection and analysis, were appropriately justified and rigorous. The researcher asked themselves questions from the CASP tool which stimulated discussion between them and their supervisors regarding decisions being made during this phase of the research. In line with the COREQ checklist a clear trail was kept in relation to information that would be important to convey in the write-up, this included all items within 'domain two' of the checklist which included information regarding participants, study setting and data collection.
Report write-up	<ul style="list-style-type: none"> The CASP tool was utilised at this stage to ensure all relevant information was included within the manuscript. Including a 'researcher reflexivity' section within the write-up, where the researcher critically examined their own role, ensured that the researcher-participant relationship had been adequately considered (item 6). Ensuring a clear statement of findings, a discussion of the credibility of study findings and consideration of study implications and future research were also reflected upon and included within the write-up (item 9 and 10). At this phase the researcher also completed the CASP tool in relation to the study which provided an opportunity to evaluate

the research and write-up and make any necessary amendments.

- The COREQ was utilized most at this phase of the research given its intended use as a checklist of information to be included within manuscripts of qualitative design. Areas that had not been included within the write-up but noted within the checklist were revisited and revised. For example, personal characteristics of the researcher and their relationship with participants prior to study commencement (item 6), were initially not included but were then added within the procedure section of the thesis.
-

Appendix L: Dissemination Statement

The findings from this study will be disseminated to interested parties through three means; presentation, feedback to participants and journal publication. The findings of the study will be presented to an academic audience as part of the Doctorate in Clinical Psychology at the University of Exeter. This will facilitate discussions and peer review. Participants who expressed an interest in receiving feedback on the study will be provided with a short summary of the findings via email. Both the empirical paper and literature review will also be prepared for submission for publication to *Psychology and Health*, which has an impact factor of 2.401 (2018).

Appendix M: Nominated Journal Guidelines

Author Guidelines for the Nominated Journal, Psychology and Health

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Contents

- [About the Journal](#)
- [Peer Review and Ethics](#)
- [Preparing Your Paper](#)
- - [Structure](#)
 - [Word Limits](#)
 - [Style Guidelines](#)
 - [Formatting and Templates](#)
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