ILLNESS REPRESENTATIONS AND PSYCHOLOGICAL HEALTH IN ADULTS WITH CANCER

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Abstract

Background: Research has shown that the emotional impact of cancer can be more difficult to cope with than practical or physical demands and a diagnosis can have significant short- and long-term psychological sequalae including depression, anxiety, difficulties in adjustment and coping and associated poor quality of life (Vachon, 2006). The common-sense model of illness representations has been widely cited as a useful theoretical framework to explain how individuals with chronic illnesses such as cancer think about and respond to their condition (Leventhal & Nerenz, 1985). **Aims:** Two systematic reviews were conducted to identify studies that had measured the prospective relationship between illness representations and the psychological health of cancer patients (Review 1) and to identify studies that had developed interventions to modify the illness perceptions of cancer patients to improve their psychological health (Review 2). **Methods:** Using best practice guidelines for systematic reviews (Centre for Reviews and Dissemination, 2009) two independent systematic reviews were conducted. **Results**: Review 1 identified seven studies that had measured the prospective relationship between illness perceptions and psychological health outcomes in cancer patients. The majority of these studies found that patients with the most negative illness perceptions had the poorest psychological health in the future. Review 2 identified thirteen studies that had developed interventions to either directly target illness perceptions or had hypothesised that other types of intervention would indirectly change patient's cancer related illness perceptions. Findings revealed some interventions were more effective than others in improving the psychological health of cancer patients, largely depending on their design and content. **Discussion**: Illness perceptions were overall predictive of several psychological health outcomes in cancer patients although there was a lack of methodological consistency in the measurement of illness perceptions making synthesis challenging. Interventions were more likely to be effective if they did not specifically target illness perceptions and if they were comprised multiple 'active' components including increased access to social support, homework based activity, group discussion, skills based training and improving the expression of emotions. Relaxation training appeared to be a significant component useful in facilitating psychological improvements in this patient group. **Conclusions**: Future research would benefit from further exploration of the process of change in such complex interventions in order determine which ingredients or indeed combination of ingredients are necessary for interventions to be effective in improving psychological health.

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Abbreviations

AMED – Allied and Complementary Medicine

B-IPQ – Brief Illness Perception Questionnaire

BPS – British Psychological Society

CBSM – Cognitive-Behavioural Stress Management

CRD – Centre for Reviews and Dissemination

CSM – Common sense model

HMIC – Health Management Information Consortium

IPQ – Illness Perception Questionnaire

IPQ-R – Illness Perception Questionnaire-Revised

MEDLINE – Medical Literature Analysis and Retrieval System

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

SES – Social Economic Scale

SRM – Self-regulation Model

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INTRODUCTION

1.1. Overview

1.1.1. Chapter structure

This chapter will first present the broad aims and rationale of the thesis. Background evidence highlighting the psychological impact of cancer and the need for psychological support will then be discussed. The common-sense model - a theoretical model of understanding the ways individuals with a chronic condition may think about and respond to their illness (Leventhal, Meyer, & Nerenz, 1980) will be described alongside research highlighting the potential impact of these beliefs on psychological health. A broad description of the literature base to be reviewed will be outlined along with the potential benefits of this review and specific research questions to be addressed.

1.1.2. Rationale, aims & methods

There are many well cited psychological sequalae associated with receiving and coping with a cancer diagnosis (see 1.2.1.). This thesis has two broad aims and will address these aims using systematic review methodology to contextualise the current research. The first aim (addressed in Review 1) is to explore research that has used illness representational theory (Leventhal & Diefenbach, 1992) to better understand the prospective relationship between the ways in which adults with a cancer diagnosis think about their illness and the impact this may have upon their future psychological health. A second aim (addressed in Review 2) is to examine whether interventions to modify 'negative/maladaptive' illness perceptions have been useful in improving the psychological health of such patients.

1.2. Background

1.2.1. The psychological impact of cancer

In 2013 more than 352,500 people were diagnosed with cancer in the UK and there were more than 163,000 deaths from cancer the following year (http://www.cancerresearchuk.org/cancer-info/cancerstats). Undoubtedly, receiving a cancer diagnosis causes significant distress to patients and their families and empirical evidence exploring both short- and long-term psychological sequalae of receiving a diagnosis and undergoing treatment has found high levels of depression, anxiety, difficulties in adjustment and coping and associated poor quality of life to be common within this patient population (Vachon, 2006; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Evidence has also shown that the psychological consequences of cancer can endure beyond diagnosis and treatment into long term survivorship for a significant proportion of patients, impeding efforts to 'return to normal' (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2005; Hoffman, McCarthy, Recklitis, & Ng, 2009; Macmillan Cancer Support, 2013).

1.2.2. The need for psychological support

The UK government has recognized the psychosocial impact of cancer and highlighted the importance of providing psychological support to patients and their families, particularly in cases of anxiety and depression (Department of Health, 2015). A survey of 1,751 people affected by cancer to assess the emotional impact of the disease (Macmillan Cancer Support, 2006) found that 45% of people with cancer found the emotional aspects of cancer care more difficult to cope with than practical or physical demands. However, while 75% of people with cancer said they had experienced anxiety and 49% had experienced depression after their diagnosis, only half of these individuals said they had received information, advice, support or treatment from clinicians to deal with this. Lack of psychological support has been shown to lead to poorer quality of life, exacerbation of physical health symptoms and subsequent increases in health care costs (Carlson & Bultz, 2004). Nearly two thirds of people affected by cancer said the emotional effects of having a cancer diagnosis should be the top priority in cancer support, ahead of medical management and practical aspects (Macmillan Cancer Support, 2006). Clearly there is a need to understand the way individuals think about living with and beyond cancer diagnosis and treatment in terms of the likely negative impact on their psychological health. The following subsection will outline one model which has been shown to be useful in increasing this understanding.

1.3. Understanding and coping with illness

1.3.1. Common sense model of illness representations

Many theoretical models have been proposed to explain the ways individuals perceive and respond to illness (Connor & Norman, 1995). A widely cited model within the chronic illness literature is the common-sense model (CSM) of illness representation (Leventhal, Nerenz, & Steele, 1984; Leventhal & Diefenbach, 1991). The CSM provides a framework for understanding how the perceptions individuals hold about their illness can affect their adjustment to having the condition.

The model proposes that when individuals are diagnosed with an illness they develop a cognitive and emotional 'representation' to help them make sense of and cope with the condition. This self-regulated representation comprises several perceptions about the illness and will be described in more detail below. Coping is considered by the CSM to be a mediator of the relationship between an illness representation, and illness behaviours and subsequent outcomes. The model also proposes a feedback loop where individuals appraise the efficacy of their chosen coping strategies. This appraisal is thought to influence their current representation and modify future coping responses. The CSM was conceptualized by Leventhal *et al.* as a parallel processing framework whereby internal or external stimuli are cognitively processed across one processing pathway while a second parallel pathway processes emotional aspects of that stimulus (Figure 1).

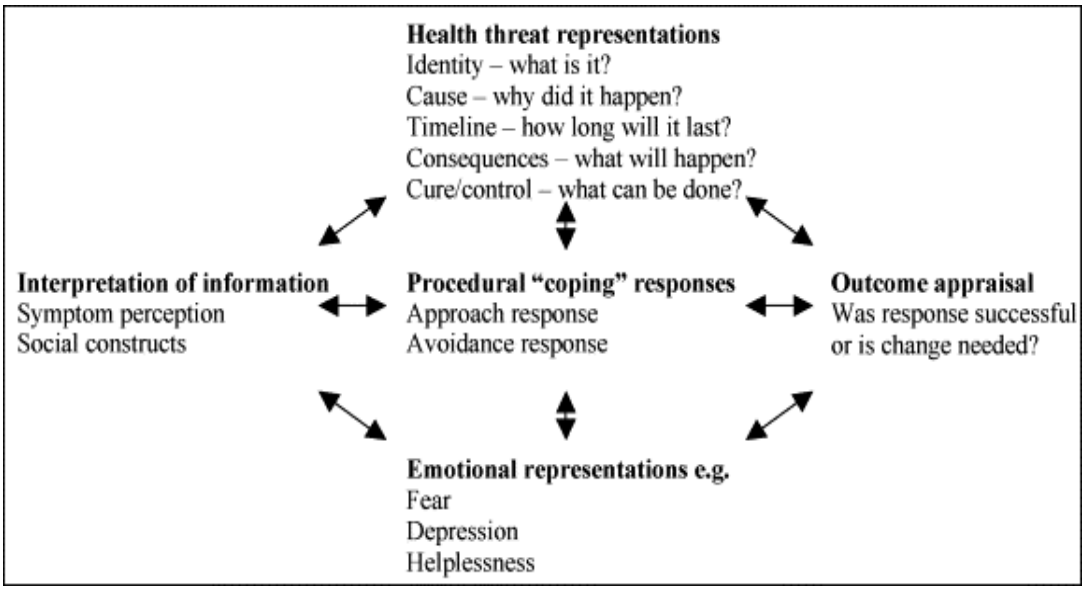

Figure 1: Common sense model of illness
(Leventhal & Diefenbach, 1992)

The CSM conceptualises individuals as active problem solvers who can use abstract and concrete sources of information to process their cognitive perceptions and emotional reactions to a health threat to guide their coping response. The model proposes that individuals use lay information (already known to them from past social communication and cultural knowledge of the illness), external/social information (from significant others and/or authoritative sources) and somatic information from their current experience of the illness to form an illness representation and engage a coping response.

After the development of the CSM, studies consistently identified four distinct dimensions of illness representation in a wide range of chronic health settings: 'identity', 'cause', 'consequences' and 'timeline'. Illness identity relates to an individual's beliefs about the illness label (e.g. I think I have cancer) combined with knowledge about its symptoms (e.g. cancer will cause me lots of pain). The cause dimension relates to perceptions about the potential cause(s) of illness (e.g. cancer is caused by being unhealthy). Research has identified several factors patients might perceive as causing their illnesses, such as biological (e.g. genetic, immunity; Heijmans, 1998), psychological (e.g. personality traits, overwork/stress; Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002), emotional (e.g. depression; Moss-Morris, Petrie, & Weinman, 1996) and environmental (e.g. pollution; Heijmans, 1998). The consequences of illness are those variables believed by an individual to impact on their physical, social and psychological functioning (e.g. cancer will have serious health consequences). The timeline component refers to an individual's beliefs about the likely duration of their illness and symptoms (e.g. cancer will be in my life for a long time/is likely to recur) and have been categorised as acute/short lasting, chronic or cyclical/episodic (Weinman, Petrie, Moss-Morris, & Horne, 1996). Later work extended the framework and added a fifth component to the model which represented beliefs about the 'cure and controllability' of the illness (e.g. cancer cannot be cured or controlled by treatment/me) (Lau, Bernard, & Hartman, 1989). This component reflects the extent to which an individual believes their illness is controllable by themselves or others, or can be cured (e.g. taking this medication will cure my disease/relieve my symptoms).

As an example of how illness perceptions are generated in response to a health threat such as cancer, an individual who finds a lump in their breast may identify this as the first symptom of breast cancer (identity). They may believe they are predisposed to

developing breast cancer (genetic causation) and determine from personal experience this is likely to be a chronic condition (timeline). They may also believe that there is likely to be a significant impact of having cancer such as giving up work and effects on relationships (consequences), and that it will not be cured by anything they can do but may respond to cancer treatments such as surgery or chemotherapy (cure/control). Their coping response may be to seek medical advice.

The CSM asserts that individuals will continuously appraise, evaluate and modify the outcome of their coping response in light of new information or an outcome which was not expected (Leventhal & Diefenbach, 1992). For example, if the person described above then discovers the lump has disappeared the following day, their earlier illness identity 'cancer' may need to be revised and a new coping response selected. Unsurprisingly, the way in which an individual identifies a health threat is believed to have a significant impact on their emotional response. For example, a lump in the breast may be labelled by one individual as breast cancer but by another as a normal breast tissue change as a result of normal hormonal changes, depending on the information they have used to reach their respective illness perceptions. The resulting emotional representation for each of these individuals will understandably be vastly different.

Diefenbach and Leventhal (1996) suggest that cognitive and emotional processing occurs in parallel and are idiosyncratically driven depending on an individual's history, personality disposition and their interpersonal and cultural context. These parallel processes and continued reappraisal will shape their coping response. Experiences of prior illnesses can generate memories or provoke feelings of anxiety, even on a subconscious level, which can have an influential effect on the cognitive and emotional representations of future health threats and subsequent coping responses (Leventhal & Everhart, 1979). For example, an individual who has a family history of breast cancer will be understandably more fearful of this happening to them. They may be more likely to interpret a breast lump as cancer than someone who does not have a family history of cancer and will this be more anxious about finding a lump.

1.3.2. Measuring illness perceptions

Early data on illness perceptions was largely obtained using open-ended unstructured interviews or descriptions of illness episodes (Baumann, Cameron, Zimmerman, &

Leventhal, 1989; Dempsey & Dracup, 1995; Leventhal & Nerenz, 1985; Savage & Clarke, 1998). While evidence consistently supported the stability of the five components of illness representations -identity, cause, cure, consequence and timeline - across a range of chronic illnesses (Lau & Hartman, 1983; Linz, Penrod & Leventhal, 1982), this methodology has been criticised as being limited by small sample sizes and having produced wide variations in the quantity and quality of responses thus (Weinman *et al.,* 1996).

To overcome this, researchers attempted to operationalise the five components of illness representations by developing quantitative questionnaires. Turk, Rudy and Salovey (1986) for example, developed the 45-item Implicit Models of Illness Questionnaire (IMIQ) to assess CSM components. Their initial study administered the measure to healthy college students, diabetic patients and teachers working in a diabetic setting. Findings from this study and others using the IMIQ or other idiosyncratic questionnaires within different patient populations (Schiaffino & Cea, 1995; Heijmans & de Ridder, 1998; Lacroix, 1991) report different structures of illness representation components to those originally proposed by Leventhal. The questionnaire development of such studies has come under scrutiny and have been criticised as being unrepresentative of the CSM and the original work by Leventhal *et al.* explaining why findings have not been comparable. Inconsistent findings have been described as 'design and analysis artefact' rather than contradictory evidence for the five components of the CSM (Weinman *et al.,* 1996).

As a means of more accurately representing and quantifying illness perceptions across a range of illnesses, Weinman *et al.* (1996) developed the Illness Perception Questionnaire (IPQ). It was anticipated this self-report measure would, unlike previous measures, be theoretically based and could be psychometrically tested for validity and reliability. The IPQ was developed to be generalizable across multiple patient populations and flexible, so that items relevant to specific illnesses or health contexts could be added or modified where necessary without compromising psychometric stability. The measure comprised items representing five illness perception components; identity, timeline, consequences, cure/control and cause. The identity subscale comprises 12 'core' symptoms (based on the 12 most common generic symptoms from other symptom checklists; Bowling, 1991) that could be added to in order to tailor the subscale depending on the specific illness being measured. A further 26 items to

represent the other four illness perception subscales were generated, partly by the researchers based on their knowledge of the CSM, and during interviews with patients with a range of illnesses (including diabetes, asthma, myocardial infarction and rheumatoid arthritis) (Weinman *et al.*, 1996).

Psychometric evaluation of the IPQ and subscales revealed good internal reliability (Weinman *et al.*, 1996). Within this study, Weinman *et al.* also compared the amount of information disclosed by patients during both qualitative interviews and on the IPQ. Findings revealed that the IPQ had good concurrent validity with patient's responses during structured interviews but that significantly more information about illness perceptions was obtained from the IPQ than in interviews. The IPQ was also shown to have good predictive validity: patient's IPQ scores were predictive of several self-reported health outcomes such as the number of doctor visits, perceived control over problems and likelihood of future health problems. This validity was maintained 3 months later (Weinman *et al.*, 1996).

To strengthen the psychometric properties of the IPQ, extend its generalizability further, and better represent the CSM, the IPQ was revised in 2002 (IPQ-R; Moss-Morris, *et al.*, 2002; Appendix I). As had been proposed earlier (Horne, 1997), this study found the scale measuring the component cure/control was comprised of two distinct subscales, 'personal control' (beliefs about how much personal behaviour can influence the illness) and 'treatment control' (beliefs about the perceived effectiveness of treatment). The IPQ-R also added new items to represent cyclical timeline beliefs as well as items to assess patient's emotional response to illness, not included in the original IPQ. Finally, the IPQ-R also added a sixth component, 'illness coherence', to assess the extent to which patients understand their illness in a coherent way. Psychometric evaluation of the IPQ-R revealed good validity and reliability in a large sample of patients (N=711) from eight illness populations (Moss-Morris, *et al*., 2002).

Researchers have since developed the 9-item Brief Illness Perception Questionnaire (B-IPQ: Broadbent, Petrie, Main, & Weinman, 2006) to reduce 'respondent burden' by including only single-item measures of each of the nine constructs; identity, cause, consequence, cure (personal/treatment), timeline (cyclical/acute), coherence and emotional representation. In a study involving a combined total of 663 renal, cardiac, asthma and diabetic outpatients, this measure was shown to have good test-retest

reliability, concurrent validity with relevant measures and predictive validity with physical and psychological functioning variables (Broadbent *et al.*, 2006).

1.3.3. Illness perception clusters

Since the development of the IPQ in 1996 and the IPQ-R in 2002, research into illness perceptions has increased exponentially. The measures have been adapted and used widely to explore the illness perceptions of patients with a range of chronic physical illnesses including asthma (Horne & Weinman, 2002), rheumatoid arthritis (Murphy, Dickens, Creed, & Bernstein, 1999; Scharloo, Kaptein, & Weinman, 1999), diabetes (Griva, Myers, & Newman, 2000), motor neurone disease (Earl, Johnston, & Mitchell, 1993), coronary heart disease (Petrie, Weinman, Sharpe, & Buckley, 1996), chronic fatigue syndrome (Heijmans, 1998; Moss-Morris *et al.*, 1996) and cancer (Anagnostopoulos & Spanea, 2005; Buick & Petrie, 2002; Miller, Purushotham, McLatchie, George, & Murray, 2005).

Leventhal *et al.* (1980) argued that a characteristic illness perception 'profile' of CSM components would depend upon the specific condition being experienced. It is beyond the scope of this chapter to present findings from each patient population. However, of relevance to these reviews, research has found a broad pattern of inter-correlations between the components. A meta-analysis of 45 empirical studies adopting the CSM to quantitatively measure illness perception clusters across 23 chronic conditions revealed several key findings (Hagger & Orbell, 2003). In support of earlier evidence (Heijmans, 1998; Heijmans & de Ridder, 1998; Weinman *et al.*, 1996), individuals with a strong illness identity (e.g. who associated their illness with having the most number of symptoms) were also those who had associated beliefs that their condition was less personally controllable, more chronic and had the most severe consequences on their lifestyle. Conversely, individuals who associated fewer symptoms with their illness were more likely to believe they had more personal control over their condition and that their illness was less chronic with fewer consequences.

1.3.4. Modifying illness representations

As Wearden and Peters (2008) point out in their discussion paper, most research has focused on describing cross-sectional associations between illness representations and

patient outcomes. However, there has been an increase in the last few years in the number of studies which have used the CSM as a framework for the development of interventions to modify illness representations and improve psychological health and/or other illness outcomes. This research has involved patients with a range of chronic conditions such as chronic heart disease and myocardial infarction (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Goulding, Furze, & Birks, 2010); asthma (Petrie, Perry, Broadbent, & Weinman, 2011), psoriasis (Fortune, Richards, Griffiths, & Main, 2004) and cancer (Fischer, Wiesenhaan, Does-den Heijeer, Kleijn, & Nortier, 2013). These interventions include a cognitive-behavioural intervention to modify illness representations to improve self-regulation of blood glucose levels in patients with type 2 diabetes (McAndrew, Musumeci-Szabo, Mora, Vileikyte, & Burns, 2008), an emotional regulation group intervention to promote emotional disclosure and reduce psychological distress in breast cancer patients (Cameron, Booth, Schlatter, Ziginskas, & Harman, 2007) and a behavioural activation intervention combined with acceptance and mindfulness techniques to improve the emotional tolerance of patients with chronic fatigue syndrome (Deary, 2008). Additional illness representation interventions developed to improve the psychological health of cancer patients will not be described further in this chapter since they will be identified in Review 2 and described in full.

Although there are comparatively fewer intervention studies overall (compared with cross-sectional correlational studies), the evidence within several chronic health domains does suggest that a range of intervention strategies to alter 'unhelpful' illness perceptions can be beneficial in improving illness related behaviours, illness outcomes and the psychological health of patients with a range of chronic health conditions. As such illness representations are an important and potentially modifiable target for both screening and intervention to improve the psychological health of patients with cancer.

1.4. Illness representations and health outcomes

In addition to the evidence for the existence of core illness representations in a range of clinical populations, studies have also explored the relationships between 'maladaptive' illness perceptions and a range of health outcomes such as disease state, health care use (Frostholm, Fink, Christensen, Toft, Oernboel & Oleson, 2005), physical activity and use of alcohol (Costanzo, Lutgendorf, & Roeder, 2011), coping (Heijmans & de Ridder, 1998), physical adaptation (Heijmans, 1998), mood (Murphy *et al.*, 1999) and treatment

adherence (Cooper, Lloyd, Weinman, & Jackson, 1999). Such studies have consistently evidenced strong cross-sectional, longitudinal and prospective relationships between the illness representations and illness outcomes of individuals with a range of chronic long-term health conditions such as osteoarthritis (Orbell, Johnston, Rowley, Espley, & Davey, 1998), psoriasis (Fortune, Richards, Griffiths, & Main, 2002), diabetes (Hampson, Glasgow, & Stryker, 2000) and asthma (Horne & Weinman, 2002).

In their meta-analysis of 45 empirical studies across 23 illness conditions, Hagger and Orbell (2003), found that individuals with strong illness identities and perceptions of more severe consequences reported worse physical functioning. Furthermore, patients who perceived they had little personal control over their illness reported worse objective disease state outcomes, regardless of the actual severity of disease. These findings were in support of previous associations found between illness representations and physical recovery rates and increased future use of health care services (Heijmans & de Ridder, 1998; Scharloo *et al.,* 1999). In terms of the relationship between illness perceptions and psychosocial outcomes, Hagger and Orbell's meta-analysis also revealed individuals with strong illness identities, perceptions of less personal control, a more chronic timeline and most severe consequences of having the illness had the worst psychological health and social and role functioning and the highest psychological distress. Conversely, individuals who perceived their illness to be more curable/controllable were those with the highest sense of wellbeing and vitality. The relationship between illness representations and psychological functioning remained even after controlling for socio-demographic and disease related predictors.

Interestingly, when it was published in 2003, Hagger and Orbell's meta-analysis included only one cancer study and this was a study of individuals *at risk* of breast cancer who did not have a diagnosis (Rees *et al.*, 2001). However, since 2003, significantly more studies have investigated the relationship between illness representations and the psychological health of individuals with breast cancer (Rozema, Vollnick, & Lechner, 2009), oesophageal cancer (Dempster M. , McCorry, Brennan, Donnelly, & Murray, 2012), lung cancer (Kaptein, Yamaoka, Snoei, Kobayashi, & Uchida, 2011), gynaecological cancer (Gould *et al.*, 2010), prostate cancer (Traeger, Penedo, Dahn, & Lechner, 2009) and head and neck cancer (Llewellyn, McGurk, & Weinman, 2007).

1.5. Review aims and benefits

Kitchenham (2004) recommends that a systematic review process identifies the need for a review. Despite a significant increase in the number of studies which have explored the association between illness representations and psychological health of adults with cancer over the last 10 years, there has to date been no published review attempting to collate and synthesise these findings[1]. The few reviews which have explored the illness representations of individuals with chronic illness have not focussed on or rarely included studies of cancer patients (Hagger & Orbell, 2003; Kaptein *et al.*, 2008; Petrie *et al.*, 2007). The Hagger and Orbell (2003) review of illness representations in individuals with chronic illness included only one study on cancer patients. This is potentially due to the possibility that the revision of the IPQ in 2002 (IPQ-R; Moss-Morris, *et al.*, 2002) resulted in an increased interest in exploring illness representations in general.

To represent an original contribution to this field of research, the first objective of these two reviews is to identify, collate and synthesise empirical evidence which has explored the *prospective* relationship between the illness representations and the psychological health of adults with cancer. Exploring the predictive nature of this relationship as opposed to the cross-sectional correlational relationship would be more beneficial to the objective of the second review which is to identify and examine studies that have developed interventions to modify illness perceptions (directly or indirectly) to improve psychological health.

Identifying the specific relationship between a patient's illness perceptions at one point in time (or how their illness perceptions change over time) and their future psychological health will be extremely useful information for health care professionals working within oncology settings to better identify which patients might struggle to cope over time after receiving a cancer diagnosis. This knowledge may also be useful for clinicians working within clinical and health psychology, to develop appropriate interventions that target specific illness perceptions to reduce the likelihood of maladaptive coping and poor psychological health in the future.

[1] This was still the case at the time data searches had all been complete and the majority of this thesis had been written. The author has since become aware of a very recently published review and meta-analysis of studies exploring the relationship between illness perceptions of adults with cancer and illness outcomes including psychological health (Richardson, Schuz, Sanderson, Scott, & Schuz, 2016).

Ultimately, there are also wider gains of these reviews which include improved clinician-patient communication, improving access to psychological services (by increasing clinician's awareness of why some patients may disengage from therapy or treatment for example) and using the findings to improvement illness outcomes, psychological health and quality of life. Finally, a published review of this kind is likely to be highly read and well cited. Hagger and Orbell's review on illness representations in chronic illness published in 2003 has been cited more than 1000 times. There have been no reviews of this kind since this time in any clinical population of patients meaning the impact in the clinical and academic population is greater than for a single study.

1.6. Research questions

Reviews 1 and 2 aim to answer four research questions and are as follows:

Review 1: The prospective relationship between illness representations and future psychological health

1. Are illness representations prospectively associated with future psychological health in adults with cancer?

2. Which illness perceptions best predict psychological health?

Review 2: Modifying illness representations to improve psychological health

3. What interventions have been developed to *directly* or *indirectly* modify illness representations for adults with cancer?

4. To what extent are these interventions effective in improving psychological health and modifying illness representations?

Research questions 1 and 2 are designed to understand the prospective relationship between illness perceptions and the psychological health of adults with a cancer diagnosis and will be addressed by Review 1. In this way, a clearer understanding might

be gained for the role for illness perceptions as a modifiable target for interventions to improve the psychological health of cancer patients. Research questions 3 and 4 aim to improve awareness of the different ways in which illness perceptions can be modified and to evaluate the extent to which such interventions have been effective in improving psychological health outcomes over time and will be addressed by Review 2.

2

METHODS

2.1. Design

This research used systematic review methods to answer four research questions (see section 1.7). Two systematic reviews were conducted. Review 1 explored the prospective relationship between illness perceptions and the psychological health of adults with cancer. Review 2 explored studies that had carried out interventions to modify illness perceptions to improve psychological health. Methods of systematic review differ from narrative or scoping reviews in the explicit process of data extraction and literature searching using published guidelines to ensure all available and relevant data is identified and thus reducing the potential for bias. This makes the process of searching, including and excluding studies, evaluating, appraising and synthesising the literature both rigorous and replicable (Garg, Hackam, & Tonelli, 2008). Systematic review methods also allow researchers to suggest areas for further investigation where gaps in current research are identified, aim to make available evidence more 'accessible' to clinicians and decision-makers and are known to provide more accurate reflection of the primary research than other types of review (Centre for Reviews and Dissemination, 2009).

2.2. Review guidelines

Best practice guidelines for systematic reviews developed by the Centre for Reviews and Dissemination[2] (CRD: 2009) were followed to search for literature and report evidence, ensuring consistency and transparency in this process. These guidelines will from this point be referred to as 'CRD guidelines'. By following these rigorous guidelines, it was anticipated that several forms of potential selection bias could be attenuated (Crowther, Lim, & Crowther, 2010; Kitchenham, 2004). Review methods

[2] The CRD was established in 1994 and is part of the National Institute for Health Research (NIHR). Based at the University of York, it is one of the largest groups in the world undertaking systematic reviews to synthesize and evaluate the research evidence on health and public health questions of national and international significance. CRD produces guidelines for researcher conducting systematic reviews in health care research (http://www.york.ac.uk/inst/crd/index.htm).

and findings are reported using the PRISMA Statement checklist[3] as a guide (Preferred Reporting Items for Systematic Reviews and Meta-analyses; Moher, Liberati, Tetzlaff, & Altman, 2009) to improve the inclusivity of reporting and the likelihood of publication (McLeroy, Northridge, Balcazar, Greenberg, & Landers, 2012).

2.3. Searching, selecting and evaluating the literature

Although two reviews were conducted, the methods employed to generate inclusion/exclusion criteria and develop a search strategy (Phases 1 & 2 – see below) were largely the same given both reviews aimed to explore the role of illness representations in the psychological health of cancer patients. Where this was not the case (e.g. year of publication), variations in search strategy will be outlined.

A structured approach to searching, selecting and evaluating the literature for both reviews was employed using five-phases recommended within CRD guidelines;

Phase 1: A priori generation of inclusion and exclusion criteria
Phase 2: Rigorous search for literature across multiple sources
Phase 3: Standardized abstract screening and study selection
Phase 4: Data extraction and standardized critical appraisal
Phase 5: Evidence synthesis

2.3.1. Phase 1: Generation of inclusion and exclusion criteria

As recommended by CRD guidelines, a broad preliminary scoping search (before the 'review proper') was carried out to enable the review author (the candidate) to become acquainted with the literature, to explore whether any similar systematic reviews existed and to assist in the development of inclusion/exclusion criteria. This type of early search has been identified as an important process in the development of inclusion criteria since it gives a broad overview of the size and nature of the evidence base (Popay, Roberts, Sowden, Petticrew, & Arai, 2006). Reviewers can then use this knowledge to determine how much research there is to review and what is achievable and of interest within the constraints of the study.

[3] The PRISMA Statement checklist was developed by the PRISMA group in 2005 (an international committee of authors, methodologists, clinicians and researchers) to assist authors in improving the reporting of systematic reviews and meta-analyses.

The scoping search was conducted using the following broad search terms; illness representations / illness perceptions / illness cognitions / common sense model AND psychological health AND cancer / oncology. These terms were entered into two generic search engines (e.g. Google Scholar, Web of Knowledge). The scoping review led to the generation of a set of preliminary inclusion and exclusion criteria that was relevant for both reviews. These criteria were revised iteratively when new information was discovered, as recommended in the systematic review literature (Kitchenham, 2004).

Inclusion criteria

The CRD guidelines recommend when deciding upon inclusion criteria, reviewers separate research questions into several key PICOS elements; (P)opulation (i.e. which population is the research question interested in?), (I)ntervention (what is the phenomenon of interest?), (C)omparators (what comparative studies are also eligible?), (O)utcomes (what are the primary or secondary outcomes of interest), and (S)tudy design (which study design will be relevant?). After familiarisation with the literature base during the scoping search and consensus discussion with supervisors, the following inclusion criteria were developed using four of the five PICOS elements (the comparators element was not relevant for either of these reviews and so was omitted);

1. **Population/participants**: Adult participants (18yrs+) with any cancer diagnosis, past or present, were included in both reviews.

2. **Intervention/phenomenon of interest**: Since Review 1 was aimed at investigating the *predictive* relationship between illness perceptions and psychological health, this review included only studies which had used a valid and reliable measure of illness perceptions (e.g. either the IPQ, IPQ-R or B-IPQ). These measures are currently the only available quantitative measures of illness perceptions which have repeatedly been shown to be both valid and reliable across a range of chronic illness settings, including cancer.

   For Review 2, the preliminary scoping search revealed only one intervention study that had made use of an illness perception measure. However, several studies were identified that reported illness representation interventions in cancer patients that had not employed an illness perception measure. It was considered unwise to

exclude such studies which could provide potentially useful information for clinicians. For this reason, inclusion criteria for this review were broadened to include studies that had attempted to modify illness perceptions whether they administered an illness perception measure or not.

3. **Outcome**: To improve the usefulness of the reviews within the field of clinical psychology, only studies that had used a valid measure of psychological health were included. The term 'psychological health' was defined by the reviewer and supervisors as 'distinct from physical health and physical functioning outcomes; relating to the psychological wellbeing, mental health, level of distress, affect, or psychological functioning of an individual'. This definition was considered broad enough to capture a wide range of relevant papers which might be useful in the field of clinical psychology. A judgement was made by the primary reviewer and supervisors (for five randomly selected studies) about whether the measure administered represented psychological health based on this definition. For studies from which it was not clear whether they had used a psychological health measure from the paper, the complete measure was obtained and a judgement made on the eligibility between the primary reviewer and supervisors using Dolan's definition. For both reviews, where studies used quality of life measures, only those that reported data on psychological health subscales were eligible for inclusion. It was anticipated that this would help to reduce the potential for bias when synthesising the data and interpreting the findings.

4. **Study design:** Using Kitchenham's (2004) recommendations as a guide, the following quantitative studies were considered appropriate for inclusion in both reviews; randomised controlled trial, quasi-randomised controlled trial, cohort study, concurrent cohort study, historical cohort study, interrupted time series and pre/post test case series.

Exclusion criteria

Using CRD guidelines, the following exclusion criteria were developed after the initial scoping search;

1. Cross-sectional studies
2. Qualitative studies

3. Unpublished/non-peer reviewed studies. Since research has shown that significant results are more likely to be published (Garg *et al.,* 2008), this criterion had the potential to increase the risk of publication bias. However, this potential is to some extent offset by the likelihood that unpublished studies, and other grey literature, are not peer reviewed and as such can introduce further bias (Crowther, Lim, & Crowther, 2010).
4. Studies not published in the English language. Although evidence suggest this may represent a potential source of selection bias (Gregoire, Derderian, & Le Lorier, 1995), it was not possible to include studies which required translation within the time and resource constraints of this research.
5. Studies reporting *only* the illness perceptions of individuals other than the person with cancer (e.g. carers/spouses/health care professionals).
6. Studies reporting *only* an outcome measure of coping (without psychological health).
7. Studies reporting *only* global quality of life scores rather than psychological/emotional/affective subscales.
8. Studies of patients without a cancer diagnosis such as those undergoing genetic or other types of cancer screening or unaffected healthy individual's perceptions of receiving a cancer diagnosis in the future
9. Review papers/opinion papers/dissertations/letters to the editor

2.3.2. Phase 2: Search for literature

Generating search terminology

CRD guidelines suggest the preliminary scoping review can be useful in developing a comprehensive list of key words relevant to each of the identified 'elements' of research questions (see section 2.2.1.) to construct a comprehensive search strategy for identifying research evidence. This list comprises keywords commonly cited in relevant articles, synonyms, abbreviations and spelling variants. It is suggested that final review search terms should be sensitive enough to identify all available relevant articles and specific enough to exclude irrelevant articles which can hamper the search process. This process should be iterative and several attempts should be made to develop a comprehensive strategy (Kitchenham, 2004). Generation of search terms for each of the four PICOS elements will be described here. These terms were used for both reviews

(for an example of the search terms and truncations used within the database MEDLINE see Appendix II):

1. Population/participants - The Macmillan cancer support website (www.macmillan.org.uk/Cancerinformation/ Cancertypes/AtoZ.aspx) was used to generate a comprehensive list of 59 cancer search terms. The inclusion criteria 'adults' was not incorporated within this element using search term parameters but applied manually when reviewing the extracted papers. The search terms developed were 'cancer' (prefixed by 37 variants of cancer), 'neoplasm', 'malignant', 'oncology', 'tumour' (prefixed by 5 types of tumour), 'sarcoma', 'carcinoma', 'leukaemia (prefixed by 4 types of leukaemia), 'lymphoma', 'lymphoblast', 'mesothelioma', 'myeloma' and 'pseudomyxoma'.

2. Intervention/Phenomenon of interest - Search terms were 'illness perceptions', 'illness representations', 'illness cognitions', 'illness perception questionnaire', 'IPQ', 'self-regulation/regulatory model/theory', 'illness attributions', 'common sense model', 'causal attributions', 'illness identity', 'illness coherence', 'emotional representations' and 'cognitive representations'. For Review 1, only studies using one of the three illness perception measures (IPQ/IPQ-R/B-IPQ) were extracted.

3. Outcome - The preliminary scoping search revealed a wide variation in the terminology used to describe and measure psychological health. A list of search terms was generated using definitions described within several review papers, discussion papers and other articles (Gomez, Gutierrez, Castellanos, Vergara, & Pradilla, 2010; King, Hicks, Krull, & Del Gairo, 2006; Moss-Morris *et al*., 2002; Ryff, 1989; Warr, 2012) and terms used within psychometric measures of psychological health and wellbeing (McMillan, Bradley, Gibney, Russell-Jones, & Sonksen, 2006; Tennant *et al.*, 2008). The search terms developed were 'distress', 'stress', 'wellbeing', 'adjustment', 'adaptation', 'recovery', 'psychological', 'functioning', 'quality of life', 'emotional', 'mental health', 'psychosocial', 'anxiety', 'depression', 'mood', 'coping', 'worry' and 'affect'.

4. Study design - It may have been possible to generate a list of relevant search terms for this facet such as observational study, randomised controlled trial, cohort study, for example. However, it was decided that these terms would add little to the overall search

strategy and may in fact represent too stringent a filter. Therefore, study design characteristics were manually searched by reading titles and abstracts in the first instance and full papers for those studies which met additional criteria.

Developing the search strategy

CRD guidelines recommend searching a broad range of sources to maximise identification of relevant articles and to reduce the risk of selection bias. The following relevant sources were identified for both reviews and applied in the order presented below;

1. **Electronic searches** – searching electronic databases comprised the largest part of the search strategy and was the most time intensive search. Databases a-d were searched via the search engine Ovid and Web of Knowledge was searched separately;
    a. MEDLINE
    b. AMED (Allied and Complementary Medicine)
    c. HMIC (Health Management Information Consortium)
    d. PsychINFO
    e. Web of knowledge

2. **Individual journal search –** The initial scoping search revealed several journals which had published relevant material and which may have contained studies not yet included and indexed by electronic databases. The following journals were searched online between November 1980 and November 2015;
    a. Psycho-Oncology
    b. Health Psychology
    c. Psychology & Health
    d. Psychosomatic Medicine
    e. Journal of Health Psychology
    f. British Journal of Health Psychology
    g. Journal of Psychosomatic Research
    h. British Journal of Cancer
    i. Psychology, Health and Medicine
    j. Journal of Psychosocial Oncology

3. **Review articles** – References and citations of extracted review articles were also searched.

4. **Reference lists** - All relevant articles retrieved and potentially eligible for inclusion were searched for any additional citations and references of articles which previous

search techniques had not already retrieved.

5. **Citations –** The search engine Google Scholar™ was used to search eligible studies for other relevant studies that had cited their work.

6. **Author search –** Once all eligible studies had been identified, all authors on each paper were searched in Google Scholar™ to determine whether they had written and published additional papers not yet identified. These authors were also contacted by email and asked a) whether they had published any work not already identified by the reviewer which might be eligible for inclusion and b) to provide details of any ongoing work pending publication. This has been identified as a good method of reducing the likelihood of publication bias (Kitchenham, 2004). All authors replied and no further papers were identified.

The search process

For both reviews, electronic searches were conducted first using key search terms in the Ovid database. It became apparent that this search engine searches titles, abstracts and keywords only as a default. This was manually overridden to enable a more comprehensive search of *all fields.* Non-English papers were excluded and the findings were de-duplicated.

It is important to delineate here between papers which were relevant for Review 1 and those for Review 2 in terms of publication dates. Since Review 1 sought studies which had used a standardized measure of illness perceptions (either the IPQ, IPQ-R or B-IPQ), studies published before 1996 when the original IPQ was developed, would be excluded. Since Review 2 would include studies that had employed an illness representation intervention but not necessarily used an illness perception measure, studies published before 1996 were still relevant. For this review, the search included all studies published between 1980, when Leventhal first proposed the common-sense model (Leventhal, Meyer, & Nerenz, 1980) and November 2015 (extraction date cut-off).

The number of papers found at each stage of both electronic and other searches and after filters were applied will be outlined in Chapter 3. It was decided that searching

would cease once all specified relevant databases, bibliographies and other relevant sources had been searched/contacted as is common in systematic reviews, particularly in those which are time and resource limited (Petticrew & Roberts, 2008).

2.3.3. Phase 3: Abstract screening and study selection

The CRD recommend that, once comprehensive search terms and a thorough strategy has been developed, a two-step approach to study selection is followed to minimize the risk of errors and bias. Step 1 involved the preliminary screening of all titles and abstracts by the primary reviewer as per inclusion and exclusion criteria. It is recommended that citations are initially reviewed independently and in duplicate by at least two reviewers at this stage to reduce the risk of incorrectly discounting or overlooking relevant papers (Garg *et al.,* 2008). This was not feasible within the constraints of this study for either review. However, to mitigate the risk of selection bias, four studies extracted in the early stages of the review were chosen at random and discussed with supervisors in terms of the search strategy and validity of the inclusion criteria. Only studies which clearly did not meet inclusion criteria were rejected at this stage. Any studies from which it was unclear from the abstract whether inclusion criteria had been met were then extracted for full review in step 2.

Step 2 involved the full review of potentially eligible studies which appeared to meet inclusion criteria based on information provided in the abstract. Studies from which a decision could not be made from the title and abstract alone were obtained in full for more detailed review. To improve selection reliability, studies for which it was ambiguous whether inclusion criteria had been met were discussed with supervisors to reach a consensus. Disagreements between reviewers (primary reviewer and two supervisors) were discussed and resolved by group consensus referring to inclusion criteria. Microsoft Access software was used to record citations of studies excluded in Stage 1 and those obtained in full or excluded in Stage 2, along with details on decisions and comments made for those papers which involved a more complex selection process.

It is worth noting here that step 1 of both reviews revealed multiple studies from the same authors which appeared to report data from the same participant group and as such was identified as a potential source of bias. Although it became apparent in step 2 after

reading the full articles that there were multiple reasons for this (e.g. reporting different outcomes, adding follow up data etc.), the CRD caution against treating such studies separately within a systematic review which can lead to overestimation of the overall efficacy of effects. In cases where it was unclear whether multiple studies referred to the same sample of participants, first authors were contacted by email to gain a clearer understanding of which studies reported data from the same sample and which were the 'best fit' of the inclusion criteria as recommended by DRC guidelines (see Figure 2 for the number of papers excluded on this basis).

2.3.4. Phase 4: Data extraction and critical appraisal

Data extraction

This part of the reviews involved extracting and documenting relevant information from each extracted paper necessary to answer each of the four research questions. Using CRD guidelines and advice from supervisors, data extraction forms were designed to collate this information for each review (see Appendices III & IV for data extraction forms). For each review, a pilot review on two articles was carried out to address the completeness of forms and any usability issues (e.g. clarity and relevance of items). CRD guidelines recommend that ideally, data extraction should be performed independently by two or more reviewers (Kitchenham, 2004) to improve reliability. This was not possible due to time and resource constraints. Instead, supervisors were asked to perform data extraction using the forms on one (each) randomly selected studies from each review. Results were cross-checked with the primary reviewer until consensus was reached.

Critical appraisal: Assessing study and reporting quality

Assessing the methodological quality of studies is an important measure of the strength of the evidence being reviewed and highlights the extent to which synthesised findings are generalizable. Furthermore, this form of critical appraisal has been recognized as an essential step in identifying factors which could bias empirical results and thus the overall conclusions drawn (Kitchenham, 2004). Four common types of bias which could potentially affect the validity of research findings extracted for this review include selection bias (the difference between the comparison groups in terms of treatment received), performance bias (the difference in conduct of comparison groups other than treatment/intervention), measurement bias and attrition bias (the differences between

comparison groups in relation to withdrawals or exclusions of participants from samples).

Both reviews involved the synthesis of studies with several different study designs. In the absence of a 'gold standard' critical appraisal tool for assessing multiple study designs (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004), a 17-item study appraisal tool was developed to aid the evaluation of material using collective guidance from a number of sources (e.g. CRD: www.casp-uk.net[4]; EPPI-Centre[5]: Harden, Oakley, & Oliver, 2001; Rees, Harden, Shepherd, Brunton, & Oliver, 2001; Thomas, Sutcliffe, Harden, Oakley, & Oliver, 2003). These items were chosen to provide the most relevant assessment of methodological quality for studies included in both reviews (See Appendix V for items). Each criterion could be answered by placing a tick in one of four columns; 'Yes' (meeting the criteria), 'No' (not meeting the criteria), 'Partly' (partially meeting the criteria), and 'Not applicable'.

One notable limitation to the assessment of methodological quality is that studies do not always report sufficient information to determine whether criteria have been met. In cases such as this, there is a risk of assuming that if this information was not reported then it has not been collected. In studies where important information is missing which might allow a more thorough assessment of methodological quality, CRD guidelines recommend contacting lead authors to clarify missing criterion. This was not feasible given the time limited nature of this research. For this reason, studies in each review were also assessed in terms of the clarity in which relevant information was *reported*, using 16 criteria designed to assess the level and quality of overall reporting based on good reporting practice guidance (CRD, 2009: see Appendix VI for items). For each of these criteria a judgement was made about the clarity of reporting across four options; 'Yes' (clearly reported), 'No' (not clearly reported), 'Partly' (the criteria was partly reported but not in sufficient detail to receive a 'Yes' judgement) and 'Not Applicable'.

The number of evident criteria (those rated with a 'yes' response) for both study and reporting quality were summed then divided by the number of applicable criteria and

[4] The Critical Appraisal Skills Programme is part of an international network helping researchers to find and interpret the best available evidence from health research.
[5] The Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) is part of the Social Science Research Unit at the Institute of Education, University of London. The centre is dedicated to both conducting systematic reviews and developing review methods for social science and public policy research.

multiplied by 100 to generate a 'Study', 'Reporting' and 'Total Quality' percentage score for each study/paper. It is recommended (Cochrane, 2011) that this type of quality assessment is conducted by more than one reviewer to improve reliability of evaluations, and so a small sample of papers (2 from each review) were made available to one of the candidate's supervisors to check they were being assessed reliably. Reliability between the two reviewers was good.

2.3.5. Phase 5: Evidence synthesis

CRD guidelines were developed predominantly to steer systematic reviews of clinical trials. Since the current reviews were likely to generate studies using a broader range of study designs, further systematic review methodology was identified to expand synthesis beyond simply quantifying the data as is common in systematic reviews of clinical trials. Findings from each study were synthesised in each review using a framework of narrative synthesis described by (Popay, Roberts, Sowden, Petticrew, & Arai, 2006). This four-stage approach recommends reviewers develop a priori theories about how interventions might work, develop preliminary syntheses using tables, cluster and content analysis, explore relationships within and between studies and acknowledge the robustness of the overall synthesis. Popay *et al.* suggest that this approach makes use of narrative interpretation at the synthesis stage to summarise and explain review findings and provides a useful alternative to simply quantifying data as is common with systematic reviews of clinical trials (Popay *et al.*, 2006, pp.67).

2.4. The potential for meta-analysis

It is commonly understood that before meta-analysis can be carried out, findings must be conceptually comparable, involving the same constructs and relationships (Cochrane, 2011). The Cochrane Collaboration recommend that meta-analyses should be conducted only where "participants, interventions and comparisons are judged to be sufficiently similar" (pp.137). There was potential to carry out a meta-analysis on a subset of extracted studies providing the following recommended criteria were met (Cochrane, 2011);

1. Studies used the same outcome measure of psychological health
2. Studies used the same/comparable measure(s) of illness perceptions

3. There was an appropriate level of statistical reporting required to perform meta-analysis
4. There were at least 10 studies meeting the above criteria[6]

Only seven studies were identified for Review 1 meaning criterion 4 was not met. For Review 2, data was considered insufficiently comparable to conduct meta-analysis. There was a wide variation in the types of cancer diagnoses (clinical diversity) and more so in the tools used to measure psychological health for this review. Attempting to quantitatively compare studies is well-known to be subjective. However, comparing studies with such wide diversity has been referred to as combining 'apples with oranges' (Cochrane, 2011, p.246) and can result in conclusions which are misleading (Garg *et al.*, 2008). Since identified studies within both reviews did not meet criteria, meta-analysis of data was not possible.

[6] Research shows meta-analysing too few studies can mean overall review conclusions can be over-or under-estimated (Cochrane, 2011)

3

RESULTS

3.1. Study selection

3.1.1. Review 1

Figure 2 below summarises the selection process for Review 1. A total of 2080 papers were retrieved using the electronic database search described in Chapter 2. One hundred and nine duplicate papers (where multiple databases had retrieved the same paper) and 97 non-English language papers were excluded. After examination of the titles and abstracts of the remaining references, 1547 papers which did not match inclusion criteria and those which were clearly ineligible were eliminated from further analysis. The remaining 327 potentially relevant papers were obtained in full for further evaluation by the primary reviewer (the candidate) after which an additional 193 papers were excluded because they failed to match inclusion criteria relating to the use of measures. For example, some excluded studies had not included a measure of psychological health or illness perceptions. Others that were excluded on this basis had administered quality of life measures which comprised psychological health subscales but had reported only overall quality of life data. A total of 119 studies were also excluded due to designs which were not relevant (e.g. qualitative studies). Finally, eight studies were excluded because data reported was for the same sample in studies that had already been included (see section 3.2 for further information on bias). The remaining seven studies were considered to fit all inclusion criteria and were included in Review 1. Searching citations, references, individual journals (for studies not yet indexed within electronic databases) and contacting key authors did not retrieve any further studies that fulfilled eligibility criteria.

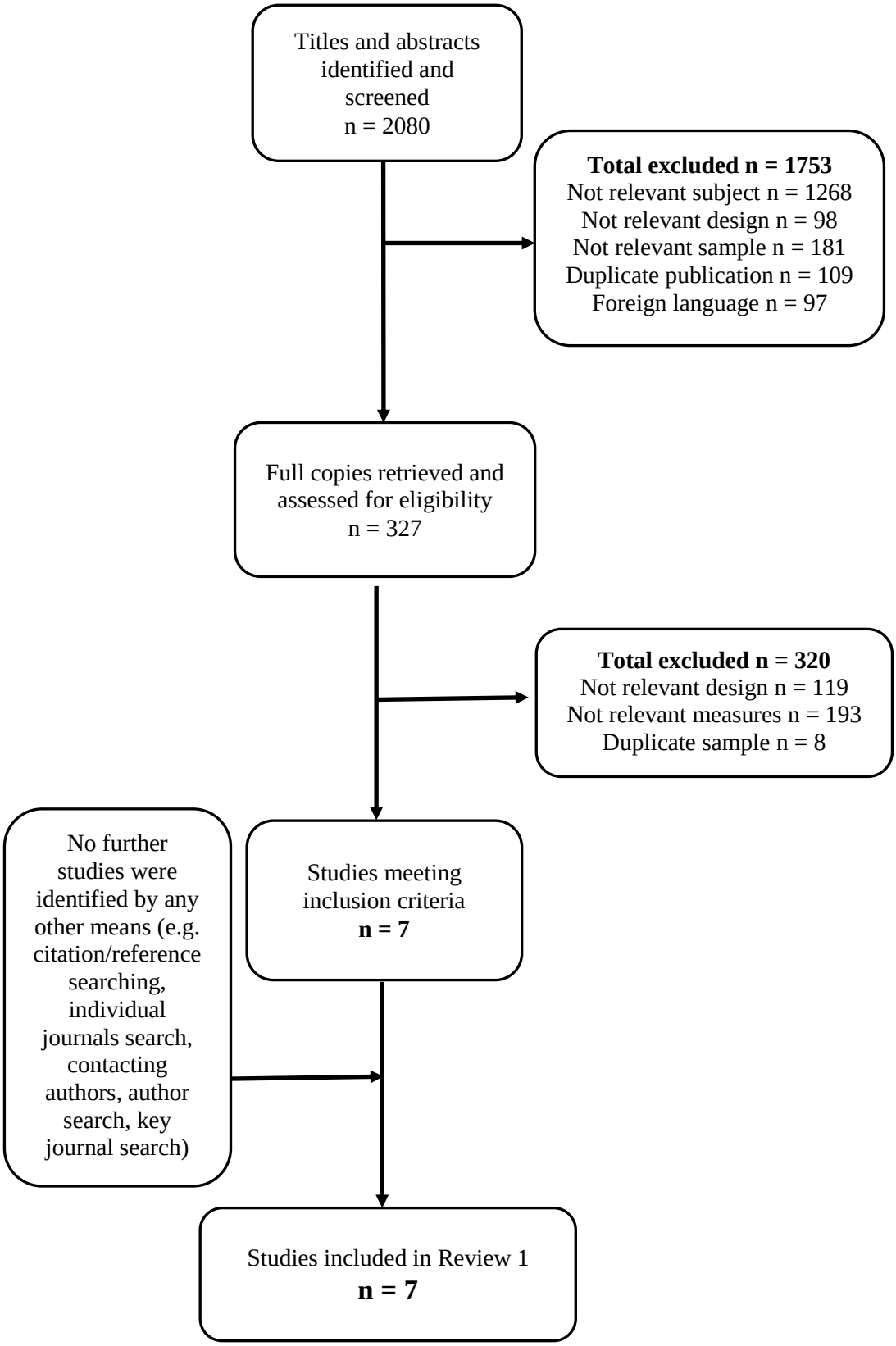

Figure 2: Flow diagram of study selection process for Review 1

3.1.2. Review 2

A total of 2230 papers were retrieved using the electronic database search described in Chapter 2. One hundred and ten duplicates (where multiple databases had retrieved the same paper) and 97 non-English language papers were excluded. A further 1666 papers were excluded because of irrelevant design, subject or sample. The remaining 357 potentially relevant papers were obtained in full for further evaluation by the primary reviewer (the candidate) after which an additional 199 papers were excluded because they failed to match inclusion criteria relating to the use of measures. Some excluded studies had not used an appropriate measure of psychological health or had administered and reported overall quality of life data rather than specific psychological health measures or subscales. A total of 141 studies were also excluded due to designs which were not relevant (e.g. qualitative studies). Finally, eight studies were excluded because data reported was for the same sample in studies that had already been included (see section 3.2 for further information on bias). Searching citations, references, individual journals (for studies not yet indexed within electronic databases) and contacting key authors retrieved four additional studies that fulfilled eligibility criteria. In total, 13 studies (10 papers) were considered to fit all inclusion criteria and were included in Review 2. Studies will be referred to throughout this review by their corresponding number (e.g. 1-7 for Review 1 and 8-20 for Review 2) for ease of understanding (see 3.2. for key to papers and references).

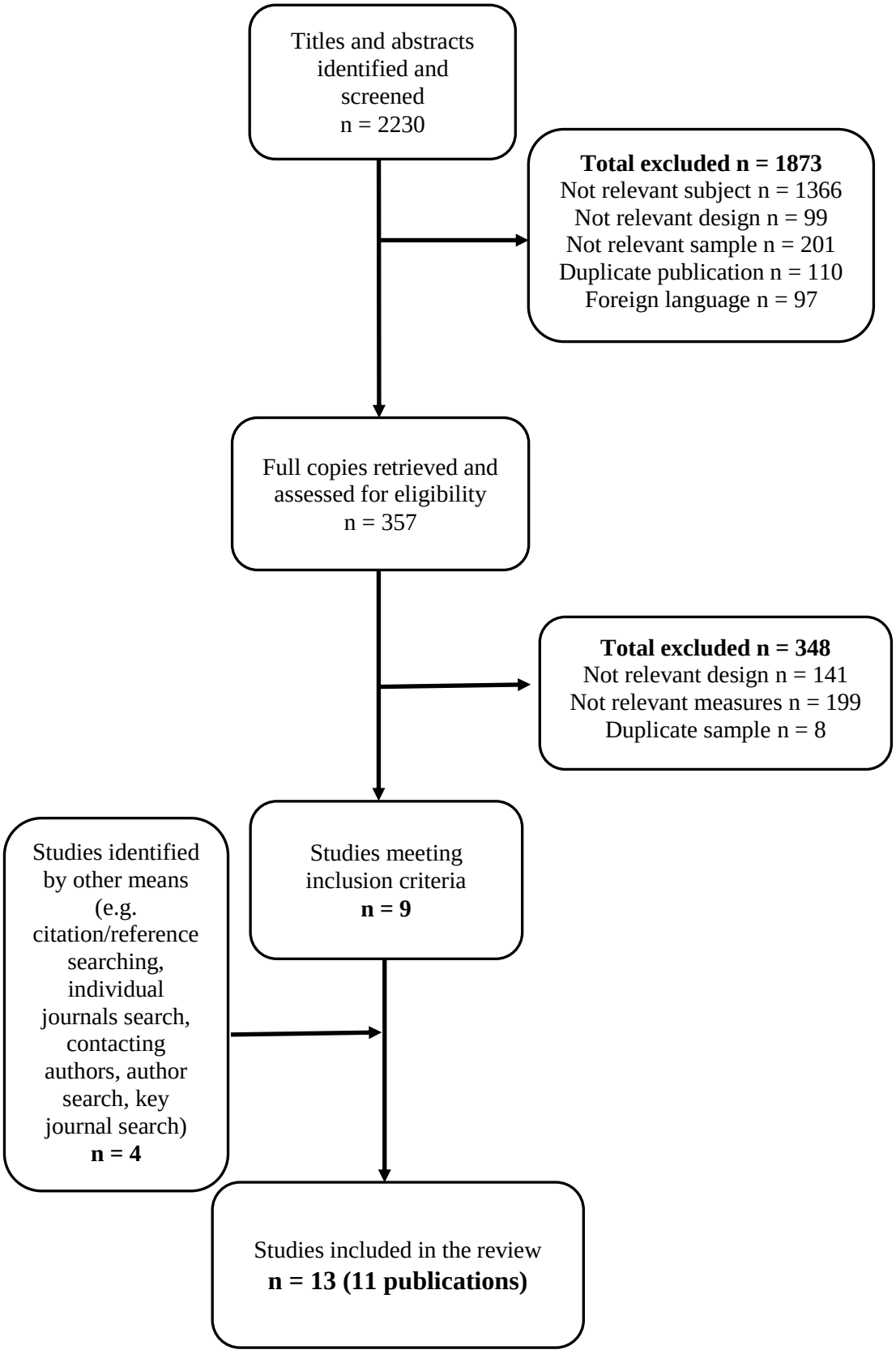

Figure 3: Flow diagram of study selection process for Review 2

3.1.3. Potential bias in study selection

As previously noted in Chapter 2, there were aspects of the data search and extraction process that had the potential for introducing bias. For example, including only peer reviewed published primary studies could have increased the risk of publication bias, since research has shown that studies yielding significant findings are more likely to be published than those yielding non-significant findings (Song, Eastwood, Gilbody, Duley, & Sutton, 2000). Furthermore, relevant unpublished (non-peer reviewed) studies were excluded which could have introduced selection bias. This may mean that the overall significance drawn from the findings in both reviews represents an over- or under-estimation of the actual significance.

However, since completing the current review, Richardson *et al.,* (2016) published a systematic review of the overall relationships (including cross-sectional) between illness representations, coping and illness outcomes in adults with cancer with similar research objectives and an almost identical search strategy to Review 1 but included published non-peer reviewed 'grey literature' such research dissertations. Richardson *et al.* identified only one study (a doctoral dissertation) not included by the current review but which would have met all other inclusion criteria (Gibbons, 2013). This doctoral dissertation was in fact identified in the search process of Review 1 as potentially relevant and the author was contacted by the candidate to ascertain whether there was a peer-reviewed publication pending - which there was not, meaning it was excluded from further analysis. The significant efforts made within the search strategy to attenuate this potential for bias by contacting key authors to check if any studies were in progress, due to be published or which had been completed but not published was considered enough to minimize the risk of publication bias in this review. The potential for sample bias was also minimised by the removal of eight studies in both Reviews 1 and 2 which reported data on duplicate samples. These studies were those that had published data for the same participants in the same study that either differed in terms of reported outcome measures, focus of the study or the point of data collection (e.g. cross sectional vs. prospective follow up).

A further potential source of selection bias in Review 1 was the inclusion of only studies which had administered the IPQ, IPQ-R or the B-IPQ. However, given that these are the only available psychometrically valid and reliable quantitative measure of illness perceptions and as such has been widely used in health settings, the risk of bias was

considered negligible. In a further effort to attenuate the risk of selection bias, the search strategies for both reviews was specifically designed to retrieve studies using a wide range of terminology to represent psychological health.

3.2. Review 1: The prospective relationship between illness representations and psychological health

3.2.1. Descriptive synthesis

The seven studies meeting inclusion criteria for this review were published between 2005 and 2015 and explored the prospective relationships between illness representations and future psychological health in adults with a cancer diagnosis. Table 1 below provides a key for reviewed studies for reference throughout this chapter.

Table 1: Key to papers in Review 1

Study #	Primary author	Title
1	Dempster (2011)	Do changes in illness perceptions predict changes in psychological distress among oesophageal cancer survivors?
2	Scharloo (2010)	Illness cognitions in head and neck squamous cell carcinoma: predicting quality of life outcome.
3	Cook (2015)	A prospective study of the association of metacognitive beliefs and processes with persistent emotional distress after diagnosis of cancer.
4	Ashley (2015)	Illness perceptions within 6 months of cancer diagnosis are independent prospective predictor of health-related quality of life 15 months post-diagnosis.
5	Llewellyn (2007)	Illness and treatment beliefs in head and neck cancer: Is Leventhal's common sense model a useful framework for determining changes in outcomes over time?
6	McCorry (2013)	Illness perception clusters at diagnosis predict psychological distress among women with breast cancer at 6-months post diagnosis.
7	Millar (2005)	A 1-year prospective study of individual variation in distress, and illness perceptions, after treatment for breast cancer.

3.2.1.1. Study characteristics

Design

All studies were questionnaire-based repeated measures prospective observation studies. All participants were recruited through outpatient cancer clinics with one exception (Study 1 used a patient support group database to recruit participants). All but Study 2 (conducted in the Netherlands) were carried out in the UK.

Clinical setting

Although the search strategy included over 40 different cancer types, included studies sampled patients from only five cancer fields: breast (3, 4, 6 & 7), prostate (3 & 4), head and neck (2 & 5), oesophageal (1) and colorectal (4). Most patients in the entire sample (57%) had a breast cancer diagnosis (n=638) sampled by four out of seven studies (3, 4, 6 & 7). The least frequent diagnosis of sampled patients was oesophageal and colorectal cancer (n=83). Only two studies included patients with different cancer diagnoses (Studies 3 & 4).

Use of measures

Papers were analysed in terms of the extent to which measures used in each study were both valid and reliable measures of illness perceptions and psychological health, acknowledging any modifications or changes in the standard or recommended administration of measures which have the potential to confound the findings of studies.

1. Illness perception measures

Administration

Studies 1-6 used the IPQ-R to measure illness perceptions and Study 7 used the IPQ since its successor had not yet been published when the study was conducted. Table 2 summarizes the components measured from the studies using the IPQ-R only. Study 7 was excluded from this summary table because items and subscales are fewer and qualitatively different to those found in the IPQ-R and as such are difficult to compare directly.

Omissions

Of the six studies using the IPQ-R, only Study 2 administered it in its entirety (all nine

subscales). Remaining studies administered eight (1,3,4,6) and seven subscales (5). Causal items and the emotional representations subscale were most often omitted. Few reasons for omitting subscales were provided except for studies 3 & 4 who cited 'potential to cause patient distress' (causal subscale omission) and the relative importance of appraising cognitive rather than emotional representations (Study 3).

Modifications

Only Study 4 explicitly stated the generic wording of the IPQ-R had been changed to make it cancer specific (e.g. "my *cancer* is a serious condition") as recommended by the developers of the measure (Moss-Morris, *et al*., 2002). Two studies modified causal items on the IPQ-R. Moss-Morris *et al.*, recommend the 18 causal items can either be analysed individually, or grouped into subscales indicated by factor analysis or based on theory. Study 2 summed only causal items endorsed by more than 20% of their sample to form an 'own behaviour' 3-item subscale and while these items were highly correlated, factor analysis was not conducted and neither theory or evidence to support the existence of this subscale was reported. Study 3 combined seven psychological and behavioural causal items to form one subscale ('psychological attributions') based on findings from previous research (Kulik & Kronfield, 2005) but did not conduct item correlations or factor analysis.

Table 2: Review 1 - Illness perceptions measured

Illness perception components	Studies measuring the component	Percentage of all studies (n=6)
Identity	1,2,3,4,5,6	100%
Timeline - Acute/chronic	1,2,3,4,5,6	100%
Timeline - Cyclical	1,2,3,4,5,6	100%
Consequences	1,2,3,4,5,6	100%
Coherence	1,2,3,4,5,6	100%
Cure/control - Personal	1,2,3,4,5,6	100%
Cure/control - Treatment	1,2,3,4,6	83%
Cause	1,2,3,6	67%
Emotional representations	2,4,5	50%

Scale/subscale reliability

As recommended (Bialocerkowski, Klupp, & Bragge, 2010), Cronbach's alpha (α) coefficient values (Cronbach, 1951) for IPQ and IPQ-R subscales were reported for five of the seven reviewed studies (2,3,4,5 & 7). Table 3 summarises these values for studies 2-5 using the IPQ-R. Values for Study 7 which used the IPQ ranged from .72 for identity and cure/control subscales and .84 for the timeline subscale (n=325) but are not included in the summary table due to incomparable items.

Table 3: Review 1 – Reliability coefficient values for illness perception subscales

Illness perception subscales	**Cronbach's alpha reliability coefficient values (α) for each study**				**Range**
	Study 2 (n=177)	Study 3 (n=229)	Study 4 (n=334)	Study 5 (n=82)	
Identity	**.79**	NS	NS	NS	NA
Timeline - Acute/chronic	**.86**	**.82**	**.90**	**.88**	**.82 – .90**
Timeline - Cyclical	**.70**	**.82**	**.77**	**.74**	**.70 – .82**
Consequences	**.76**	NS	**.83**	**.69**	**.69 – .83**
Coherence	**.75**	NS	**.87**	**.78**	**.75 - .87**
Cure/control - Personal	**.74**	**.64**	**.81**	**.61**	**.61 - .81**
Cure/control - Treatment	**.78**	NS	**.82**	NM	**.78 - .82**
Cause	**.80**	NS	NM	NM	NA
Emotional representations	**.92**	NS	**.89**	**.87**	**.87-.92**

NS=Not stated; NM=Not measured; NA=Not applicable

It is commonly acknowledged that alpha values falling below .70 indicate less than acceptable internal reliability between items of that subscale: subscales with alpha values below .60 are considered to have poor or unacceptable internal reliability (Cortina, 1993). Only two studies (3 & 5) reported alpha values below .70, both for the personal control subscale and Study 5 for the consequences subscale. Conversely, subscale alpha values above .80 are considered to represent good internal reliability and those above .90 considered excellent. The two subscales of the IPQ-R with the best internal reliability were acute/chronic timeline and emotional representations, both of which yielded values over .80 across all four studies.

2. Psychological health measures

Administration

Five different measures of psychological health were administered by the seven studies. Table 4 provides a summary of each of these measures including a brief description of their purpose and structure.

Table 4: Review 1 – Questionnaires used to measure psychological health

Study	Outcome measure*	Cancer specific measure	Validated in cancer population#	Description	Psychological health construct(s) measured
1,3,5,6	HADS	No	Yes	14 items measuring health related anxiety and depression	Anxiety and depression
2	QLQ-30	Yes	Yes	30 items across 9 subscales measuring quality of life in cancer patients	Emotional functioning (1 subscale - 4 items)
3	IES	No	Yes	15 items across 2 subscales measuring subjective distress	Distress
4	QLACS	Yes	Yes	47 items across 7 generic and 5 cancer specific subscales measuring health related quality of life in cancer patients	Positive affect (4 items); negative affect (4 items); distress over recurrence (4 items); family-related distress (3 items)
5	SF-12	No	No	12 items across 8 domains measuring mental and physical health	Mental health (12 items)
7	GHQ	No	No	28 items across 4 subscales measuring emotional distress in medical settings	Emotional distress

HADS - Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); **QLQ-30** – Quality of Life Questionnaire (Sherman, Simonton, Adams, Vural, & Owens, 2000); **IES –** Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979); **QLACS** – Quality of Life in Adult Cancer Survivors (Avis, *et al*., 2005); **SF-12** – Short form health survey (Ware, Kosinski, & Keller, SF-12: An even shorter health survey, 1996); **GHQ** – General Health Questionnaire (Goldberg & Williams, 1988); **#** As reviewed in Vodermaier, Linden, & Siu, 2009.

The most commonly administered measure of psychological health was the HADS, measuring anxiety and depression and was used by four studies. Only Studies 3 and 5 administered more than one measure of psychological health. Studies 1, 3, 5, 6 and 7 administered specific measures of psychological distress (HADS & GHQ). Studies 2 and 4 used broad quality of life measures which incorporated affective, psychological distress or emotional functioning subscales. Although only two of the six measures administered were cancer specific (QLQ-C30 & QLACS), two additional non-cancer specific general measures of distress (HADS & IES) have shown good psychometric properties within cancer populations (Vodermaier, Linden, & Siu, 2009).

Omissions & modifications

No studies reported modifying any psychological outcome measures or omitting any subscales or items.

Scale/subscale reliability

Four of the seven studies provided data on the internal reliability of their psychological outcome measures or subscales. Table 5 summarises reported values. These were within the good-excellent range of internal consistency (Cronbach, 1951).

Table 5: Review 1 – Reliability coefficient values for psychological health measures

Psychological health measure		**Cronbach's alpha reliability coefficient values (α) for each study**			
		Study 3 (n=229)	Study 4 (n=334)	Study 5 (n=82)	Study 7 (n=325)
HADS	Depression	**.84**	NA	**.81**	NA
	Anxiety	**.88**	NA	**.89**	NA
IES		**.90**	NA	NA	NA
QLACS	Negative feelings	NA	**.89**	NA	NA
	Positive feelings	NA	**.94**	NA	NA
	Distress over recurrence	NA	**.90**	NA	NA
	Family related distress	NA	**.88**	NA	NA
GHQ		NA	NA	NA	**.82**

NA=Not applicable

Procedure

The point at which patients completed baseline and follow up measures varied widely between studies. Table 6 summarises the time between receiving a cancer diagnosis or commencing/ending treatment and completion of measures for each study.

Table 6: Review 1 – Time between diagnosis/treatment and completion of measures

Study	Time between pre-intervention baseline measures and diagnosis	Time between pre-intervention baseline measures and treatment cessation	Number of follow ups	Time between pre-intervention baseline and final follow up measures
1	4 years (median)	'Post-surgery'	1	NS
2	'During diagnostic testing'	'Pre-treatment'	2	24 months
3	'Soon after diagnosis'	'Pre-treatment'	1	12 months
4	3.5 months (mean)	NS	1	12 months
5	'Newly diagnosed'	'Pre-treatment'	2	6-8 months
6	1-2 weeks after diagnosis	'Post-surgery'	1	6 months
7	NS	7-10 days post-surgery	3	12 months

NS=Not stated; *= Where exact time values were not reported, specific phrases used to describe the time point have been used as a proxy.

Completion of baseline measures

The exact time between patients receiving a cancer diagnosis and the completion of baseline measures was only provided by three studies (1, 4 & 6); this varied hugely from 1-2 weeks to a median of 4 years' post diagnosis. The time between receiving treatment and completion of baseline measures also varied across the studies. For example, while three studies reported baseline measures were administered around the time of diagnosis *before* patients had undergone any form of treatment, patients in Studies 1 and 6 had undergone curative surgery at the point of baseline. Study 7 did not provide any details on the time between baseline and diagnosis but stated measures were administered 'shortly after surgery'.

Completion of follow up measures

Studies administered follow up measures between 6-8 months (5) and 2 years after baseline (2). Three studies followed patients approximately one year after baseline measures had been administered. However, reporting of the administration of these measures was inconsistent and measured using different time point references (e.g. post-diagnosis/treatment cessation/post baseline) making it difficult to calculate exact time points to make direct comparisons. Patients in *all studies* had undergone at least one form of cancer treatment at the point of administration of final follow up measures. Although studies tended to report the types of treatment patients had already undergone at final follow up, most studies did not explicitly report whether any patients were still undergoing any form of cancer treatment at this point.

3.2.1.2. Patient characteristics

Sample sizes and attrition

It is difficult to ascertain true baseline statistics because several studies reported only data from patients who had completed measures at *all* time points and did not provide separate baseline data. However, taking the overall data provided by these studies into consideration (Table 7), there were *at least* 1,403 participants completing measures at baseline and *a definite* 1,223 participants completing measures in final follow ups.

Table 7: Review 1 – Sample sizes and attrition

Study	Total n at baseline	Total n at final follow-up	Overall attrition (%)
1	189*	189	NK
2	177	95	46%
3	206*	206	NK
4	334*	334	NK
5	82	50	39%
6	90	75	17%
7	325	274	16%
Total	**1403**	**1223**	**12.8%**

*Studies only report data for patients who provided data at all time points and actual baseline figures are unknown. Final time point data has been recorded in these instances; NK=Not known

In terms of attrition, taking only the four studies which reported both baseline and final follow up sample sizes, the overall attrition was 27%. However, two of these studies reported attrition levels significantly higher than this at 39% (5) and 46% (2). The overall attrition rate of 27% is therefore likely to be an underestimation of the actual attrition of data and simply an artefact of the poor reporting of baseline information. Loss to follow-up greater than 20% could be a potential source of bias for these studies (Schulz & Grimes, 2002).

Demographics

Ages of participants in the entire sample ranged from 23 to 98 years old, although mean ages of participants in each study ranged from 57 (Study 6) to 65 (Study 1) years old. Most patients in the collective sample were female (62%). Two studies sampled only female participants (6 & 7), and the remaining five studies sampled both men and women. Only two studies reported patient's ethnicity, stating between 92% (4) and 99.7% (5) of recruited patients were Caucasian.

Cancer occurrence, severity and tumour stage

Four studies included only or mostly patients for whom this was their first cancer diagnosis (2, 3, 5 & 6): the remaining three studies did not report this information. In terms of cancer severity upon recruitment, only one study included patients who had metastatic cancer (Study 2, 9.6% of baseline patients). Three studies (1, 4 & 7) did not provide data on metastases prevalence in their sample and the remaining three studies (3, 5 & 6) included only patients who had no metastases. Only four papers provided data on participants' cancer stage or tumour severity at the point of recruitment (2, 3, 5 & 6). However, it is not possible to directly compare participants in terms of their tumour stage, due to studies using incomparable indices to measure severity.

3.2.2. Quality assessment

3.2.2.1. Overall quality

Each of the seven studies were evaluated according to 14 applicable study quality criteria and 14 applicable reporting quality criteria (see page 34 for full description of the item development and rating system). Percentage quality scores for each study (the total number of evident criteria out of applicable criteria) are presented in Table 8 in descending order of score.

Table 8: Review 1 – Study quality, reporting quality and total quality scores

Study	Study quality score (%)	Reporting quality score (%)	Total quality score (%)
3	93%	86%	89%
2	71%	100%	86%
4	93%	79%	86%
5	86%	86%	86%
7	86%	71%	79%
6	79%	64%	71%
1	64%	50%	57%

Study quality scores ranged from 64% (1) to 93% (3 & 4) with a median score of 86%. Reporting quality scores ranged from 50% (1) to 100% (2), with a median score of 79%. Total quality scores ranged from 57% (16/28 items) for Study 1 to 93% (26/28 items) for Study 3 with a median of 86% across all seven studies. Although Study 1 had the lowest study and reporting quality scores, it had only two criteria judged as completely absent; the provision of internal consistency data for measures/subscales (recommended as best practice in questionnaire studies; Bennett, *et al.,* 2011) and a well defined research question, remaining applicable items judged as either partially evident or unclearly reported.

3.2.2.2. Study quality

Table 9 summarizes criteria judged as evident (the criteria was fulfilled within the study) to illustrate overall study quality for each paper. Fifty-seven percent of criteria (8/14 items) were judged as present in *all* reviewed studies (see Appendix VII for complete breakdown of study quality ratings for each study). All studies had referred to Leventhal's common sense model as a basis of understanding. The remaining six criteria not met by all studies was, for the majority, partially met rather than completely absent. Criteria not evident in all studies but which needs to be considered further as

potentially introducing bias to the overall findings (and which hasn't already been addressed within this chapter) will be outlined below.

Table 9: Review 1 – Study quality criteria judged as evident

Criterion*	Studies	Percentage of all studies (n=7)
1. Based on theoretical framework	1,2,3,4,5,6,7	100%
3. Appropriate methods used to answer research question	1,2,3,4,5,6,7	100%
9. Use of valid and reliable psychological health measure	1,2,3,4,5,6,7	100%
10. Recommended use of psychological health measure	1,2,3,4,5,6,7	100%
13. Adequate length of follow up	1,2,3,4,5,6,7	100%
14. Appropriate quantitative analysis to test hypothesis	1,2,3,4,5,6,7	100%
15. Accurate interpretation of findings	1,2,3,4,5,6,7	100%
16. Conclusions consistent with results	1,2,3,4,5,6,7	100%
11. Recommended use of illness perception measure	1,3,4,5,6,7	86%
2. Well defined research question/hypothesis	2,3,4,5,6	71%
4. Appropriate recruitment procedure	2,3,5,6,7	71%
5. Adequate sample size for statistical analysis	3,4,5,7	57%
12. Acceptable internal consistency	3,4,7	43%
17. Findings generalizable	3,4	29%

*Criterion numbers 6, 7 and 8 were not included in Review 1 as they referred to details about interventions

Recommended use of measures

In terms of the use of illness perception measures, only Study 2 was judged as only partly using their measure (IPQ-R) in a recommended way, due to their inclusion of only causal items endorsed by at least 20% of their sample. Developers of the IPQ recommend that causal items should be used as a subscale as indicated either by factor

analysis (not conducted by Study 2) or by a priori theory (Moss-Morris, *et al*., 2002). All studies administered valid and reliable measures of psychological health in full as recommended.

Adequate sample sizes

Five studies were judged as using adequate sample sizes required for statistical analysis. This judgement was based upon the general recommendation that between 10-15 participants are required per predictor in regression analysis (Field, 2013). Two studies did not meet this criterion due to having proportionately smaller sample sizes for the number of variables regressed either at baseline (Study 6) or at final follow up after high attrition rates (Study 2).

Generalisability

The criterion with the poorest quality rating was the generalisability of findings. Only Studies 3 and 4 were rated as having findings which were generalizable due to having the largest samples of both male and female participants sampled from several different hospitals with a large age range, different cancer diagnoses and a long follow up period. The remaining five studies were judged to be partially generalizable to similar patient groups or settings but not necessarily beyond these groups due to smaller sample sizes (Study 5), high levels of attrition (Studies 2, 5, 6 & 7) and lack of clinical (Studies 1, 2, 5, 6 & 7) or demographic (Studies 6 & 7) diversity. This potential for bias is notably common within this type of research in specific clinical settings if only one field of cancer is being studied as was the case for five out of seven studies reviewed (Miller, *et al.*, 2005).

3.2.2.3. Reporting quality

To avoid assuming that studies with low study quality scores were necessarily poorly conducted studies, but indicative of insufficient reporting of information, papers were analysed per the quality of information provided. Table 10 summarises criteria with 'Yes' ratings (criteria which was reported to a good standard) for each paper to evaluate the quality of reporting (see Appendix VIII for complete breakdown of reporting quality ratings for each study). The only criterion evident in *all* reviewed studies was whether papers had provided a clear description of their psychological health outcome measure. 'Partial' ratings were common within all studies for some criteria such as the reporting

of potentially confounding variables (criterion 14) and clear descriptions of recruitment procedures (criterion 4). Item 4 was the most poorly reported: well reported in only three studies.

Table 10: Review 1 – Reporting quality criteria judged as evident

Criterion*	Studies	Percentage of all studies (n=7)
7. Clear definition of psychological health measure	1,2,3,4,5,6,7	100%
2. Clear description of sample	2,3,4,5,6,7	86%
3. Clear description of setting	1,2,3,4,5,6	86%
12. Strengths and limitations of study stated	1,2,3,4,5,7	86%
13. Problems with study design reported	2,3,4,5,6,7	86%
15. Discussion of clinical relevance of findings	1,2,4,5,6,7	86%
16. Recommendations for clinical practice discussed	1,2,3,4,5,6	86%
1. Clearly reported aims and objectives	2,3,4,5,6	71%
8. Clear description of data collection	2,3,4,5,7	71%
9. Reliability of administered measures reported	2,3,4,5,7	71%
10. Clear description of data analysis conducted	1,2,3,4,6	71%
11. Provision of attrition data	2,3,5,6,7	71%
14. Potentially confounding factors reported	2,3,5,7	57%
4. Clear description of recruitment procedures	1,2,7	43%

*Items 5 and 6 were removed from this table since they related to the reporting of interventions

3.2.3. Overall findings

3.2.3.1. Results of individual studies

To answer research questions, findings from each study will be summarized in Table 11. Each study is described according to findings relating to Research questions 1 and 2.

Table 11: Review 1 – Summary of individual study findings

Study 1: Dempster, *et al.*, (2011). Do changes in illness perceptions predict changes in psychological distress among oesophageal cancer survivors? **Study description:** Evaluated the relationship between illness perception 'clusters' (patients with similar illness perception changes over time) and changes in anxiety and depression over time	
Research question 1 Are illness representations prospectively associated with future psychological health?	**Research question 2** Which illness perceptions best predict psychological health?
• Illness perception 'clusters' (determined by cluster analysis of illness perception change scores) explained 3% of the variance in *change* in anxiety over time after the 5% variance explained by demographic (age & gender) and clinical (number of other conditions, months since diagnosis) variables had been accounted for • Illness perception 'clusters' explained an additional 4% of the variance in *change* in depression over time after the 1% variance explained by demographic and clinical variables had been accounted for	• The only significant differences in anxiety and depression ($p<.05$) between patients was between illness perception Cluster's 1 and 3: Cluster 1 patients having significantly more positive cognitions over time and Cluster 3 patients experiencing greater increases in negative cognitions. • Key illness perceptions of Cluster 3 patients (over time): o decreasing beliefs in- ▪ treatment control ▪ personal control ▪ illness coherence o increasing beliefs in- ▪ cyclical nature of cancer ▪ chronicity ▪ severity of consequences ▪ the number of symptoms attributed to the disease

Table 11: Review 1 – Summary of individual study findings (continued)

Study 2: Scharloo, *et al.*, (2010). Illness cognitions in head and neck squamous cell carcinoma: predicting quality of life outcome. **Study description:** Measured the relationship between baseline illness perceptions and emotional functioning 1 and 2 years later	
Research question 1 Are illness representations prospectively associated with future psychological health?	**Research question 2** Which illness perceptions best predict psychological health?
• Illness perceptions did not predict emotional functioning at either 1 or 2 years follow up	• None. Best predictor of emotional functioning at both 1 and 2 years follow-up was baseline emotional functioning (which explained 42% of variance in scores)
Study 3: Cook, *et al.*, (2015). A prospective study of the association of metacognitive beliefs and processes with persistent emotional distress after diagnosis of cancer. **Study description:** Measured the relationship between baseline illness perceptions and anxiety and depression 12 months later	
Research question 1	**Research question 2**
• Baseline illness perceptions explained 3% of the variance in anxiety and 3% in depression scores 12 months later after controlling for age, gender, and baseline anxiety and depression (which collectively accounted for 38% of the variance in depression & anxiety at T2)	• Perceived lack of personal control predicted 1% of the variance in T2 anxiety • Negative perceptions of the consequences of cancer predicted 2% of the variance in T2 anxiety • Poor illness coherence predicted 3% of the variance in T2 depression

Table 11: Review 1 – Summary of individual study findings (continued)

Study 4: Ashley *et al.,* (2015). Illness perceptions within 6 months of cancer diagnosis are independent prospective predictor of health-related quality of life 15 months post-diagnosis. **Study description:** Measured the relationship between illness perceptions measured within 6-months post diagnosis and affect and distress measured 15-months post diagnosis	
Research question 1 Are illness representations prospectively associated with future psychological health?	**Research question 2** Which illness perceptions best predict psychological health?
• Illness perceptions accounted for 18.6% of the variance in negative affect, 17.9% in positive affect, 27.9% in distress over cancer recurrence and 10.5% in family-related distress, after controlling for socio-demographic (age, gender, SES) and clinical (diagnosis, treatment received) variables • Socio-demographic and clinical variables accounted for less variance than illness perceptions in T2 negative affect (7.5%), positive affect (2.8%), distress over recurrence (10.5%) and family-related distress (1.4%)	• Illness identity was significantly predictive of T2 distress over cancer recurrence and family-related distress • Perceptions of the severity of consequences were significantly predictive of both T2 negative and positive affect • Emotional representations were significantly predictive of both positive and negative affect, distress over recurrence and family-related distress
Study 5: Llewellyn *et al.,* (2007). Illness and treatment beliefs in head and neck cancer: Is Leventhal's common sense model a useful framework for determining changes in outcomes over time? **Study description:** Measured the relationship between baseline pre-treatment illness perceptions and anxiety and depression 6-8 months after treatment completion.	
Research question 1	**Research question 2**
• Baseline illness perceptions* predicted 28% of the variance in depression 6-8 months later (T3) • Baseline illness perceptions did not predict T3 'mental health' or anxiety	* Only illness perceptions about the chronicity of cancer (timeline) were predictive of scores in depression at T3 • Only baseline anxiety was predictive of T3 anxiety and accounted for 27% variance

Table 11: Review 1 – Summary of individual study findings (continued)

Study 6: McCorry, *et al.*, (2013). Illness perception clusters at diagnosis predict psychological distress among women with breast cancer at 6-months post diagnosis **Study description:** Measured the relationship between illness perceptions at diagnosis and anxiety and depression 6 months after diagnosis	
Research question 1 Are illness representations prospectively associated with future psychological health?	**Research question 2** Which illness perceptions best predict psychological health?
• Illness perception 'cluster' membership predicted 9.5% of the variance in anxiety and 11.3% of the variance in depression 6 months later (T2) after controlling for socio-demographic (age, no. of dependents, living arrangements) and clinical (tumour stage, treatment received, tumour severity, previous psychiatric input) variables	• Participants in Cluster 1 had more negative illness perceptions overall and higher levels of depression and anxiety at T2 than participants in Cluster 2 • Cluster 1 patients had a less coherent understanding of their illness and were more likely to believe their illness was chronic, cyclical, less controllable and severe, and had more associated symptoms and causes than patients in Cluster 2 • Cluster analysis enabled the identification of an 'at risk' subgroup of women in Cluster 1 with 'problematic anxiety', identified as potential target for intervention

Table 11: Review 1 – Summary of individual study findings (continued)

Study 7: Millar *et al.,* (2005). A 1-year prospective study of individual variation in distress, and illness perceptions, after treatment for breast cancer. **Study description:** Measured the relationship between illness perceptions 7-10 days after surgery and psychological distress 12 months later	
Research question 1 Are illness representations prospectively associated with future psychological health?	**Research question 2** Which illness perceptions best predict psychological health?
• Baseline illness perceptions* explained 5.9% of the variance in emotional distress' after 12 months (T2) after controlling for baseline emotional distress (which predicted 29% of the variance in T2 emotional distress)	* Only illness identity predicted emotional distress 12 months later

3.2.3.2. Data synthesis

Approaches

Three main approaches were used by the seven studies to measure the prospective relationship between illness perceptions and psychological health (depicted in Figure 3). Before attempting to synthesize outcomes and answer Research question 1, it is important to first outline and consider the differences in these approaches.

Approach 1

Study 1 measured illness perceptions and psychological distress at Time 1 (T1) and Time 2 (T2) to calculate change scores for both variables (T2 scores - T1 scores). Illness perception change scores were then subject to cluster analysis to group together patients whose illness perceptions changed in similar patterns between T1 and T2. Regression analysis was then used to determine the predictive relationship between clusters (changes in illness perceptions over time) and psychological distress change scores.

Approach 2

Studies 2, 3, 4, 5 and 7 used multiple regression analysis to examine the predictive relationship between illness perception scores across several IPQ and IPQ-R domains measured at T1 and psychological health scores measured at T2.

Approach 3

Study 6 also conducted cluster analysis, but only on T1 illness perception scores to determine clusters of patients who shared similar patterns of illness perceptions at baseline. Regression analysis was then used to determine the predictive relationship between T1 illness perception clusters and T2 psychological distress.

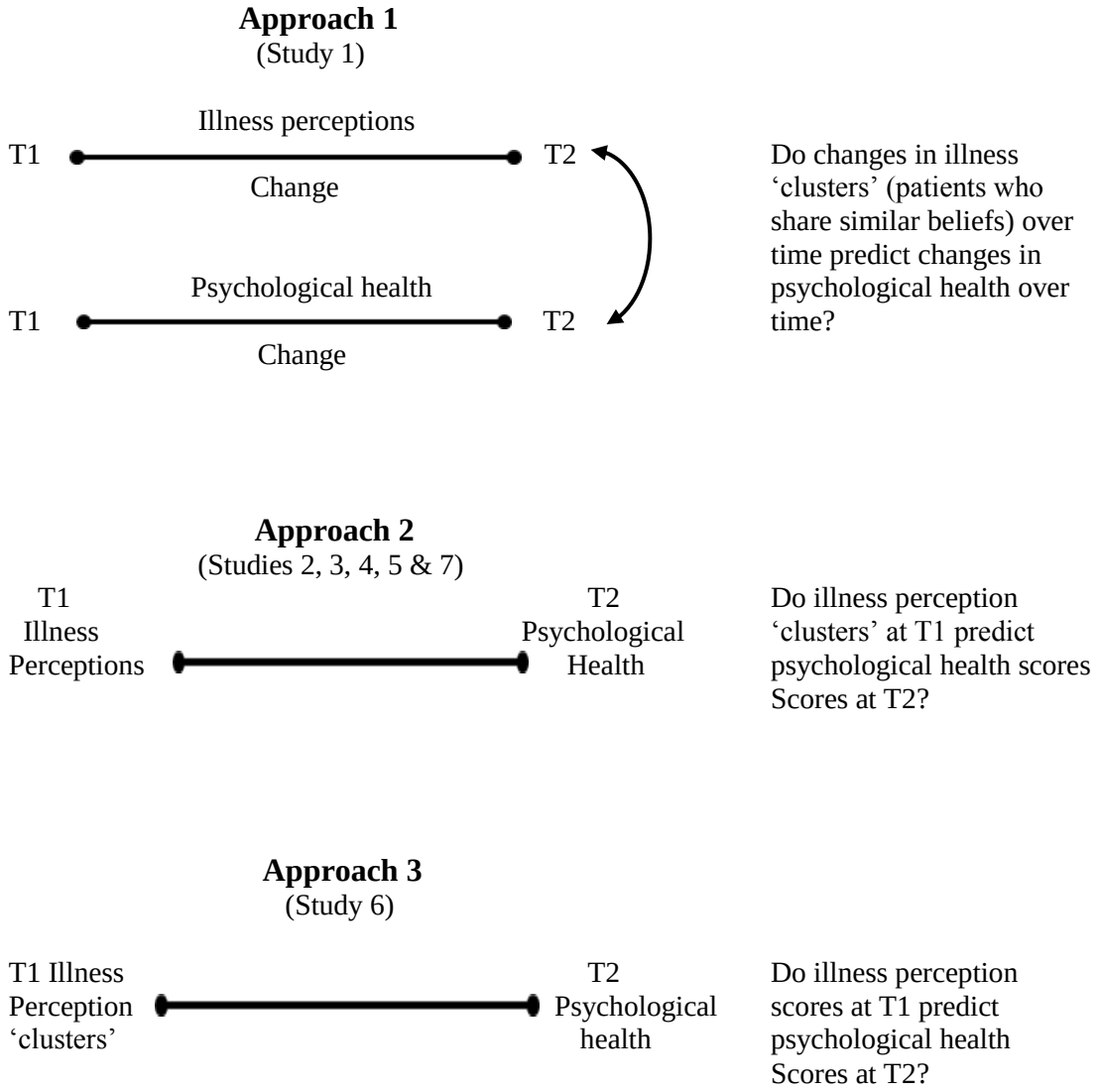

Figure 4: Three approaches to measuring the prospective relationship between illness perceptions and psychological health

Review 1: Research question 1
Are illness representations prospectively associated with future psychological health in adults with cancer?

Findings from each study varied depending on the approach used to measure the relationship between illness perceptions and psychological health. As the only study using Approach 1, Study 1 found 3% and 5% of the variance in *changes* in anxiety and depression respectively could be explained by *changes* in illness perceptions over time. Studies using Approach 2 reported between 0 (Study 2) and 28% (Study 5) of the variance in several psychological outcomes could be explained by baseline illness perceptions. Using Approach 3, Study 6 found that 9.5% and 11.3% of the variance in anxiety and depression respectively at T2 could be explained by illness perception clusters at T1.

The strongest relationships between illness perceptions and psychological health were found by Studies 4 and 5. Study 4 found that illness perceptions measured within 6-months of receiving a breast, colorectal or prostate cancer diagnosis predicted between 10.5% and 27.9% of the variance in positive and negative affect, distress over cancer recurrence and family-related distress 15-months post diagnosis. This variance was over and above the comparatively smaller variance in the same outcomes predicted by age, gender, socioeconomic status, diagnosis and type of treatment received. Study 5 found that illness perceptions, measured pre-treatment, accounted for similarly high levels of the variance in depression (28%) 6-8 months after treatment cessation in a sample of head and neck cancer patients. However, it is unclear from the Study 5 paper whether this variance was in addition to those explained by sociodemographic and/or clinical variables since their regression was not hierarchical and the outcomes were not clearly reported.

Several studies found comparatively less variance in psychological health could be explained by illness perceptions once sociodemographic and disease related variables had been entered hierarchically in to regression models (2, 3 & 7). For example, Study 3 found that illness perceptions measured shortly after diagnosis accounted for 12% of the variance in anxiety and depression 12 months later after accounting for age and gender

but this decreased to only 3% once baseline anxiety and depression levels had also been considered by the regression model. Baseline anxiety and depression levels independently accounted for significantly more of the variance in anxiety and depression (25% and 21%) than illness perceptions 2 years later. Study 7 also found that only 6% of the variance in emotional distress could be explained by illness perceptions measured 12 months previously in a sample of breast cancer patients once baseline levels of emotional distress had been explained. In fact, baseline emotional distress in Study 7 was the biggest predictor of emotional distress 12 months later, accounting for 29% of the overall variance. This was a common finding within studies that entered baseline psychological health variables into their regression analyses before illness perception variables. The largest degree of explained variance in psychological health was reported by authors of Study 2 who found that emotional functioning of patients with head and neck cancer at the point of diagnosis explained 42% of the variance in their level of emotional functioning 2 years later.

Review 1: Research question 2
Which illness perceptions best predict psychological health?

This research question aimed to explore which illness perceptions were the *most* predictive of future psychological health. Since not all illness perceptions were measured by every study and those measured were not all independently predictive of future psychological health, it would first be helpful to reconsider the main approaches employed to measure this relationship: namely, studies that used cluster analysis and those that did not (see Figure 3). Studies that did not conduct cluster analysis examined which illness perceptions of those measured were *independently predictive* of psychological health over time. By comparison, studies which used a clustering approach (Studies 1 & 6) examined whether *cluster membership* was predictive of psychological health. This method assumes that *all* illness perceptions measured are predictive of outcomes: neither study reporting the predictive relationship between specific illness perception dimensions and future psychological health. Table 12 provides a summary of the relationships found for all studies combined.

Table 12: Review 1 – Significant relationships matrix

Illness perception components	Relationship							%*
	Study 1	Study 2	Study 3	Study 4	Study 5	Study 6	Study 7	
Identity	**C**	-	-	**I**	-	**C**	**I**	57%
Consequences	**C**	-	**I**	**I**	-	**C**	-	57%
Coherence	**C**	-	**I**	-	-	**C**	NM	50%
Cause	**C**	-	-	NM	NM	**C**	NM	50%
Timeline - Acute/chronic	**C**	-	-	-	**I**	**C**	-	43%
Cure/control - Personal	**C**	-	**I**	-	-	**C**	-	43%
Cure/control - Treatment	**C**	-	-	-	NM	**C**	NM	40%
Timeline - Cyclical	**C**	-	-	-	-	**C**	NM	33%
Emotional representations	NM	-	NM	**I**	-	NM	NM	33%

C = Relationship found only as part of a cluster of illness perceptions; I = Independent relationship between illness perception and psychological health; NM = Not measured; - = no predictive relationship found; * = percentage of studies that measured the illness perception finding a significant relationship with psychological health

All illness perceptions were found to be significantly predictive of future psychological health by at least one study. Only one study did not find any of their measured illness perceptions to be significantly predictive of psychological health (2). Perceptions of illness identity and consequences were measured by all seven studies and were found to be significantly predictive of psychological health in four studies. By comparison, emotional representations were the least measured dimension and found to be predictive of outcomes in only one study.

Studies using cluster analysis (Approaches 1 and 3)

Study 1

Using Approach 1, Study 1 conducted cluster analysis to determine whether changes over time across all eight illness perceptions measured were predictive of psychological distress and found, within a sample of 189 oesophageal cancer patients, four distinct clusters of patients.

Patients identified as ‘Cluster 1’ had the most *positive* changes across all illness perceptions over time: negative illness perceptions decreased and positive perceptions increased between T1 and T2. Patients identified as ‘Cluster 2’ had increasing beliefs over time in their own ability to control their illness but decreasing beliefs that treatment would be effective in controlling their cancer over time. Locus of control was thought to be a defining feature of this cluster. ‘Cluster 3’ patients reported the most *negative* changes in all illness perceptions over time with increasing beliefs that their illness was chronic, cyclical, had severe consequences with a low sense of personal and treatment control. Although there were similarities in the illness perceptions of Cluster 3 patients and patients in other clusters, the key feature of this cluster was that patients increasingly believed their illness could not be controlled by themselves or by treatment: more so than patients in any other cluster. It is suggested within the paper that this sense of hopelessness/helplessness may make these patients particularly vulnerable to poor psychological wellbeing.

Finally, patients in ‘Cluster 4’ were those who attributed more symptoms to their condition over time, increasingly found their condition confusing but were more hopeful than patients in clusters 2 and 3 that it could be controlled either by themselves or with treatment.

Study 6

Using Approach 3, Study 6 also conducted cluster analysis, finding their sample of 90 breast cancer patients could be categorised into two distinct groups of patients who shared similar illness perceptions. Unlike Study 1, cluster membership was determined using only illness perceptions measured shortly after diagnosis rather than the degree to which perceptions changed over time. Findings revealed women in ‘Cluster 1’ had a poorer sense of illness coherence, were more likely to believe their illness was chronic and cyclical, attributed more symptoms and causation to their illness and had stronger beliefs that it could not be controlled. Patients in this cluster fared less well psychologically than patients in other clusters and were more likely to become significantly depressed or anxious 6 months later compared to women in ‘Cluster 2’ who had more positive perceptions of their cancer overall.

Studies not using cluster analysis (Approach 2)

The remaining studies (2, 3, 4, 5 & 7) did not use a clustering approach, but more simply measured the degree to which scores on specific illness perceptions were independently predictive of future psychological health scores. Their findings will be presented according to each of the nine illness perception domains.

Identity

Study 4 reported that illness identity perceptions within 6 months of receiving a cancer diagnosis were significantly predictive of distress over cancer recurrence and family-related distress 15-months post diagnosis in a sample of breast, prostate and colorectal cancer survivors. Patients who associated more symptoms with having cancer were more likely to be fearful their cancer would return and would report more distress over family related issues into long-term survivorship. Similarly, Study 7 reported that women who attributed more symptoms to their cancer within 2 weeks of breast cancer surgery were more likely to be emotionally distressed 12-months later. Interestingly, this was the only illness perception domain found to predict future psychological health in this study although it is also important to acknowledge that this study was the only study using IPQ which represented only five of the current nine illness perception domains measured by the IPQ-R.

Illness coherence

Only Study 3 found a significant independently predictive relationship between illness coherence and psychological outcomes. Breast and prostate cancer patients in this study who reported a poorer understanding of their illness shortly after being diagnosed were more likely to feel depressed 12 months later, after controlling for age, gender and baseline depression. Interestingly, illness coherence was not predictive of future anxiety symptoms.

Timeline – acute/chronic

Only Study 5 found an independently predictive relationship between perceptions about the chronicity of cancer and psychological health. Newly diagnosed patients with head and neck cancer who had stronger beliefs that their illness was chronic pre-treatment were significantly more likely to report feeling depressed 6-8 months after treatment

cessation. This was the only illness perception found to be predictive of depression in this study.

Timeline – cyclical

Other than studies using cluster analysis, there were no other studies that found illness perceptions about the cyclical nature of cancer to be independently predictive of future psychological health.

Consequences

Studies 3 and 4 found perceived consequences of having (had) a cancer diagnosis to be significantly predictive of future psychological health. Study 3 found that breast and prostate cancer patients who believed their illness would have more severe consequences shortly after being diagnosed were more likely to suffer anxiety 12 months later. Study 4 reported that patients who believed their cancer would have more severe consequences within 6 months of receiving a diagnosis reported significantly worse negative affect 15-months post-diagnosis. An inverse relationship was found in this study between positive affect and consequential beliefs: patients who had perceptions their cancer had less of an impact upon themselves and others were more likely to report positive affect into survivorship.

Cause

Other than Study 6 that used cluster analysis, there were no other studies that found illness perceptions about cancer causation to be significantly and independently predictive of future psychological health.

Emotional representations

Of the 3 studies which measured emotional representations, only Study 4 found an independently predictive relationship between emotional representations and psychological outcomes. This study reported that breast, colorectal and prostate cancer patients who felt more negative about their illness within 6 months of receiving a diagnosis were those with the most negative affect, least positive affect and greatest distress over cancer recurrence and family-related distress 15-months post-diagnosis.

Treatment control

Other than studies using cluster analysis, no other studies found perceptions of treatment control to be significantly and independently predictive of future psychological health.

Personal control

Study 3 found personal control to be significantly predictive of future emotional distress. Breast and prostate cancer patients who believed they had less personal control over their condition shortly after diagnosis experienced higher levels of anxiety 12 months later than patients who believed they had more personal control over the disease.

3.2.4. Review 1: Summary

There was much methodological variability in the seven papers reviewed in Review 1, in terms of type and number of patients, use of measures, and the point at which patients were asked to complete baseline and follow up measures which may have increased the possibility for bias and made synthesis and between-study comparisons challenging. Studies used three different approaches to assessing the relationship between illness perceptions and psychological health which added further complexity to the synthesis of data. Nevertheless, six of the seven studies found at least one illness perception to be predictive of psychological health; some independently predictive (Studies 3, 4, 5 & 7), others as part of a cluster of illness perceptions (Studies 1 & 6). Variance in psychological health explained by illness perceptions ranged from 3% to 28% after socio-demographic and other disease related variables were considered by regression analyses. It is difficult to report definitively which illness perceptions were the *best* predictors of future psychological health due to considerable differences in measurement and analyses. Taking the six studies which found significant associations into consideration, perceptions about illness identity and the consequences of having cancer were the two most commonly observed predictors of psychological health. However, all nine illness perceptions measured were found to be significantly predictive of psychological health by at least one study either independently or as part of an illness perception cluster. Perceptions about causes, the curability/controllability and the timeline of cancer were only predictive of psychological health as part of a cluster of perceptions, as opposed to being independently predictive.

3.3. Review 2: Modifying illness representations to improve psychological health

3.3.1. Descriptive synthesis

The thirteen studies meeting inclusion criteria were published between 2007 and 2015. The studies described a range of interventions to modify illness perceptions directly or indirectly with a view to improving psychological health, among other illness outcomes, in cancer patients. Studies will be referred to throughout this section by their corresponding number for ease of understanding. To avoid confusion, the following thirteen studies extracted for Review 2 will be numbered continuously from Review 1 (e.g. 8-20) and a key is provided in Table 13 for ease of reference.

Table 13: Review 2 - Key to papers reviewed

Study #	Primary author	Title
8	Traeger (2013)	Identifying how and for whom cognitive-behavioral stress management improves emotional well-being among recent cancer survivors
9	Lichtenstein Jorgensen (2009)	An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer
10	Fischer (2013)	From despair to hope: A longitudinal study of illness perceptions and coping in a psycho-educational group intervention for women with breast cancer
11	Schuurs (2013)	A feasibility study of group cognitive rehabilitation for cancer survivors: enhancing cognitive function and quality of life
12	King (2015)	Psychological intervention for improving cognitive function in cancer survivors: a literature review and randomized controlled trial
13	Cameron (2007)	Changes in emotion regulation and psychological adjustment following use of a group psychosocial support program for women recently diagnosed with breast cancer
14	Humphris (2012)	AFTER and beyond: cancer recurrence fears and a test of an intervention in oropharyngeal patients
15	Ward (2008)	A randomized trial of a representational intervention to decrease cancer pain
16	Ward (2009)	A randomized trial of a representational intervention for cancer pain: Does targeting the dyad make a difference?
17	Heidrich (2009)	An individualized representational intervention to improve symptom management in older breast cancer survivors: Three pilot studies
18		
19		
20	Smith (2015)	Pilot of a theoretically grounded psychologist-delivered intervention for fear of cancer recurrence (Conquer Fear)

3.3.1.1. Study characteristics

Design

There were eight randomised controlled trials (8, 9, 12, 14 - 18), two non-randomised controlled trials (11 & 13) and three before/after studies (10, 19 & 20).

Clinical setting

Table 14 summarises clinical specialities and sample sizes for each clinical area.

Table 14: Review 2 - Clinical specialties and combined dataset sizes

Cancer specialty	Articles	Percentage of total studies reviewed	Combined total N at final follow up
Breast	9,10,11,12,13,15,16,17,18,19,20	85	556
Prostate	8,11,12	23	219
Haematological	12,15,16	23	20
Lung	15,16	15	50
Gastrointestinal	15,16	15	82
Colorectal	11,12	15	9
Gynaecological/ Genitourinary	15,16	15	80
'Mixed'	11,16	15	11
'Other'	15,16	15	26
Ovarian	11,12	15	2
Head and neck	11	8	1
Testicular	11	8	1
Not stated	20	8	3
Oral/Oropharyngeal	14	8	77
Total N			**1219**

Studies sampled patients from eleven specific fields of oncology. Four studies reported the inclusion of patients with unspecified diagnoses (Studies 11, 15, 16 & 20). Most studies (n=8) sampled patients from only one cancer specialty. One study included patients from two clinical areas (20), one from five areas (12), one from six areas (15) and two from seven clinical areas (11 & 16). The most frequent diagnosis of patients across the thirteen studies was breast cancer, making this the largest sample of patients

overall at final follow up and comprising 46% of the total sample. The least frequent diagnosis of sampled patients was head and neck cancer (n=1), testicular cancer (n=1) and ovarian cancer (n=2) and comprising of only .3% of the total sample combined.

Recruitment

Seven studies recruited only patients known to the clinic/service via current referral lists or waiting lists (13-16 & 18-20). The remaining six studies made use of one or more methods of 'opt-in' recruitment including hospital and community advertisement material such as brochures and posters (8-11 & 17), state cancer registries and mailing lists (8 & 12) and local cancer support groups (11 & 12).

Location

Studies were conducted within several countries worldwide including the USA (8, 15-19), Australia (11, 12 & 20), Denmark (9), the Netherlands (10), New Zealand (13). Only one study was conducted in the UK (14). Most studies (62%) involved interventions conducted within specialist outpatient or inpatient cancer clinics or other rehabilitative medical centres.

Measures

Papers were analysed in terms of the extent to which measures used in each study were valid and reliably used, acknowledging any modifications or changes in the standard or recommended administration of measures which have the potential to confound the findings of studies.

1. Illness perception measures

Administration

Only six of the thirteen studies (46%) directly measured patient's illness perceptions using a quantitative measure. Four of these studies administered the IPQ-R (8, 9, 10 & 13) and two used the B-IPQ (11 & 12). Table 15 summarizes the illness perception dimensions measured by each study.

Table 15: Review 2 - Illness perceptions measured

Illness perception dimension measured	Studies	Percentage of studies which could measure the dimension
Cure/control - Personal	8,9,10,11,12,13	100%
Concern*	11,12	100%
Consequences	8,9,10,11,12	83%
Cure/control - Treatment	8,9,10,11,12	83%
Identity	9,10,11,12	67%
Timeline - Acute/chronic	9,10,11,12	67%
Coherence	8,10,11,12	67%
Emotional representations	9,10,11,12	67%
Cause	8,9	33%
Timeline – Cyclical#	10	25%

*Only measured within the B-IPQ scale; #Could not be measured by studies using B-IPQ as this is not one of the subscales

Omissions

No study administered the IPQ-R or B-IPQ in their entirety (e.g. all nine subscales/items). Of the two studies using the B-IPQ (11 & 12), the same eight out of a possible nine illness perception items were administered by both studies. Neither study provided a reason for the omission of causal items. From the four studies using the IPQ-R, one administered eight subscales (Study 10), one used seven subscales (Study 9), one used five subscales (Study 8) and Study 13 used only the personal control subscale since this was their main target for change. Personal control was the only illness perception dimension to be administered by all six studies. The least utilized subscale was cyclical timeline: only one of the four studies which *could have* administered the cyclical timeline subscale (the B-IPQ does not have this as an independent item) did so. Reasons for omission were not provided in Studies 9 and 13, while authors of Study 8 suggested this omission, along with the omission of three other subscales was because they were considered "ambiguous targets for change" within their patient group (men over 50 years old with a diagnosis of prostate cancer).

Modifications

Two of the six studies using an illness perception measure did not report making any modifications to administered items and subscales (Studies 10 & 11). The remaining four studies made several modifications. Study 8 developed a 'composite causal scale' based on previous findings. Study 9 translated the IPQ-R into Danish. Study 12 developed two versions of the B-IPQ. The first one, designed for cancer patients, asked respondents to complete the measure in relation to their cognitive difficulties (as opposed to their cancer). The second version, developed specifically for their community control group of healthy individuals, asked participants to respond by 'imagining' what they thought it would be like to experience cognitive difficulties. Study 13 used only half of the personal control subscale without reporting coefficient values for the three items.

Scale/subscale reliability

Only three of the four studies which administered the IPQ-R (the B-IPQ does not have any subscales) reported Cronbach's alpha (α) coefficient values (Cronbach, 1951). Table 16 summarises these values for Studies 8, 10 and 13.

Table 16: Review 2 – Reliability coefficient values for illness perception subscales

Illness perception subscales	**Cronbach's alpha reliability coefficient values (α) for each study**		
	8 (n=257)	**10 (n=74)**	**13 (n=154)**
Identity	NM	NS	NM
Timeline - Acute/chronic	NM	**.88**	NM
Timeline - Cyclical	NM	**.71**	NM
Consequences	**.65**	**.78**	NM
Coherence	**.83**	**.73**	NM
Cure/control - Personal	**.72**	**.71**	**.80**
Cure/control - Treatment	**.78**	**.73**	NM
Cause	**.68**	NM	NM
Emotional representations	NM	**.91**	NM

NS=Not stated; NM=Not measured; NA=Not applicable

As reported previously, alpha values falling below .70 indicate less than acceptable internal reliability between items of that subscale: subscales with alpha values below .60 are considered to have unacceptable internal reliability (Cortina, 1993). None of the studies reported alpha values below .60, although Study 8 reported both their consequences and cause subscales to have values below .70. All seven subscales administered by Study 8 were found to have a good to excellent internal consistency as was the personal control subscale administered (the only subscale of the IPQ-R administered) by Study 13.

2. Psychological health measures

Administration

Thirteen different questionnaires were used to measure psychological health. Table 17 provides a summary of these measures including a brief description of their purpose. Ten studies administered one or more measures specifically designed to assess *only* psychological difficulties such as depression (10-12, 14, 17-19), anxiety (10-14 & 17-19), mood disturbance (9 & 19), distress (20), mental adjustment (14) and mental health (17-19). Four of these studies administered more than one specific measure of psychological health (14 & 17-19). Five studies administered measures of quality of life or general health which comprised several 'functioning' subscales including psychological/emotional functioning (8, 12, 13, 15 & 16). Three of these studies (8, 15 & 16) administered a single broad quality of life measure, reporting affective or emotional functioning subscales, meaning psychological health was measured in as few as four items (8, 15 & 16).

Omissions & modifications

No studies reported modifying any psychological health measure or omitting any subscales or items.

Scale/subscale reliability

Only four of the thirteen studies provided data on the internal reliability of their psychological health measures or subscales (Studies 8, 10, 13 & 16). The highest alpha value was reported by Study 10 which revealed a coefficient value of .90 for the 25-item Hopkins Symptom Checklist. Studies 13 and 16 reported similarly high levels of internal consistency for the 40-item STAI (α=.89) and the 6-item mood subscale of the

QLQ-C30 (α=.85) respectively. The lowest coefficient values were reported for the 6-item emotional wellbeing subscale of the FACT-G by Studies 8 (α=.70) and 13 (α=.66). These values would indicate less than acceptable internal reliability between items of that subscale (Cortina, 1993) and could be potentially problematic for Study 8 since this was their only measure of psychological health whereas Study 13 administered two measures: one of which had excellent internal consistency (STAI).

Table 17: Review 2 - Questionnaires used to measure psychological health

Studies	Psychological health measure*	Measure description	Cancer/chronic illness specific measure	Psychological health construct(s) measured
8,13	FACT-G	27-items measuring multiple domains of wellbeing during cancer treatment	✓	Emotional wellbeing (subscale-6 items)
9,19	POMS-SF	37 items across 6 subscales measuring total mood disturbance	✗	Emotional distress
10	HSCL-25	25-items measuring depression and anxiety related symptoms	✗	Psychological distress
11,12	K10	10-items measuring anxiety and depression related symptoms	✗	Psychological distress
12,16	QLQ-C30	30 items across 9 subscales measuring quality of life in cancer patients	✓	Study 12 - Emotional functioning (subscale - 4 items) Study 16 - Mood (subscale – 6 items)
13,17,18,19	STAI	20 items measuring state anxiety	✗	State anxiety (Study 13 used short form - 6 items)

*__FACT-G__ – Functional Assessment of Cancer Therapy-General Module (Cella, Tulsky, & Gray, 1993); __POMS-SF__ – Profile of Mood States (Shacham, 1983); __HSCL-25__ – Hopkins Symptom Check List (Veijola, Jokelainen, Lasky, Kokkonen, & Jarveline, 2003); __K10__ – Kessler Psychological Distress Scale (Kessler, Andrews, & Colpe, 2002); __QLQ-C30__ – Quality of Life Questionnaire (Sherman *et al.*, 2000); __STAI__ – Spielberger State-Train Anxiety Inventory (Marteau & Bekker, 1992)

Table 17: Review 2 - Questionnaires used to measure psychological health (continued)

Studies	Psychological health measure*	Measure description	Cancer/chronic illness specific measure	Psychological health construct(s) measured
14	HADS	14 items measuring health related anxiety and depression	✘	Anxiety and depression
14	MAC	40 items measuring adjustment to cancer across 5 subscales	✓	Mental adjustment to cancer
15	QLI-CV	34 items measuring quality of life in cancer patients across 4 subscales	✓	Psychological wellbeing (subscale - items)
17,19	SF-36	36 items measuring physical and mental health across 2 subscales	✘	Mental health
17,18,19	CES-D	10 items measuring depressive symptoms	✘	Depression
18	SF-12	12 items measuring physical and mental health across 2 subscales	✘	Mental health
20	IES	15 items measuring subjective distress across 2 subscales	✘	Distress

*** HADS** - Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); **MAC** – Mental Adjustment to Cancer Scale (Watson, Greer, Young, Inayat, & Burgess, 1988); **QLI-CV** – Quality of Life Index-Cancer Version (Ferrans, 1990); **SF-36** – MOS short form health survey (Ware & Sherbourne, 1992); **CES-D** – Centre for Epidemiologic Studies-Depression Scale (Irwin, Artin, & Oxman, 1999); **SF-12** – Short form health survey (Ware *et al.*, 1996); **IES** – Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979).

Procedure

The point at which patients completed baseline and follow up measures varied widely between studies. Table 18 summarises the time between receiving a cancer diagnosis or ending treatment and administration of measures for each study.

Table 18: Review 2 – Time between diagnosis/treatment and completion of measures

Study	Time between diagnosis and pre-intervention baseline measures	Time between treatment cessation and pre-intervention baseline measures	Number of follow ups	Time between pre-intervention baseline and final follow up measures
8	15.5 months (mean)	10.3 months (mean)	1	3 months
9	'Within last 5 years'	12.7 months (mean)	2	6 months
10	NS	'Completed curative treatment'	2	12 months
11	57 months (mean)	42 months (mean)	2	4-5 months
12	58 months (mean)	42 months (mean)	2	3 months
13	Diagnosed within last 6 weeks	3 weeks	3	12 months
14	NS	3 months	2	8 months
15	NS	NS	2	2 months
16	NS	NS	2	2 months
17	9 years (mean)	NS	2	2-3 months
18	2.7 years (mean)	NS	5	4 months
19	3.6 years (mean)	NS	2	4 months
20	2.3 years (mean)	'Completed curative treatment'	2	2 months

NS=Not stated; * = Where exact time values were not reported, specific phrases used to describe the time point have been used as a proxy.

Completion of baseline measures

Most studies reported the time between patients receiving a cancer diagnosis and the completion of baseline measures (9/13). This varied hugely from less than 6 weeks since diagnosis (Study 13) to a mean of 9 years since receiving a diagnosis (Study 17). The time between finishing treatment and completion of baseline measures also varied

across the eight studies which reported this time, although overall the reporting of this was generally unclear. Two studies simply reported baseline measures were administered after 'primary curative treatment' had finished (Studies 10 & 20). Other studies were more explicit and reported that baseline measures were administered between 3 weeks of treatment cessation (Study 13) and 42 months (Studies 11 & 12). Despite not being explicitly reported within the paper, it is likely that patients in Studies 17-19 had completed their treatment at the point baseline measures had been administered given the length of time since a diagnosis had been received (3.6 - 9 years). Three studies failed to report the time between administration of baseline measures and either diagnosis or treatment cessation (Studies 14-16).

Completion of follow up measures

In terms of follow up, all but one study (8) followed patients up more than once. Ten of the remaining twelve studies followed patients up twice, one followed patients up 3 times (13) and another five times (18). Most studies followed patients up less than 4 months after baseline measures had been administered (8, 12, 15-20). Only two studies followed patients up for 12 months after baseline (10 & 13). This was the maximum follow up duration of any study.

3.3.1.2. Patient characteristics

Sample sizes and attrition

All studies reported both baseline and follow up sample sizes. Table 19 summarises sample sizes for each study at both baseline and final follow up time points. There were 1345 participants in total across all thirteen studies and 1024 participants remaining in the total sample at final follow up. Although it should be noted that for two of these studies (11 & 12) only two of the original three participant groups were included in administration of final follow up measures. This represents an overall attrition of 23.9% with attrition levels for each study ranging from 4.8% (Study 19) to 37.5% (Study 20). It has been argued that loss to follow-up greater than 20% could be a potential source of bias in RCTs (Schulz & Grimes, 2002). Three of the eight RCTs in this review had attrition levels higher than 20% (9, 15 & 16). Two of the five non-RCT studies reviewed also had attrition levels greater than 20% (10 & 20).

Table 19: Review 2 – Sample sizes and attrition

Study	Total n at baseline	Total n at final follow-up	Overall attrition (%)
8	257	214	16.7%
9	246	177	28%
10	74	57	23%
11	55	20*	NK
12	45	27*	NK
13	154	124	19.5%
14	87	77	11.5%
15	176	136	22.7%
16	161	109	32.3%
17	41	39	4.9%
18	20	19	5%
19	21	20	4.8%
20	8	5	37.5%

* These values included only participants from two of the original three groups sampled at baseline as the third group was not followed to the final time point; NK = Not known

Demographics

The mean age of patients across the entire dataset was 58.6 years old although mean ages for each study varied hugely from 48 to 73 years old. Most sampled patients were female (n=863; 64%). Seven of the thirteen studies reviewed included *only* female patients (9, 10, 13, 17-20), one included *only* male patients (8) and the remaining five studies sampled *both* men and women (11, 12, 14-16).

Less than half of studies reported the ethnicity of patients in their sample. From the studies that did, between 41% (Study 8) and 100% (Study 19) of recruited patients were white Caucasian.

In general, studies used proxy measures to determine the social status of participants such as education (9-13, 17-19), occupation (14) or level of income (13, 15-19). Of the eight studies measuring patient's education level, five measured the number of years' patients had spent in education, reporting patients had spent on average 15 years in education. Studies 9 and 10 used categorical measures of educational level. Study 9

found most recruited patients (53%) had attended 'higher education' (college and university) while Study 10 reported that only 14% of patients in their sample had achieved a similar level, the majority achieving only basic and intermediary education levels. Study 13 reported that most patients in their sample (52%) had not received a 'tertiary' level of education but provided no definition of this classification. Six studies measured income levels. It was not possible to directly compare these values between studies due to the use of incomparable categorical measures which would render any conclusions meaningless. Only Studies 8 and 20 provided no measure of patient's social status or any proxy measures to ascertain this.

3.3.2. Quality assessment

3.3.2.1. Overall quality

It is important to distinguish between failure to report a criterion and failure to meet a criterion (CRD, 2009), and so each of the thirteen studies were evaluated according to the same quality criteria as in Review 1 with the addition of three study quality and two reporting quality items relevant to intervention studies (see page 34 for full description of the item development and rating system). Scores for both study quality and reporting quality based on evident criteria only (those scoring a 'yes') were summed and divided by the total number of applicable items to obtain a total quality percentage score for each study (presented in Table 20 in descending order of total quality).

Study quality scores ranged from 33% (Study 20) to 81% (Study 14), with a median score of 65%. Reporting quality scores ranged from 40% (Study 20) to 100% (Study 8) with a median score of 69%. Total quality scores ranged from 37% (Study 20) to 82% (Study 8) with a median of 72% across all thirteen studies. Although Studies 11 and 17-20 had the lowest study and reporting quality ratings overall, this is likely to be because they were feasibility pilot studies and as such methodologies and findings were described in only minimal details. Many of the details required to score more highly for study and reporting quality (e.g. recruitment and data collection details, reporting internal consistency etc.) were either absent or else only partially reported.

Table 20: Review 2 – Study quality, reporting quality and total quality scores

Study	Study quality score (%)	Reporting quality score (%)	Total quality score (%)
8	65%	100%	82%
10	80%	80%	80%
12	71%	81%	76%
13	76%	75%	76%
16	69%	81%	75%
9	65%	81%	72%
14	81%	63%	72%
15	69%	69%	69%
11	53%	56%	55%
19	57%	47%	52%
17	50%	44%	47%
18	50%	44%	47%
20	33%	40%	37%

3.3.2.2. Study quality

Table 21 summarizes criteria judged as evident (rated with a 'Yes') to illustrate overall study quality for the dataset. Twenty-nine percent of applicable criteria (5/17) were met by *all* reviewed studies (see Appendix IX for complete breakdown of study quality ratings for each study). All studies were based on one or more theoretical frameworks including, Leventhal's common sense model. All studies were judged as using appropriate methods to answer research questions and administering valid and reliable psychological health measures. Furthermore, all studies were considered to interpret findings accurately and make appropriate conclusions consistent with their results. Criteria which was not evident in all studies but which needs to be considered as potentially introducing bias to the overall findings (and which hasn't already been addressed elsewhere in this chapter) will be outlined below.

Table 21: Review 2 – Study quality criteria judged as evident

Criterion*	Studies	Percentage of all studies (n=13)
1. Based on theoretical framework	8,9,10,11,12,13,14,15,16,17,18,19,20	100%
3. Appropriate methods used to answer research question	8,9,10,11,12,13,14,15,16,17,18,19,20	100%
9. Use of valid and reliable psychological health measure	8,9,10,11,12,13,14,15,16,17,18,19,20	100%
15. Accurate interpretation of findings	8,9,10,11,12,13,14,15,16,17,18,19,20	100%
16. Conclusions consistent with results	8,9,10,11,12,13,14,15,16,17,18,19,20	100%
14. Appropriate quantitative analysis to test hypothesis	8,9,10,11,12,13,14,15,16,17,18,19	92%
10. Recommended use of psychological health measure	8,9,10,12,13,14,15,16,17,18,19	85%
5. Adequate sample size for statistical analysis	8,9,10,11,12,13,17,18,19	69%
7. Equal group numbers	12,13,14,15,16	50%*
8. Groups well matched at baseline	8,11,12,14,17	50%*
6. Measures used to reduce bias	8,9,12,14,15,16	46%
2. Well defined research question/hypothesis	10,12,13,14,15	38%
4. Appropriate recruitment procedure	8,11,13,14,15	38%
11. Recommended use of illness perception measure	9,10	33%*
13. Adequate length of follow up	9,10,13,14	31%
12. Acceptable internal consistency	10,16	15%
17. Findings generalizable	16	8%

* From the studies for which this criterion was applicable

Recommended use of measures

Only six of the thirteen studies administered illness perception measures. Of these, only Studies 9 and 10 were judged as using their measure (IPQ-R) in a recommended way. Studies 8 and 12 were judged as only partly using the measured as recommended due to omission of items and modifications to subscales. Study 11 did not provide enough detail to determine whether they had administered the measure appropriately and Study

13 was judged as not having administered the measure as recommended by developers due to their use of only half of one subscale without providing alpha values for internal reliability. All studies administered valid and reliable measures of psychological health in full as recommended.

Well defined research question/hypothesis

Only 38% of the studies reviewed were deemed to have provided a well-defined research question and/or hypothesis. The remaining studies provided general aims and broad objectives but did not specific what research question they were testing nor did they hypothesis what they were expecting to find.

Matched groups

Only half of the studies which included a control group were judged to have matched participants in terms of demographic information, clinical details, sample size or any other variable (items 7 & 8). The remaining studies which employed control groups were judged as providing unclear details about whether patients had been matched on any variables at baseline (Studies 9, 13, 15, 16 & 18).

Measures used to reduce bias

Less than half the studies were considered as having employed any methodological measures to reduce bias. Of the 50% of studies that did not, Study 10 was judged as having not used any appropriate measures and Studies 11, 13 and 17-20 were judged as having provided some indication they had employed measures such as randomisation of participants to experimental and control groups for instance, but insufficient details to make a definitive 'yes' judgement. Again, this may have been because these studies (except for Study 13) were pilot studies and provided less detail than most other studies.

Acceptable internal consistency

Only two of the thirteen studies reviewed were judged to have acceptable internal consistency (Cronbach's alpha coefficient values >.70). Of the remaining eleven studies, two (8 & 13) were judged as having partially fulfilled this criterion since *some* of their measures had values within the acceptable range and others did not. A further nine studies did not provide alpha coefficients.

Generalisability

The criterion with the poorest quality rating was generalisability of findings. Only Study 16 was judged as having findings which were generalizable due to having a large sample of both male and female participants sampled from several different hospitals with a large degree of demographic and clinical diversity (e.g. equal numbers of men and women, different cancer diagnoses, wide range of incomes) and had used multiple measures to reduce potential bias and included multiple control groups. The remaining twelve studies were judged to be partially generalizable to similar patient groups or settings but not necessarily beyond these groups due to small sample sizes (Studies 18-20), high levels of attrition (Studies 9, 10, 15 & 20) and lack of clinical (Studies 8-10 & 13) or demographic (Studies 8-10 & 13) diversity.

3.3.2.3. Reporting quality

Papers were analysed according to the quality of information provided. Table 22 summarises criteria with 'Yes' ratings (criteria which was reported to a good standard) for each paper to evaluate the quality of reporting (see Appendix X for complete breakdown of reporting quality ratings for each study). No single criterion was present in all thirteen studies. The most commonly reported criterion was the provision of clear intervention details, evident in all but one study (14) which had provided only partial information. Thirteen criteria (81%) were present in at least half of all studies. Criteria that were not well reported included provision of clear information about control groups, reporting of the internal reliability of measures and the explicit acknowledgement of potentially confounding variables: each criterion reported by only four studies.

Table 22: Review 2 – Reporting quality criteria judged as evident

Criterion*	Studies	Percentage of all studies (n=13)
5. Clear description of the intervention	8,9,10,11,12,13,15,16,17,18,19,20	92%
4. Clear description of recruitment procedures	8,9,10,11,12,13,14,16,17,18,19	85%
8. Clear description of data collection	8,10,11,12,13,14,15,16,17,18,19	85%
10. Clear description of data analysis conducted	8,9,10,11,12,13,14,15,16,19,20	85%
11. Provision of attrition data	8,9,10,11,13,14,15,16,19,20	77%
15. Discussion of clinical relevance of findings	8,9,10,12,13,14,15,17,18,20	77%
2. Clear description of sample	8,9,10,11,12,13,14,15,16	69%
3. Clear description of setting	8,9,12,14,15,16,17,18,19	69%
7. Clear definition of psychological health measure	8,9,10,14,15,16,17,18,19	69%
12. Strengths and limitations of study stated	8,9,10,11,12,13,15,16,20	69%
13. Problems with study design reported	8,9,11,12,13,15,16,20	62%
1. Clearly reported aims and objectives	8,9,10,12,13,14,15	54%
16. Recommendations for clinical practice discussed	8,10,12,14,16,17,18	54%
6. Clear description of the control group	8,9,12,13	31%*
9. Reliability of administered measures reported	8,10,13,16	31%
14. Potentially confounding factors reported	8,9,12,16	31%

* From the studies for which this criterion was applicable

3.3.2.4. Overall risk of bias

Evaluating the potential impact caused by study quality issues on potential bias is an important consideration in the systematic review process to avoid over or underestimation of the significance of findings (CRD, 2009). All studies used only self-report measures of psychological health commonly known to be subjective, relying on

patient's individual interpretation of items (Robson, 2002). Most studies stated patients were 'sent' questionnaires to complete at home, thus increasing the risk that questionnaire items may have been misunderstood. Five studies administered questionnaires at assessment sessions either in the patient's home or in a hospital clinic (Studies 8, 11-14) where support to complete the measures was available. This is likely to increase the reliability of findings. The fact that all studies administered valid and reliable measures of psychological health without modifications may also offset some of the potential for measurement bias.

Regarding sample bias, several studies reported that their participants were not necessarily experiencing psychological difficulties at baseline. Three studies excluded patients from their study if they had evidence of current 'psychopathology' during clinical interview (Study 13), current 'psychiatric symptoms' (Study 8) or major depression (Study 20). Several studies also postulated that the participants who remained in their studies until the final follow up may have constituted a more physically and psychologically healthy patient group compared to drop outs who reported worse physical symptoms (Study 16) or who reported worse psychological health (Studies 8, 9, 14 & 17-19). Two further studies reported that intervention participants reported experiencing below clinical levels of physical and psychological distress at baseline (15 & 16). An under-representation of patients who were physically and/or psychologically distressed pre-intervention may have impacted upon the ability to detect changes or improvements in psychological health post-intervention.

3.3.3. Overall findings

3.3.3.1. Interventions

Review 2 – Research question 3:
What interventions have been developed to directly or indirectly modify illness representations for adults with cancer?

Types of intervention

Twelve different interventions were developed by the thirteen studies and are described in Table 23. These interventions can be subdivided into two distinct types: '*indirect* illness perception interventions' and '*direct* illness perception interventions'.

Indirect illness perception interventions: studies 8-13

Six studies developed interventions that were not based on the common-sense model (CSM), and hypothesised that some form of group-based intervention, not directly targeting illness perceptions, would improve patient's psychological health via *indirect* changes in their illness perceptions. In terms of content, one intervention delivered a Cognitive-Behavioural Stress Management (CBSM) group programme (Study 8) and five studies described their interventions as educational/rehabilitation group rehabilitation programmes, incorporating a range of techniques such as increasing physical exercise (Study 9), relaxation training (Studies 8 & 10-13), 'cognitive restructuring' (e.g. challenging maladaptive thoughts in an attempt to modify them: Studies 8 & 10) and group discussion surrounding the experience of having cancer (Studies 8-13).

Direct illness perception interventions (studies 14-20)

Seven studies described interventions which adopted the CSM as a framework with the explicit aim of *directly* modifying patient's 'maladaptive' illness perceptions to improve psychological health. All direct interventions were delivered to individual patients or to patients and their spouse/carer (16). Although there was some variation in the exact nature of these interventions, a common feature was that patients were actively encouraged to discuss their perceptions of having (or having previously had) a cancer

diagnosis using the common-sense model as a framework for discussion to identify and address inaccurate or maladaptive perceptions about their illness.

Four of the direct illness perception interventions (16-19) were variations and extensions of the 'RIDcancerPain' intervention described in Study 15 for patients experiencing cancer pain (see Table 23 for full description). RIDcancerPain is a 60-minute single session intervention, led by a specialist oncology nurse, using a five-part educational approach to encourage patients to describe their beliefs about reporting cancer related pain and the use of analgesics using five illness perception domains as a structure for discussion (cause, timeline, consequences, cure/control). This intervention aimed to identify patient's misconceptions, discuss the potential losses and limitations of these and provide educational information to fill knowledge gaps and facilitate change in illness perceptions. Variations and extensions of this intervention included incorporating the patient's spouse/care-giver into the consultations (Study 16), changing the patient group (to older adults) and allowing patients to focus the intervention on their 'most bothersome symptom' (Study 17), increasing the length of contact between patients and their specialist nurse (Study 18) and changing the way the intervention was delivered from face to face with some telephone support to telephone contact only (Study 19).

The two studies not based around the RIDcancerPain intervention (14 & 20) described using an 'individual psychological therapy approach' to encourage patients to discuss their illness perceptions and incorporated additional therapeutic techniques such as relaxation (Study 14), reduction of threat monitoring and values based goal setting (Study 20).

Intervention delivery

All thirteen interventions except one were delivered face to face: Study 19 was delivered over the telephone. Interventions were delivered by a range of health care professionals. Seven interventions were delivered by psychologists, either as the main facilitator (Studies 8 & 11-13) or as part of a team which included a specialist nurse (Study 16), a psychiatrist (Study 20) or 'unspecified team' (Study 9). The remaining six interventions were delivered by nurses, either as the main facilitator (Studies 14, 15 & 17-19) or with a social worker (Study 10).

Table 23: Review 2 – Intervention descriptions

Studies	Intervention	Based on CSM	Illness perceptions measured	Description
8	CBSM (Cognitive Behavioural Stress Management)	No	Yes	Manualised group intervention focussing on stress management and health maintenance. Strategies included cognitive restructuring, psychoeducation, relaxation training, interpersonal skills and enhancement of social support networks
9	FOCARE The Research in Cancer Rehabilitation Care (in Danish)	No	Yes	Psychosocial group rehabilitation course. Comprised moderate physical exercise, lectures and group work on themes such as physical symptoms post-treatment, concerns about returning to work and psychological reactions to having cancer
10	Psychoeducational group programme	No	Yes	Psychoeducational group programme including homework assignments, sharing experiences, breathing exercises, relaxation skills, educational topics (what is cancer, coping with anxiety and depression, social support, stress management).
11,12	ReCog (Responding to Cognitive Concerns)	No	Yes	Psychoeducational group programme incorporating, thematic group discussion, focus on developing and applying skills, goal setting, problem solving, relaxation, compensatory and enhancement strategies related to emotional adjustment, fatigue, sleep and self-care
13	Adaptation of the 'Healing Journey' program	No	Yes	Manualised education about emotion and cancer; training in relaxation, imagery, meditation, setting priorities and goals, emotional disclosure through writing, and anger management; and group discussion

Table 23: Review 2 – Intervention descriptions (continued)

Studies	Intervention	Based on CSM	Illness perceptions measured	Description
14	AFTER (Adjustment to Fears, Threat and Expectation of Recurrence)	Yes	No	Manualised 'psychological' intervention. After initial assessment, patients given opportunity to discuss diagnosis, treatment and recovery. Patients are encouraged to expressed fears of cancer recurrence and perceived risk, illness beliefs and explore self-management and checking behaviours. Relaxation skills practised in sessions. Patient invited to include caregiver in sessions to address their fears of cancer recurrence.
15	RIDcancerpain (Representational Intervention to Decrease cancer pain)	Yes	No	One-to-one structured psychological intervention comprising 5 parts; 1. Patients describe beliefs about their cancer pain across 5 illness perception domains (cause, timeline, consequences, cure, control) 2. Misconceptions about reporting pain and using analgesics are identified and discussed between patient and intervener 3. Discussion of the potential limitations and losses resulting from these misconceptions 4. Patient given credible psychoeducational information to replace misconceptions and fill gaps in knowledge 5. Summary and discussion of the benefits of adopting the new information
16	RIDcancerpain+ (Representational Intervention to Decrease cancer pain) Extended version	Yes	No	As with RIDcancerpain intervention (above) **with both patients and their 'significant other'** and the addition of the following 2 elements; 6. Patient is asked to make goals and a plan in initial session for making changes to their pain self-management 7. Inclusion of follow-up telephone consultation to evaluate progress and revise coping plans where necessary

Table 23: Review 2 – Intervention descriptions (continued)

Studies	Intervention	Based on CSM	Illness perceptions measured	Description
17	IRIS (Individualised Representational Intervention to improve Symptom Management)	Yes	No	One-to-one structured psychoeducational intervention with the same structure and content to RIDcancerpain+ but allowing for patients to focus the session on their 'most bothersome or distressing' cancer symptom
18	IRIS+	Yes	No	As with IRIS intervention with the addition of biweekly telephone sessions with the practice nurse to reinforce goals and discuss progress
19	IRIS++	Yes	No	As with IRIS+ intervention but all contact between nurse and patients occurs by telephone
20	Conquer Fear	Partly (among other theories)	No	Manualised intervention teaching strategies to control worry, modify unhelpful beliefs and reduce excessive threat monitoring behaviour, provide information about health behaviour change to reduce risk of recurrence, discuss existential changes and promote values based goal setting. Homework practice is also encouraged to consolidate learning

Table 24: Review 2 – Intervention session length, frequency & overall duration

Study	No. of sessions	Session duration	Frequency	Total duration of intervention	Overall length of intervention (hrs/mins)
*13	12	2 hrs	Weekly	12 weeks	24 hrs
*10	9	2 ½ hrs	Weekly then fortnightly	5 months	22.5 hrs
*8	10	2 hrs	Weekly	10 weeks	20 hrs
*11	4	2 hrs	Weekly	4 weeks	8 hrs
*12	4	2 hrs	Weekly	4 weeks	8 hrs
*20	5	1 ½ hrs	NS	NS	7.5 hrs
14	6	1 hr	Weekly	6 weeks	6 hrs
16	3	1 x 20-80 mins + 2 x 10 mins	Fortnightly	4 weeks	2 hrs 40 mins (max)
18	6	30-75 mins + 5 x 10 mins	Fortnightly then bi-monthly	16 weeks	2 hrs 5 mins (max)
19	6	30-75 mins + 5 x 10 mins	Fortnightly then bi-monthly	16 weeks	2 hrs 5 mins (max)
17	2	30-75 mins + 1 x 10 mins	Monthly	4 weeks	1 hr 15 mins (max)
15	1	20-60 mins	Once	1 day	1 hr (max)
9	6	NS	Daily	6 days	NK*

NS = Not stated; NK = Not known; *This information cannot be calculated since session duration was not reported in the paper; * studies were all effective in improving psychological health and modifying illness perceptions

3.3.3.2. Results of individual studies

Findings from the thirteen studies are summarized in Table 25 ('indirect illness perception interventions') and Table 26 ('direct illness perception interventions'), in relation to Research question 4.

*Table 25: Review 2 - Main findings for '**indirect** illness perception interventions'*

Study 8: Traeger *et al.*, (2013). Identifying how and for whom cognitive-behavioral stress management improves emotional well-being among recent cancer survivors **Study description:** Explored whether a cognitive-behavioural stress management (CBSM) intervention would improve emotional wellbeing in men treated for prostate cancer via changes to their illness perceptions
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• CBSM patients had significantly higher emotional wellbeing (EWB) 2 weeks after the 10-week intervention than control group patients, even after controlling for SES (household income & years of education) and pre-test EWB • Improvements in EWB were not *directly* explained by changes in the five illness perceptions measured (personal and treatment control, coherence, personality and behavioural causes) • Higher levels of perceived stress pre-treatment predicted greater increases in perceptions of illness coherence and treatment control over time only for intervention participants • Greater increases in these perceptions *combined* (not independently) predicted greater increases in post-intervention EWB • The intervention was effective in increasing illness perceptions of treatment control and illness coherence which buffered CBSM patients from the negative impact of stress on EWB

*Table 25: Review 2 - Main findings for '**indirect** illness perception interventions' (continued)*

Study 9: Lichtenstein Jorgensen *et al.*, (2009). An exploratory study of associations between illness perceptions and adjustment and changes after psychosocial rehabilitation in survivors of breast cancer **Study description:** Explored patterns of illness perception changes and subsequent changes in distress in breast cancer survivors after participation in a rehabilitation course
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• The intervention was not effective in improving emotional distress for either the intervention or 'standard care' control group • Illness perceptions did not change significantly over time in either intervention or control group • Patients were recruited more than 1 year after surgery and may therefore represent an 'emotionally well-adjusted' sample who did not need an intervention so therefore did not benefit from it
Study 10: Fischer *et al.*, (2013). From despair to hope: A longitudinal study of illness perceptions and coping in a psycho-educational group intervention for women with breast cancer **Study description:** Explored changes in both the illness perceptions and distress of women with breast cancer 12 months after a 9-session psychoeducational group intervention
Research question 4
• Participants distress scores decreased significantly immediately after the 5-month intervention (T2) and remained stable over the next 7 months (T3) • The number of patients in the sample with 'clinical levels' of distress decreased from 49% at baseline to 23% and 21% at T2 and T3 respectively • Change scores between baseline and T2 in illness identity, timeline chronic and cyclical predicted an additional 9% of the variance in T2 distress after accounting for baseline distress and education level • Change scores between baseline and T3 in illness identity, consequences and cyclical timeline explained an additional 20% variance in T3 distress after accounting for baseline distress and education level • Changes in cyclical timeline beliefs were the strongest predictor of T2 and T3 distress

*Table 25: Review 2 - Main findings for '**indirect** illness perception interventions' (continued)*

Study 11: Schuurs & Green (2013). A feasibility study of group cognitive rehabilitation for cancer survivors: enhancing cognitive function and quality of life. **Study description:** Evaluated the feasibility of a 4-week cognitive group rehabilitation programme on cognitive functioning and psychological outcomes
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• Psychological distress did not improve significantly for patients in either the intervention group or either of the control groups between baseline and 4 weeks (T2) and 2 months (T3) follow ups. • Psychological distress only decreased significantly between baseline and T2 for intervention patients who were considered 'clinically distressed' pre-intervention - this improvement was maintained 3 months later • The only illness perception to change over time was illness coherence (regarding cognitive difficulties associated with cancer) which increased significantly for intervention participants immediately after the intervention – these benefits were maintained 3 months later
Study 12: King & Green (2015). Psychological intervention for improving cognitive function in cancer survivors: a literature review and randomized controlled trial **Study description:** Evaluated the efficacy of a 4-week cognitive group rehabilitation programme on cognitive functioning and psychological outcomes
Research question 4
• Psychological distress and emotional functioning improved significantly for intervention participants between baseline and 2-weeks after the end of the intervention (T2) – these improvements were maintained 3-months later (T3) • Illness perceptions improved significantly between baseline and both T2 and T3 for intervention participants only • Cognitive self-efficacy (confidence in managing symptoms improved significantly between T1 and T3 for intervention participants only • There was no correlation between changes in illness perceptions over time and any other variable, including cognitive self-efficacy

*Table 25: Review 2 - Main findings for '**indirect** illness perception interventions' (continued)*

Study 13: Cameron *et al.*, (2007). Changes in emotion regulation and psychological adjustment following use of a group psychosocial support program for women recently diagnosed with breast cancer **Study description:** Examined the efficacy of a 12-week psychosocial group program on a range of outcomes including appraisal of personal control, emotional wellbeing and anxiety
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• Intervention participants reported greater improvements in emotional wellbeing (EWB) between baseline (T1) and the end of the intervention 12 weeks later (T2) compared to 'standard care' and 'intervention decliner' control groups (which also improved significantly but not to the same degree). However, *all* groups improved significantly between baseline and 6- (T3) and 12- (T4) month follow-ups • Intervention participants reported significantly decreased levels of anxiety between baseline and T2, whereas control group participants did not. However, *all* groups decreased significantly in anxiety levels between baseline and T3 and T4 follow ups • At T2, intervention participants reported higher perceptions of personal control (the only illness perception measured) than participants in either control group • At T3, there was no differences between intervention and control group participants on perceived control • At T4, intervention participants had significantly higher perceptions of personal control than 'decliners' • There was no significant difference between T1 and T4 perceptions of personal control for intervention participants • Personal control scores continuously decreased between T1 and T2, T2 and T3 and T3 and T4 for both control groups, these decreases were statistically significant in the 'decliner' group

*Table 26: Review 2 - Main findings for '**direct** illness perception interventions'*

Study 14: Humphris & Rogers (2012). AFTER and beyond: cancer recurrence fears and a test of an intervention in oropharyngeal patients **Study description:** Examined the efficacy of a 6-week manualised representational intervention on fear of cancer recurrence and psychological distress in patients with oral and oropharyngeal cancer patients
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• There were no significant decreases in either anxiety or depression for intervention participants at 4 or 8 month follow ups. • Control group participants increased in anxiety between baseline and 8 month follow up • Intervention participants level of 'anxious preoccupation' and 'fear of recurrence' decreased significantly between baseline and 4 month follow up but improvements were not sustained at 8 month follow up • Poor session attendance levels (2 session median attendance) • Participants were significantly below the clinical threshold for anxiety and depression at baseline
Study 15: Ward, *et al.*, (2008). A randomized trial of a representational intervention to decrease cancer pain **Study description:** Measured the effects of a one-session representational intervention on pain management and quality of life
Research question 4
• There was no significant change in psychological functioning for intervention or control group participants at 1- (T2) or 2- (T3) month follow ups • Intervention participant's perceptions of 'usual pain severity' improved and perceived barriers to using analgesic medication decreased significantly after the intervention • High number of sample reported their pain was 1/10 on a 0-10 scale of severity. Patients who dropped out were more unwell so remaining sample were not necessarily in need of an intervention

*Table 26: Review 2 - Main findings for '**direct** illness perception interventions' (continued)*

Study 16: Ward, *et al.,* (2009). A randomized trial of a representational intervention for cancer pain: Does targeting the dyad make a difference? **Study description:** Examined the comparative efficacy of a representational intervention with individual patients ('solo') and with a significant other (dyad) to improve cancer pain, quality of life and mood
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• Participants in either intervention group ('solo' or 'dyad') did not significantly improve in negative mood between baseline and 5- (T2) or 9- (T3) week follow up • Intervention participants in both groups (solo and dyad) showed greater decreases in attitudinal barriers such as reporting pain to health care professionals and use of analgesics between baseline and T3 follow up compared to participants in standard care control group • Attitudinal barrier change scores between baseline and T3 mediated the effects of both solo and dyad interventions on negative mood
Study 17: Heidrich, *et al.,* (2009). An individualized representational intervention to improve symptom management in older breast cancer survivors: Three pilot studies **(Pilot study 1)** **Study description:** Evaluated the feasibility and acceptability of a 2-session representational intervention (IRIS) for older breast cancer survivors and the effects upon symptom distress and management, depression and anxiety
Research question 4
• The intervention was not effective in reducing anxiety or improving mood. Ten weeks after the intervention scores for intervention participants did not differ significantly from 'usual care' control participants • The intervention was effective at reducing symptom distress but not overall quality of life (including psychological functioning) which may reflect stability of quality of life in older adults with other comorbidities

*Table 26: Review 2 - Main findings for '**direct** illness perception interventions' (continued)*

Study 18: Heidrich *et al.,* (2009). An individualized representational intervention to improve symptom management in older breast cancer survivors: Three pilot studies – (**Pilot study 2)** **Study description:** Evaluated the feasibility and acceptability of an extended 6 session IRIS for older breast cancer survivors and the effects upon symptom distress and management, depression, anxiety and mental health
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• Intervention participants did not improve in either depression, mental health or level of anxiety 16 weeks after the intervention and did not differ from waitlist control participants • The intervention was effective at reducing negative mood from symptoms but not overall quality of life (including anxiety and depression) which may reflect stability of broader quality of life in older adults • Multiple comorbidities and life events may delay implementation of changes in this patient population
Study 19: Heidrich *et al.,* (2009). An individualized representational intervention to improve symptom management in older breast cancer survivors: Three pilot studies **(pilot study 3)** **Study description:** Evaluated the feasibility and acceptability of a 6 session IRIS delivered over the telephone for older breast cancer survivors and the effects upon symptom distress and management, depression, anxiety and negative mood
Research question 4
• Intervention participants did not improve in mental health or level of anxiety at either 8- (T2) or 16- (T3) weeks follow up • Intervention participants decreased significantly in their 'negative mood attributed to symptoms' (e.g. anger, confusion, tension and depression) from baseline to both 8 (T2) and 16 (T3) week follow up • Barriers to symptom management (e.g. communication difficulties with health care professionals) may have mediated the influence of the intervention on distress

*Table 26: Review 2 - Main findings for '**direct** illness perception interventions' (continued)*

Study 20: Smith, *et al.*, (2015). Pilot of a theoretically grounded psychologist-delivered intervention for fear of cancer recurrence (Conquer Fear) **Study description:** Evaluated the feasibility, acceptability and efficacy of a psychologist-delivered 5-session intervention to reduce fear of cancer recurrence and cancer-specific anxiety
Research question 4 To what extent are these interventions effective in improving psychological health and modifying illness perceptions?
• Cancer specific anxiety improved significantly immediately post intervention and increased further 2 months later • Fear of cancer recurrence decreased significantly between baseline and follow up time points

3.3.3.3. Data synthesis

Review 2 - Research question 4:
To what extent are these interventions effective in improving psychological health and modifying illness representations?

Findings from each study were collated and summarised according to intervention details and relative efficacy in improving psychological health and modifying illness perceptions. Findings are summarised in Tables 27 and 28 and described below.

Indirect illness perception interventions

Studies 8-13 measured whether a variety of interventions were effective in improving psychological health and changing illness perceptions.

Changes in illness perceptions

Illness representations changed significantly for all but one indirect intervention study (9). One study reported illness representations (measured by the B-IPQ as a whole scale only) improved significantly between pre- and post-intervention time points (12) but did not expand on changes in any individual illness perceptions. The remaining four studies reported improvements over time for intervention participant's levels of illness coherence (8 & 11), perceptions of treatment control (8), personal control (13), consequences, illness identity, chronicity and the cyclical nature of their illness (10). Although it should be noted that for Study 13, greater increases in participant's perceptions of personal control compared to control participants were only evident immediately after the intervention: this difference was not maintained at 6- and 12-month follow ups.

Improvements in psychological health

In terms of psychological health, four studies found that their interventions were effective in improving emotional wellbeing (8 & 13) and decreasing psychological distress (10 & 12). One study found their intervention was *somewhat* effective in reducing psychological distress but only for participants in the intervention group whose distress scores were in the clinical range at baseline (11). Only one indirect intervention study found their intervention was not effective in reducing emotional distress (9).

Direct illness perception interventions

Studies 14-20 measured whether interventions specifically designed to directly modify patient's illness perceptions would improve some aspect of their psychological health.

Improvements in psychological health

Only one study reported improvements for intervention participants in psychological health (20). The remaining six direct intervention studies reported no benefits for participants in terms of their overall psychological health.

Changes in illness perceptions

None of the direct interventions measured illness perceptions.

Changes in other variables

Several other variables were reported to have improved and, while not representing overall psychological health, are worthy of note. For example, several studies reported that their interventions were effective in reducing participants fear of cancer recurrence (14 & 20), their level of anxious preoccupation (8), negative mood or distress from symptoms[7] (17, 18 & 19) and attitudinal barriers to symptom management such as difficulties communicating pain to health care professionals and appropriate use of analgesics (16 & 19).

3.3.4. Review 2: Summary

There was much methodological variability in the thirteen papers reviewed, making synthesis and between-study comparisons challenging and which may have increased the possibility for bias. From the thirteen studies reviewed, seven designed illness perception interventions based on Leventhal's common sense model to directly modify illness perceptions. Only one of these studies reported their intervention had been effective in improving the psychological health of participants. The remaining six studies employed indirect interventions to improve psychological health, five of which found beneficial effects of the intervention on psychological health of participants and all reported improvements in one or more illness perceptions over time.

[7] This was described as a variable distinct from general mood

*Table 27: Review 2 – Summary of the content of **effective*** interventions*

Study	Direct (D)/ Indirect (I) approach	(G)roup/ (I)ndividual approach	Teaching elements	Relaxation training	#Cognitive-restructuring	Group discussion	Homework	Physical exercise	Improved psychological health	Illness perceptions modified
8	I	G	✓	✓	✓	✓	✓	×	✓	Illness coherence & treatment control
9	I	G	✓	×	×	✓	×	✓	×	None
10	I	G	✓	✓	✓	✓	✓	×	✓	Illness identity, consequences, chronicity, cyclical timeline
11	I	G	✓	✓	×	✓	✓	×	✓	Illness coherence
12	I	G	✓	✓	×	✓	✓	×	✓	All (measured by single scale of B-IPQ)
13	I	G	✓	✓	×	✓	✓	×	✓	Personal control at end of intervention only – not maintained after 6 & 12 months
20	D	I	✓	✓	✓	×	✓	×	✓	NA

* effective in improving psychological health; # active challenging of maladaptive beliefs in an attempt to restructure them

*Table 28: Review 2 – Summary of the content of **ineffective*** interventions*

Study	Direct (D)/ Indirect (I) approach	(G)roup/ (I)ndividual approach	Teaching elements	Relaxation training	#Cognitive-restructuring	Group discussion	Homework	Physical exercise	Improved psychological health	Illness perceptions modified
14	D	I	✓	✓	×	×	×	×	×	NA
15	D	I	✓	×	×	×	×	×	×	NA
16	D	I	✓	×	×	×	×	×	×	NA
17	D	I	✓	×	×	×	×	×	×	NA
18	D	I	✓	×	×	×	×	×	×	NA
19	D	I	✓	×	×	×	×	×	×	NA

NA = Not applicable as illness perceptions were not measured; * ineffective in improving psychological health; #active challenging of maladaptive beliefs in an attempt to modify them

4

DISCUSSION

4.1. Overview

Two systematic reviews were conducted to explore the prospective relationship between illness representations and the psychological health of adults with a cancer diagnosis and to evaluate interventions which have attempted to modify illness perceptions to improve psychological health. This chapter will firstly summarize and interpret overall findings for each review relating to each of the four research questions. Important strengths and limitations of reviewed studies and of the review methodology process will then be considered in terms of their potential impact upon overall conclusions. Finally, clinical implications of these findings will then be discussed.

4.2. Review 1: Principal findings

This review evaluated studies which measured the prospective relationship between illness representations and future psychological health. Seven studies were identified which measured this relationship in patients with a range of cancer diagnoses including breast cancer, prostate cancer, colorectal cancer, head and neck cancer and oesophageal cancer.

Research question 1: Are illness representations prospectively associated with future psychological health in adults with cancer?

All but one of the seven studies reviewed reported that illness representations (i.e. the collective term for illness perceptions) were predictive of future psychological health in cancer patients. Overall, patients with the most negative illness representations had the worst psychological health over time. This finding is in line with two similar published

systematic reviews for patients with a range of chronic illnesses (Hagger & Orbell, 2003) and for those with a cancer diagnosis (Richardson *et al.*, 2016).

Three main approaches to exploring this prospective relationship were undertaken to determine the strength of this association. Two approaches involved clustering patients into groups with similar illness perceptions either at one point in time (Study 6) or over time as a function of change (Study 1). Both studies found that patient clusters (patients with similar illness perceptions) were significantly predictive of future depression and anxiety. Using a clustering approach was useful in determining which patient clusters were particularly 'at risk' of developing psychological difficulties in the future. Four of the remaining five studies not using a clustering approach found baseline illness representations were predictive of future psychological health.

Research question 2: Which illness perceptions *best* predict psychological health?

All nine illness perceptions suggested by the CSM (i.e. identity, cause, consequence, timeline-acute/chronic, timeline-cyclical, illness coherence, emotional representation, personal control, treatment control), were found to be significantly predictive of future psychological health by at least one study, either as part of an illness perception cluster or independently of other illness perceptions. Perceptions about illness identity and the consequences of having cancer were found to be predictive of psychological health in four of the seven studies (57%) that measured them. Comparatively, emotional representations were least often found to be predictive of psychological health (33%) but were also least often measured.

Only Study 2 did not find a significant association between any illness perception and psychological health, despite measuring all nine possible illness perception domains using the IPQ-R. However, this study did find small but significant relationships between illness perceptions and global quality of life, which included nine subscales of functioning. It is possible therefore, that the lack of a significant association may be a methodological artefact of using only a 4-item 'emotional functioning' subscale to

represent psychological health. This subscale may not have been comprehensive or sensitive enough to detect a relationship.

The two studies which conducted cluster analysis to group patients together according to similarities in illness perceptions revealed that some patients were more likely to experience poor psychological health over time than others. In Study 1 (Dempster *et al.,* 2010), four distinct patient clusters were identified in a large sample of oesophageal cancer survivors. Only one of these groups of patients (Cluster 1) reported increasingly positive illness perceptions over the 12-month study. Illness perceptions became increasingly negative over time to varying degrees in the remaining three patient clusters. Patients in Cluster 3 reported a significantly greater deterioration in most measured illness perceptions over time compared to patients in Clusters 2 and 4 which had decreases in some but not all. Dempster *et al.,* suggest that increased perceptions that their cancer could not be controlled either by themselves or by treatment differentiated Cluster 3 patients from those in other clusters. They suggest that this sense of hopelessness/helplessness is characteristic of patients in this cluster and could be key to understanding the comparatively greater increases in both depression and anxiety over time.

Using a different clustering approach on baseline illness perception scores only, Study 6 (McCorry *et al.,* 2012) found two illness perceptions clusters in a sample of newly diagnosed breast cancer patients. Women in Cluster 1 had a poorer sense of illness coherence, were more likely to believe their illness was chronic and cyclical and had more severe consequences, attributed more symptoms and causation to their illness and had stronger beliefs that it could not be controlled at baseline. These patients were significantly more likely to experience depression and anxiety 6 months later than women Cluster 2 who had significantly more positive baseline illness perceptions.

Findings from Studies 1 and 6 share similarities with patients in a study of chronic pain patients (Hobro, Weinman, & Hankins, 2004). Cluster analysis of patient's illness perceptions in Hobro *et al's.* study revealed two distinct groups of patients; 'adaptors' and 'non-adaptors'. Patients identified as non-adaptors reported poorer understanding of their pain, a higher number of attributable symptoms, higher perceived consequences and more negative beliefs in the efficacy of pain treatment than adaptors and were more likely to experience depression than adaptors. As with Cluster 3 patients in Study 1 in

this review, a key characteristic of non-adaptors was their comparatively poor perceptions of personal control. Hobro *et al.*, suggest that this negative pattern of thinking for non-adaptors may represent a cognitive process known as 'catastrophizing' common in individuals with psychological difficulties such as depression which may represent a tangible and modifiable target for psychological intervention.

4.3. Review 2: Principal findings

This review aimed to identify what interventions have been developed to modify illness representations in cancer patients. Thirteen studies described twelve different interventions to modify illness representations and improve several psychological outcomes in cancer patients. Interventions were evaluated for their effectiveness in improving psychological health and modifying illness perceptions.

Research question 3: What interventions have been developed to modify illness representations for adults with cancer?

Seven studies described 'direct' illness perception interventions (14-20). These studies adopted the common-sense model (Leventhal & Diefenbach, 1992) as a theoretical basis for the intervention's development, to directly modify 'maladaptive' illness representations. All direct interventions were delivered to individual patients. Although there was some variation in the exact nature of these interventions, their common feature was that patients were actively and explicitly encouraged to discuss their perceptions of having (or having previously had) a cancer diagnosis along multiple illness perception domains in order that facilitators could identify and address inaccurate or maladaptive beliefs about their illness.

The remaining six studies (8-13) developed 'indirect' illness perception interventions that did not aim to directly influence patient's illness perceptions. Instead, these studies evaluated whether a range of interventions would lead to improvements in psychological health and whether these improvements could be explained by changes in

illness perceptions, hypothesising interventions would modify illness perceptions indirectly. All indirect interventions were delivered as group programmes. One study used a manualised Cognitive-Behavioural Stress Management approach (CBSM: Study 8) and the remaining five studies employed a broad range of rehabilitation techniques such as goal setting, increasing exercise levels, increasing social networks and opportunities, education and general group discussion. Several studies also incorporated therapeutic techniques such as breathing exercises (Study 10) relaxation (Studies 8 & 11-13), imagery and mediation (Study 13).

Research question 4: To what extent are these interventions effective in improving psychological health and modifying illness representations?

Indirect illness perception interventions

Five of the six indirect intervention studies reported they were effective in improving the psychological health of patients with cancer (8 & 10-13). Although the cognitive rehabilitation intervention described in Study 11 was only effective for patients who were within the clinical range of significant distress upon entering the intervention.

Indirect interventions that were effective in improving psychological health were also effective in modifying a range of different illness perceptions. Levels of illness coherence were significantly higher post-intervention for patients in two studies (8 & 11), although given all six of these interventions delivered group programmes that incorporated teaching elements (e.g. increasing knowledge of cancer, side effects of medication & expected difficulties etc.), it is perhaps surprising that more studies did not report improvements in patient's coherent understanding of their condition. Perceptions of personal and treatment control were also significantly improved by two interventions (Studies 8 & 13). However, post-intervention increases in perceptions of personal control were short-lived for patients in Study 13 whose perceptions, after 12 months, had returned to baseline levels despite maintaining improvements in their levels of anxiety. The intervention described in Study 10 yielded the greatest degree of changes to patient's illness perceptions over time, reporting decreases in illness identity,

perceived consequences, chronicity and cyclical timeline in a sample of women with breast cancer after 12 months.

Direct illness perception interventions

Only one of the seven direct illness perception interventions reported significant improvements in patient's psychological health (Study 20). This manualised intervention aimed to reduce the impact of fears of cancer recurrence and patient anxiety by addressing illness perceptions in 'individual therapy sessions'. Unlike the other six direct interventions that were not effective in improving psychological health, this intervention incorporated relaxation training, "cognitive restructuring" and homework based activities to facilitate in-session discussions and support the consolidation of learning. In this regard, it was more like the content delivered by the generally more effective indirect illness perceptions interventions.

4.4. Clinical implications

4.4.1. Review 1: Illness representations as useful and modifiable targets for intervention

Overall, illness representations were prospectively predictive of psychological health in adults with a range of cancer diagnoses. Patients with the most negative illness perceptions (or the most significant decline in illness perceptions over time) were those who were more likely to experience psychological difficulties such as anxiety, depression, distress and poor psychological wellbeing at some point in the future. Two studies were also able to identify cancer patients who might be considered 'at risk' of developing significant anxiety difficulties in the future based on their illness perceptions at the point of diagnosis or the changes in their illness perceptions over time. As such, it is evident that illness representations do represent an important modifiable target for intervention in this patient group.

4.4.2. Review 2: Using the CSM as a model for developing interventions

The appropriateness of using the CSM to predict psychological health outcomes

The CSM theorises that when individuals become unwell, they will rely upon their cognitive and emotional representations of illness to make sense of their condition and

select an appropriate coping strategy. The model further hypothesises that coping responses are continuously monitored and evaluated by the individual and/or changed in terms of their relative success or failure. Illness perceptions may also need to be revised by the individual depending on the success of a coping response. In their meta-analysis of research exploring links between illness perceptions and coping in physical illness, Dempster, Howell and McCorry (2015) describe the evolving use of the CSM in health care research. Research has often used behavioural measures to represent patient's coping responses to illness (e.g. self-care, medication adherence, routine clinic attendance). However, the CSM has more recently been used to explain both physical and psychological outcomes such as quality of life, physical functioning, anxiety and depression. Dempster *et al.,* argue that while there is lots research linking elements of the CSM to psychological outcomes in physical illness, using the CSM in this way is an 'extrapolation of the original model' (pp.506) which does not explicitly acknowledge the role of illness representations in psychological outcomes such as distress, anxiety or mood for example. Dempster *et al.,* argue that this may have led to a lack of consistency in the application of the CSM in research focussing on individuals with physical illness and the subjective interpretation of the definition of psychological outcomes (potentially as a proxy for coping responses) and the ability of the CSM to explain these.

Interestingly, findings from two studies in Review 2 (17 & 18) revealed that although direct illness perception interventions were largely ineffective in improving psychological health outcomes, they were effective in modifying health behaviours such as re-engaging with health care providers, initiating a new treatment regime and changes to self-care strategies to more effectively manage pain symptoms. Ward *et al.,* (2009: Study 16) suggest that using a 'Representational Approach' (an intervention based around the CSM) can be effective in guiding the content and process of an intervention and can facilitate changes in beliefs, for these changes to be translated into improved outcomes, additional steps are also needed. Some of these steps might be better conceptualised by using additional health models such as the transtheoretical model of behaviour change (Prochaska, DiClemente, & Norcross, 1992): an integrative biopsychosocial model which acknowledges explain individual's readiness to make behavioural changes to improve their physical and psychological health. Research has shown this to be an effective model for assessing which patients are likely to make use of and benefit from intervention (Brogan, Prochaska, & Prochaska, 1999). The Theory of Planned Behaviour (Ajzen, 1985) may also prove useful in understanding the relative

importance of the health beliefs of significant others and an individual's behavioural intention which is likely to predict whether they will make changes.

Poor conceptualisation and measurement of the CSM model in interventions

Findings from Review 2 would suggest that on the whole using a direct approach to changing illness perceptions to improve psychological health is not effective. However, of the seven studies which had explicitly used the CSM as a framework for developing their intervention (direct interventions), none measured illness perceptions using a quantifiable measure, despite describing themselves as 'representational approaches'. Without measuring illness perceptions, it would be difficult to surmise how well represented the CSM was in these types of intervention. The poor operationalisation and measurement of illness perceptions in direct interventions makes it difficult to draw conclusions about using the CSM to directly inform interventions. However, it would be unwise to conclude on the basis of such studies whether 'representational approaches' are ineffective: we simply don't know enough about why they didn't work. If an intervention doesn't measure the key component it is aiming to modify then it is impossible to conclude why it is or isn't effective. The fact remains that we don't really know how well these interventions tapped into illness perceptions at all because they didn't measure illness perceptions. It is possible that they may have *accessed* illness perceptions (e.g. identified what they were) but been unable to *convert* them into meaningful improvements in psychological health because of missing elements necessary for 'successful' interventions. It is important for the development of illness representational interventions to consider how to translate changes in illness perceptions into successful outcomes: talking about illness perceptions alone is clearly insufficient.

4.4.3. Important considerations in effective interventions

Findings revealed that indirect illness perception interventions (those which aimed to modify illness perceptions indirectly – not using the CSM as a framework) were generally effective in improving psychological health and changing illness perceptions but that interventions designed to *direct* modify illness perceptions were largely ineffective in improving psychological health. However, there are a number of factors which require further consideration before making generalised conclusions about the efficacy of these interventions.

4.4.3.1. Group vs. individual approaches

There was a general superiority of group interventions over individual approaches in improving psychological health in Review 2. Ascher-Svanum and Whitesel (1999) suggest that several important factors are likely to play a role in the efficacy of group approaches to improve psychological distress such as level of interpersonal support from peers, opportunities to share concerns and receive group validation, the presence of positive peer role models, being part of a cohesive group and on a basic level, understanding their difficulties are not theirs alone. The benefits of peer support groups and psychosocial/psychoeducational groups within cancer populations are well cited within health care literature and there are multiple published reviews on their efficacy (Gottlieb & Wachala, 2007; Hoey, Leropoli, White, & Jefford, 2008).

4.4.3.2. Complex vs. simple interventions: Active components

Complex interventions have been described as those containing several components which may interact with one another to improve efficacy of an intervention (Craig , *et al.*, 2008). In this regard, effective interventions reviewed here were significantly more complex than ineffective interventions, and comprised multiple components. With only one exception (Study 20), effective interventions were delivered as part of a group programme and so also had the added benefit of increasing social support. By comparison, ineffective interventions reviewed here were significantly less complex, comprising only a teaching component which consisted of one or more structured conversations between individual patients and 'interveners' who attempted simply to challenge misconceptions and replace them with 'correct' information.

Research has suggested that more complex interventions may be effective because they are more likely to contain 'active ingredients' helpful in facilitating change (Craig , *et al.*, 2008), particularly in relation to improving psychological health and subsequent health behaviour changes (Collins & Dozois, 2008; Moos, 2007). Indeed, effective interventions reviewed here reported many active ingredients which may have facilitated improvements in psychological health including increased access to social support, provision of information, homework based activity, group discussion to reinforce skills, focus on increasing self-efficacy by encouraging problem-solving, training in goal setting, improving interpersonal skills, encouraging open discussion of shared experiences, increasing physical exercise, increasing relaxation, behavioural

experimentation and written emotional disclosure to improve expression of emotions. The potential disadvantage of such complex interventions is that often, and this was the case for this review, insufficient information is available to allow replication of the intervention or to determine which ingredients or indeed combination of ingredients are *absolutely necessary* for the intervention to be effective (Michie & Abraham, 2004). In other words the more complex the intervention, the more difficult it becomes to identify the mechanisms of change.

Interestingly, relaxation training was part of all effective interventions in Review 2. Conversely, relaxation training was notably absent from six of the seven non-effective interventions. In a recent large scale meta-analysis of 198 studies of both individual and group psychotherapy and group psychoeducational (provision of education and information to help individuals better understand and cope with a condition) approaches to improve the psychological health of cancer patients, Faller *et al.*, (2013) found that while small to medium effect sizes were observed, relaxation training was key to many intervention's success. As such this is potentially a key active component of such interventions and may be a useful guide to developing future interventions in this patient group.

4.4.3.3. Intervention intensity

Effective interventions were all conducted weekly over a number of weeks or months with a minimum session duration of 90 minutes and a minimum overall patient/facilitator contact of 7 ½ hours. The only direct intervention to effect change had the longest therapeutic contact between patients and therapists/facilitators of any study (Study 20). This supports a recent review and meta-analysis of psychosocial intervention studies for cancer patients (Faller, *et al.*, 2013) which found a moderation effect of intervention duration in that longer interventions produce more sustained effects on psychological distress. Ineffective interventions in Review 2 were those of the shortest duration with less overall patient-therapist contact (Studies 14-19). The indirect intervention described in Study 9 was conducted over 6 consecutive days rather than several weekly sessions and may not have provided sufficient time for patients to consolidate learned material before the end of the intervention to translate this information into perceptual and/or psychological changes. This intervention may simply have been too intense for patients. There may be an optimum way of delivering these

interventions regardless of content. As a benchmark for effectiveness, patients in Study 10 reported the most significant improvements in psychological health and illness representations. This intervention delivered 2 ½ hour sessions weekly for several weeks then fortnightly to allow patients to consolidate learning. All ineffective interventions involved either the *least* patient contact or the *most* but delivered too close together to be useful.

4.4.3.4. Intervention recipients and baseline levels of psychological health

Faller *et al.* found intervention studies that preselected participants based on their level of distress (i.e. selected those who were within clinical ranges of psychological distress), tended to be more effective. Multiple studies in Review 2 reported that patients were not 'clinically' distressed before entering the intervention (Studies 9, 10, 14, 17-19), most of which were ineffective in improving psychological health or changing illness perceptions. Furthermore, greater and potentially problematic attrition rates (Schulz & Grimes, 2002) reported by several studies could suggest that those who dropped out were more physically or psychologically unwell. It has been suggested that in studies with high rates of attrition, 'completers' may be less in need of an intervention to improve their psychological health than those who drop out of the study - something which may in fact impact true effect sizes (Hui, Glitza, Chisholm, Yennu, & Bruera, 2013).

4.4.4. Recommendations

- Future interventions need to measure illness representations using a valid and reliable measure such as the IPQ-R to determine the mechanisms of change, particularly if their intervention aims to modify illness perceptions. Most interventions which aimed to directly modify illness representations weren't effective in improving psychological health but may have made changes to illness perceptions. This information would be extremely useful in terms of developing future useful interventions.

- Research has noted there are potential difficulties in developing group programmes such as those described by the intervention studies identified in Review 2 to

improve psychological outcomes (Colom, 2011). She outlines the importance of developing a therapeutic relationship between the therapist/group facilitator and the patient 'founded on trust rather than authority' and which empowers patients to feel able to make necessary changes. She acknowledges that this therapeutic trust is more difficult to achieve in educational programmes given the relative position of power of the facilitator and the comparative lack of time resources compared to individual therapy approaches. Future interventions should consider these variables when designing such interventions, particularly in the climate of limited resources within the NHS.

- Relaxation training was part of *all* effective interventions in the current review but was absent from all but one of the non-effective interventions. Relaxation training may play an important role in making interventions helpful in alleviating psychological distress and as such is potentially a key consideration and useful guide to developing future interventions in this patient group.

- Interestingly, while all but one of the direct illness perception interventions were ineffective in improving psychological health, they were successful to some extent in improving other specific and perhaps more transient mood-related outcomes in the short-term such as 'anxious preoccupation' and fear of cancer recurrence, symptom distress and 'negative mood from symptoms'. Heidrich *et al.,* suggest that for older cancer patients at least, short-term mood difficulties associated with physical symptoms may represent a better target for psychosocial intervention in this subgroup of patients with multiple comorbid health concerns than global quality of life or general psychological health which may be more stable and/or resistant to change.

- Donovan, Kwekkeboom, Rosenzweig, and Ward (2009) recommend that psychoeducational and cognitive-behavioural interventions such as those developed in the studies reviewed should consider and measure 'non-specific' factors which may play an important mediational role in the effectiveness of such interventions in improving psychological outcomes. Factors such as the therapeutic alliance, perceived kindness and compassion, patient expectations and beliefs in the credibility of the intervention are all thought to play an important collective role in determining whether an intervention will be effective. Donovan *et al.* also note that

these non-specific factors are rarely measured within intervention studies, as was the case for the studies reviewed here.

4.5. Strengths and limitations

In line with the CRD guidelines and using recommendations detailed in the PRISMA checklist for reporting systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009), strengths and limitations will now be considered at the study level (e.g. confounding variables and potential risk of bias), at the review level (e.g. incomplete retrieval of identified research, reporting bias) and at the reviewer level (e.g. professional perspectives).

4.5.1. Study level

Attrition bias

Most studies reported data on patients who had completed *all* measures at all time points and provided minimal information on who, how many and why people dropped out between baseline and follow up. Although several studies compared completers from those who dropped out on demographic variables, very few studies compared the groups on psychological health or illness perception variables to determine any differences in the ways they think or felt emotionally. It is possible that patients who completed the study/intervention were more psychologically or clinically well compared to those who dropped out.

Measurement bias

Another potential source of bias within these reviews could be the use of only self-report measures of illness perceptions and psychological health and the absence of any other objective measure (Robson, 2002). Using only self-report measures relies heavily upon patient's individual interpretation of items. Similarly, most studies did not specify exactly *where* patient's completed questionnaires which increases the risk that items may have been misinterpreted. However, the absence of other clinically relevant and psychometrically valid and reliable ways to measure illness perceptions means this risk of bias would always have been present. The fact that most studies used illness perception measures as recommended by developers is likely to have increased the internal validity of the dataset overall.

Sample bias

Regarding sample bias, several studies in both reviews recruited participants who were not necessarily experiencing psychological difficulties at baseline. Study 7 excluded patients who were experiencing high levels of anxiety. This finding could mean a lack of sensitivity in the ability to detect changes or improvements in psychological health or illness perceptions over time (since these perceptions may be relatively stable if participants are psychologically 'well'). Several studies found differences between participants who completed all measures at all time points and those who dropped out, in terms of both physical or psychological health or levels of social and emotional support (Studies 2, 3, 5 & 7). Patients who dropped out of Study 5 for example were not only those with worse tumour stages but were also more likely to have had combined therapy. Conversely, patients who remained in the study had been diagnosed earlier in their disease progression in line with previous evidence showing a link between high patient attrition and the wellbeing of 'completers' (Miller *et al.*, 2005).

Only eight studies in both reviews (40%) reported the ethnicity of their sample. Of these, seven studies reported more than 90% of patients in the study were Caucasian white ethnicity. Given minority groups are equally likely to receive a cancer diagnosis, this significant underrepresentation of minority groups depreciates the generalizability and validity of findings and may also highlight potential issues surrounding access to interventions (Giuliano, *et al*., 2000). Speaking a primary language other than English was an exclusion factor for more than one of the studies in the current review and has been cited as a significant barrier to both the participation and recruitment of minority groups in cancer studies (Giuliano, et al., 2000). Illness perception studies might benefit from knowing the IPQ-R has been translated and is freely available in 16 languages and the B-IPQ in 24 languages (http://www.uib.no/ipq/ - accessed on 01/09/2016).

Recruitment point

There were two main issues surrounding the recruitment of participants for both reviews. First, reporting *when* patients entered the studies or when they received intervention was particularly poor. Of the studies that did report the exact time at which patients were recruited, there was a great degree of variability in terms of time since diagnosis and/or treatment. Some studies reported patients were 'pre-treatment', some were 'newly diagnosed', some were immediately 'post curative treatment' and others had had a diagnosis for up to 4 years. To draw conclusions about the links between

illness representations and psychological health and the efficacy of interventions, this information is vital. The Institute for Health Research (2001) suggests that to explore or indeed effect psychosocial changes for cancer patients, it is first essential to appreciate the differential needs at different points in the cancer trajectory. They hypothesise four 'critical moments' in cancer trajectories distinct from more clinical definitions of cancer in 'stages'. These critical moments are defined as being within one month of: diagnosis, the end of the first treatment, the first recurrence and the move from active treatment to palliative care only. During these critical moments, patients are significantly more likely to suffer psychological distress. Interestingly, Study 14 noted that patients in their intervention suggested in qualitative feedback to their facilitators that they would have preferred the intervention earlier in their recovery (within 3 months of medical/surgical treatment) which lends some support to the idea of critical moments and is worthy of consideration when designing studies for cancer patients.

Statistical suppression effects

While illness representations were predictive of future psychological health in 6/7 studies in Review 1, the strength of this association varied and diminished considerably in several studies once the variance explained by other baseline sociodemographic (e.g. age, gender, SES) and disease related (cancer type, tumour stage) variables had been considered during statistical analysis. Baseline psychological health was the most significant predictor of future psychological health in most studies that accounted for this variable within regression analyses. The strongest predictive relationship between illness representations and future psychological health was reported by Study 4. This study did not measure baseline psychological health because it was not appropriate to do so at that point in time with this sample of patients and therefore could not be controlled for within regression analyses. This may to some extent explain the significantly stronger relationship between baseline illness perceptions and follow up psychological health observed in this study compared to others which did control for this variable. Study 2 for example, found no significant relationship between baseline illness perceptions and future psychological health once baseline psychological health had been accounted for in regression analyses.

Cook *et al.,* (2015: Study 3) suggested that the *true* relationship between illness perceptions and psychological health may be underestimated in their study, even though

it was still statistically significant. They argue that relationship sizes may be artificially 'suppressed' by hierarchical regression analysis due to the strong cross-sectional association between Time 1 and Time 2 symptoms of distress. Artificial suppression in regression analysis is a distinct possibility for several of the studies reviewed and discussed within social science research as introducing potentially confounding effects (Ludlow & Klein, 2014).

4.5.2. Review level

There were several strengths of the two reviews. Current guidelines on best practice in systematic reviews were followed to ensure a rigorous approach to searching the literature base to improve the chances that key studies were not missed. Reporting the search process using these and other national review guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009) improved the transparency of the review, increasing its replicability and likelihood of publication. The study selection criteria were deliberately over-inclusive to ensure all relevant studies were retrieved. Several checks to ensure all relevant papers had been retrieved such as contacting relevant authors and hand searching key journals is also likely to have reduced the likelihood of publication bias. Studies were also subjected to rigorous evidence based methodological and reporting quality assessment to attenuating the risk of bias (EPPI-Centre; Katrak *et al.*, 2004; Harden *et al.*, 2001).

In terms of the potential limitations, only peer reviewed papers published in the English language were included which may have led to publication bias. Had it been feasible in terms of time and resources, this could have been minimised by including non-English papers and making use of translation services. It may also have been possible to include non-peer reviewed 'grey-literature' in the inclusion criteria, which may have reduced the possibility of including only significant findings (Garg, Hackam, & Tonelli, 2008).

4.5.3. Reviewer level

CRD guidelines recommend reviews are conducted by a 'review team – a minimum of two reviewers, who can minimize bias and error throughout all stages of the review'. The guidelines also recommend the review team consults with an 'advisory group'

which might consist of both clinical and research professionals to provide a range of clinical expert skills in the review process. As the candidate for this thesis, I was the primary and only reviewer. It was neither possible due to time and resource constraints to have a team of reviewers nor an advisory group. Nevertheless, I have received training in conducting systematic reviews using recommended guidelines and I was able to make use of both a field supervisor with expertise in using the CSM model and working in cancer research and an academic supervisor with significant expertise in research methods and systematic reviews. Substantial attempts were made to make use of supervisor's expertise at various points (already outlined) in the literature search and data extraction to minimise bias. However, as noted within the CRD guidelines, sometimes data extraction can be prone to human error and often subjective decisions are required. As with any systematic review, my occupation as a Clinical Psychologist may have introduced a level of subjective bias to the review process since I have my own ideas about what might be useful for clinicians to know about the studies reviewed and have used these opinions to develop the parameters of the search strategy (e.g. evaluating *only* psychological health outcomes and excluding other outcomes which could have potentially been useful for interpreting the data). While the use of standardised guidelines for limiting the potential for bias in several ways has been helpful to attenuate this subjectivity, undoubtedly bias could have been further reduced by having one or more additional reviewers.

4.6. Conclusions

The common-sense model of illness representations is a widely cited theoretical framework within health literature to explain the ways in which individuals with chronic illness think about and respond to their condition (Leventhal & Diefenbach, 1992; Leventhal & Nerenz, 1985). Since the development of quantitiative measures of illness representations over the last 20 years, studies exploring the relationship between illness perceptions and psychological health have grown exponentially, particularly and more recently in the field of cancer research. Review 1 aimed to identify studies which had measured the prospective relationship between illness representations and psychological health in order to investigate the potential of illness representations as a modifiable target to guide interventions for adults struggling to cope with having cancer.

In total, seven studies were identified which had measured this relationship. An inverse relationship was found for six of these studies indicating that the more negative illness perceptions patients have about their cancer, the worst their overall psychological health was likely to be in the future. Review 2 aimed to identify interventions which had attempted to improve the psychological health of cancer patients by modifying illness perceptions. Thirteen intervention studies were identified and revealed that seven studies reported interventions that had attempted to improve psychological health by *indirectly* affecting change in illness perceptions (not targetting illness beliefs specifically) and a further six studies had attempted to *directly* manipulate patient's illness perceptions. Findings revealed that on the whole, indirect interventions were the most effective in improving psychological health. Most direct illness perception interventions were not effective in improving psychological health. Indirect interventions were more likely to be complex, comprising multiple facets which may have facilitated their efficacy. Interventions were more likely to be effective in improving psychological health if they were run as a group programme, did not attempt to directly modify illness perceptions, were delivered weekly over several weeks and included relaxation training. These findings are likely to be particularly useful in planning future research studies and guiding psychosocial interventions for this particularly vulnerable patient group.

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APPENDICES

Appendix I – Illness Perception Questionnaire – Revised (Moss-Morris *et al.,* 2002)

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

***Name*……** ***Date*……**

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom *since my illness*			**This symptom is *related t* *my illness***	
Pain	**Yes**	**No**	_____	**Yes**	**No**
Sore Throat	**Yes**	**No**	_____	**Yes**	**No**
Nausea	**Yes**	**No**	_____	**Yes**	**No**
Breathlessness	**Yes**	**No**	_____	**Yes**	**No**
Weight Loss	**Yes**	**No**	_____	**Yes**	**No**
Fatigue	**Yes**	**No**	_____	**Yes**	**No**
Stiff Joints	**Yes**	**No**	_____	**Yes**	**No**
Sore Eyes	**Yes**	**No**	_____	**Yes**	**No**
Wheeziness	**Yes**	**No**	_____	**Yes**	**No**
Headaches	**Yes**	**No**	_____	**Yes**	**No**
Upset Stomach	**Yes**	**No**	_____	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	_____	**Yes**	**No**
Dizziness	**Yes**	**No**	_____	**Yes**	**No**
Loss of Strength	**Yes**	**No**	_____	**Yes**	**No**

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					
IP7	My illness has major consequences on my life					
IP8	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17	My actions will have no effect on the outcome of my illness					
IP18	My illness will improve in time					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP19	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

CAUSES OF MY ILLNESS

We are interested in what <u>you</u> consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused **<u>YOUR illness</u>**. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____
2. _____
3. _____

Appendix II – Example search strategy for MEDLINE

MEDLINE was searched using the Ovid interface on 02/05/13 for the period 1996 to 2013 using the following search strategy;

1. Exp Cancer/
2. Exp Neoplasm$/
3. Cancer adj (skin or liver or breast or testicular or bowel or lung or anal or bile?duct or bladder or bone or brain or colon or rectal or eye or fallopian$ or gall?bladder or head or neck or kidney or larynx or lymph?node or ovarian or oesophag$ or pancrea$ or penis or prostate or small?bowel or stomach or thymus or thyroid or trachea or primary or vagina or secondary or vulva or womb or endometri$). ti,ab.
4. Malignan$. ti,ab.
5. Exp oncolog$/
6. Tumo?r. ti,ab.
7. Tumo?r adj (brain, endocrine, neuro?endocrine, spinal cord, secondary). ti,ab.
8. Exp sarcoma/
9. Exp carcinoma/
10. Leuk?emia. ti,ab.
11. Leukaemia adj (acute, chronic, lymphoblast$, myeloid). ti,ab.
12. Lymphoblast$. ti,ab.
13. Lymphoma. ti,ab.
14. Lymphoma adj (Hodgkin$, non?hodgkin). ti,ab.
15. Mesothelioma.ti,ab.
16. Myeloma. ti,ab.
17. Pseudomyxoma. ti,ab.
18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. Illness adj (perception$ or represent$ or cognition$)
20. “Illness Perception Questionnaire”
21. IPQ$
22. Self adj regulat$ adj (model or theory)
23. Exp attribution$/
24. Common adj sense adj (model or theory)

25. Causal adj attribution$
26. Illness adj coherence
27. Illness adj identity
28. Emotion$ adj represent$
29. Cognitive adj represent$
30. 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29
31. Exp distress/
32. Exp stress/
33. Exp well?being/
34. Exp adjust$/
35. Exp adaptation/
36. Exp recover$/
37. Exp emotion$/
38. Exp anxiety/
39. Exp depression
40. Exp mood/
41. Exp coping/
42. Exp worry/
43. Exp happiness/
44. Life adj satisfaction/
45. Exp "quality of life"/
46. Psycholog$ adj (distress or health or stress or well?being or function$ or adapt$ or adjust$ or recover$ or quality of life). ti,ab.
47. Emotion$ adj (distress or health or stress or well?being or function$ or adapt$ or adjust$ or recover$ or quality of life). ti,ab.
48. Mental adj (distress or health or stress or well?being or function$ or adapt$ or adjust$ or recover$ or quality of life). ti,ab.
49. (positive or negative) adj (mood or mental adj health or cognition$ or affect$)
50. (eudemonic or affective or evaluative) adj (wellbeing or well?being)
51. 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50
52. 18 and 30 and 51

Appendix III: Data extraction form for Review 1

General information

Date of data extraction:……..…..

Author(s) & citation:…….

Title:……..……..…

……

Study characteristics

Aim/objectives of the study:……..……..……....…...

.....

.....

Study design:

□ RCT □ Non-randomised controlled trial □ Cohort study □ Observation study

□ Case-control study □ Time-series □ Cross-sectional study □ Case series

□ Post-test case series □ Before/after study

Number of times of follow-up: .....

Length of follow-up: .....

Recruitment procedures used (e.g. details of randomization, blinding):

……..……..……

……

Consent rate:……....

Participant characteristics

Age (mean):……. Gender ratio:……...……..……..

Ethnicity:.....

Socioeconomic status:……..…….

Cancer type:….....….....……

Co-morbidities:……...……..

Time post diagnosis (mean & range):…….....……...……

Setting

Setting description(s):……..…….……..

……

……

Description of the control (if applicable):

.....…….**.....**……..

……

Number of participants enrolled:

Total:..... Experimental group:..... Control: .....

Number of participants lost to attrition, exclusion & follow-up:

Total: ..... Experimental group: ..... Control: .....

Measures used

Psychological health measures used:

.....

.....

Total number of psychological measures used: .....

Definition provided for:

□ All illness peerceptions measured □ Outcome measure 1 □ Outcome measure 2

□ Outcome measure 3 □ Outcome measure 4 □ Outcome measure 5

Illness perception measure used:

□ IPQ □ IPQ-R □ IPQ-B

Illness perception constructs measured:

□ Cause

□ Consequence

□ Illness Coherence

□ Identity

□ Timeline □ acute-chronic □ cyclical

□ Emotional representations

□ Cure/controllability □ Personal □ Treatment

Modifications to IPQ/IPQR:.....

.....

.....

.....

Results/analysis

Results reported for:

□ All illness perceptions measured

□ Outcome measure 1 □ Outcome measure 2 □ Outcome measure 3

□ Outcome measure 4 □ Outcome measure 5

Summary outcome data:

.....……..……..

……

……

……

……

Type of analysis used in study:

…….....……..……

…….……

……..

Authors conclusions:

Reviewers comments:

Appendix IV: Data extraction form for Review 2

General information

Date of data extraction:……..…..**.....**

Author(s) & citation:…….**.....**

Title:……..……..…

……

Study characteristics

Aim/objectives of the study:……..……..……....…...

.....

.....

Study design:

□ RCT □ Non-randomised controlled trial □ Cohort study □ Observation study

□ Case-control study □ Time-series □ Cross-sectional study □ Case series

□ Post-test case series □ Before/after study

Number of times of follow-up: **.....**

Length of follow-up: **.....**

Recruitment procedures used (e.g. details of randomization, blinding):

……..……..……

……

Consent rate:……....

Participant characteristics

Age (mean):……. Gender ratio:……...……..……..

Ethnicity:**.....**

Socioeconomic status:……..…….

Cancer type:….**.....**….**.....**……

Co-morbidities:……...……..

Time post diagnosis (mean & range):…….....……...……

Intervention & setting

Setting(s):……..…….……..

Description of the intervention & control (if applicable):

.....…….....……..

……

……

Description of co-interventions (if applicable):

.....…….……

……

……

Number of participants enrolled:

Total:..... Intervention:..... Control: .....

Number of participants lost to attrition, exclusion & follow-up:

Total: ..... Intervention: ..... Control: .....

Measures used

Psychological health measures used: …….....

……

Total number of psychological measures used: .....

Definition provided for:

□ All illness perceptions measured □ Outcome measure 1 □ Outcome measure 2

□ Outcome measure 3 □ Outcome measure 4 □ Outcome measure 5

Illness perception measure used:

□ IPQ □ IPQ-R □ IPQ-B □ Other: .....

Illness perception constructs measured:

□ Cause □ Consequence □ Illness Coherence □ Identity

□ Timeline □ acute-chronic □ cyclical

□ Emotional representations

□ Cure/controllability □ Personal □ Treatment

Modifications to IPQ/IPQR:.....

.....

.....

.....

Results/analysis

Results reported for:

□ All illness perceptions measured □ Outcome measure 1 □ Outcome measure 2

□ Outcome measure 3 □ Outcome measure 4 □ Outcome measure 5

Summary outcome data:

.....……..……..

……

……

……

……

Type of analysis used in study:

…….....……..……..……

…….……

……..

Authors conclusions:

Reviewers comments:

Appendix V – Study quality appraisal tool

	Criteria	Yes	No	Partly	NA
Overall	1.Based on theoretical framework				
	2.Well defined research question/hypotheses				
Methodological design	3.Appropriate methods used to answer research question				
	4.Appropriate recruitment procedure				
	5.Adequate sample size for statistical analysis				
	6.Measures taken to reduce bias (e.g. sampling methods, randomisation, blinding)				
	7.Equal group numbers				
	8.Groups well matched at baseline				
	9.Use of valid and reliable psychological health measures				
	10.Recommended use of psychological health measure(s)				
	11.Recommended use of illness perception measure				
	12.Acceptable internal consistency of measures				
	13.Adequate length of follow-up				
Results	14.Appropriate quantitative analysis to test hypothesis				
	15.Accurate interpretation of findings				
	16.Conclusions consistent with results				
	17.Findings generalizable				
Total					

Appendix VI – Reporting quality appraisal tool

	Criteria	Yes	No	Partly	NA
Quality of reporting	1.Clearly reported aims & objectives				
	2.Clear description of sample				
	3.Clear description of setting				
	4.Clear description of recruitment procedures				
	5.Clear description of intervention				
	6.Clear description of control group(s)				
	7.Clear definition of psychological health measure				
	8.Clear description of data collection				
	9.Reliability of administered measures reported				
	10.Clear description of data analysis conducted				
	11.Provision of attrition data				
	12.Strengths and limitations stated				
	13.Problems with study design reported				
	14.Confounding factors reported				
	15.Discussion of clinical relevance of findings				
	16.Recommendations for clinical practice discussed				
Total					

Appendix VII – Review 1: Complete study quality ratings

	Study	Criterion																	Total %[$]		
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Y	N	P	U
	1	Y	N	Y	P	U	NA	NA	NA	Y	Y	Y	U	Y	Y	Y	Y	P	64	7	15	14
	2	Y	Y	Y	Y	P	NA	NA	NA	Y	Y	P	P	Y	Y	Y	Y	P	71	0	29	0
	3	Y	Y	Y	Y	Y	NA	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	100	0	0	0
	4	Y	Y	Y	P	Y	NA	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	93	0	7	0
	5	Y	Y	Y	Y	Y	NA	NA	NA	Y	Y	Y	P	Y	Y	Y	Y	P	86	0	14	0
	6	Y	Y	Y	Y	N	NA	NA	NA	Y	Y	Y	U	Y	Y	Y	Y	P	79	7	7	7
	7	Y	N	Y	Y	Y	NA	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	P	86	7	7	0
	YES*	100	71	100	71	58	-	-	-	100	100	86	43	100	100	100	100	29				
Total %	NO^	0	29	0	0	14	-	-	-	0	0	0	0	0	0	0	0	0				
	PARTLY#	0	0	0	29	14	-	-	-	0	0	14	28	0	0	0	0	71				
	UNCLEAR>	0	0	0	0	14	-	-	-	0	0	0	28	0	0	0	0	0				

Q1 = based on theory; Q2 = well defined research question; Q3 = appropriate methods; Q4 = appropriate recruitment; Q5 = adequate sample for stats; Q6 = measures to reduce bias; Q7 = equal group numbers; Q8 = groups well matched; Q9 = valid & reliable psychological health measure; Q10 = recommended use of psychological health measure; Q11 = recommended use of illness perception measure; Q12 = acceptable internal consistency; Q13 = adequate length of follow up; Q14 = appropriate quantitative analysis for hypothesis; Q15 = accurate interpretation of findings; Q16 = conclusions consistent with findings; Q17 = generalizable findings; * Items were judged to be evident within the study; ^ Items were judged to be absent from the study; # Items were partly described in the study but more detail would be required to make a definitive 'yes' judgement; > insufficient information had been provided with which to make a definitive judgement; $Percentage calculated from applicable questions only

Appendix VIII – Review 1: Complete reporting quality ratings

	Study	Criterion																Total %[$]		
		18	**19**	**20**	**21**	**22**	**23**	**24**	**25**	**26**	**27**	**28**	**29**	**30**	**31**	**32**	**33**	**Y**	**N**	**P**
	1	P	P	Y	Y	NA	NA	Y	P	N	Y	P	Y	P	P	Y	Y	50	8	42
	2	Y	Y	Y	Y	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100	0	0
	3	Y	Y	Y	P	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	P	Y	86	0	14
	4	Y	Y	Y	N	NA	NA	Y	Y	Y	Y	N	Y	Y	P	Y	Y	79	14	7
	5	Y	Y	Y	P	NA	NA	Y	Y	Y	P	Y	Y	Y	Y	Y	Y	86	0	14
	6	Y	Y	Y	P	NA	NA	Y	P	N	Y	Y	P	Y	P	Y	Y	64	7	29
	7	P	Y	P	Y	NA	NA	Y	Y	Y	P	Y	Y	Y	Y	Y	N	71	8	21
Total %[$]	**YES***	71	86	86	43	-	-	100	72	72	72	72	86	86	57	86	100			
	NO^	0	0	0	14	-	-	0	0	28	0	14	0	0	0	0	0			
	PARTLY#	29	14	14	43	-	-	0	28	0	28	14	14	14	43	14	0			

Q1 = Clearly reported aims & objectives; Q2 = Clear description of sample; Q3 = Clear setting description; Q4 = Clear description of recruitment; Q5 = Clear description of intervention; Q6 = Clear description of control group(s); Q7 = Clear definition of psychological health measure; Q8 = Clear description of data collection; Q9 = Reliability of administered measures reported; Q10 = Clear description of data analysis; Q11 = Provision of attrition data; Q12 = Strengths and limitations discussed; Q13 = Problems with study design discussed; Q14 = Confounding factors reported; Q15 = Clinical relevance discussed; Q16 = Recommendations for clinical practice discussed; * Items were judged to be evident within the study; ^ Items were judged to be absent from the study; # Items were partly described in the study but more detail would be required to make a definitive 'yes' judgement; $Percentage calculated from applicable questions only

Appendix IX – Review 2: Complete study quality ratings

Study	Criterion																	Total %[$]			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	Y	N	P	U
8	Y	P	Y	Y	Y	Y	P	Y	Y	Y	P	P	N	Y	Y	Y	P	65	6	29	0
9	Y	N	Y	U	Y	Y	N	U	Y	Y	Y	U	Y	Y	Y	Y	P	65	12	6	17
10	Y	Y	Y	U	Y	N	NA	NA	Y	Y	Y	Y	Y	Y	Y	Y	P	80	7	7	7
11	Y	N	Y	Y	Y	U	N	Y	Y	U	U	U	P	Y	Y	Y	P	53	12	12	24
12	Y	Y	Y	U	Y	Y	Y	Y	Y	Y	P	U	P	Y	Y	Y	P	70	0	18	12
13	Y	Y	Y	Y	Y	P	Y	U	Y	Y	N	P	Y	Y	Y	Y	P	70	6	18	6
14	Y	Y	Y	Y	P	Y	Y	Y	Y	Y	NA	U	Y	Y	Y	Y	P	81	0	13	6
15	Y	Y	Y	Y	P	Y	Y	U	Y	Y	NA	U	P	Y	Y	Y	P	69	0	12	19
16	Y	P	Y	U	P	Y	Y	U	Y	Y	NA	Y	P	Y	Y	Y	Y	69	0	19	12
17	Y	N	Y	P	Y	U	U	Y	Y	Y	NA	U	P	Y	Y	Y	N	56	13	13	19
18	Y	N	Y	P	Y	U	U	U	Y	Y	NA	U	P	Y	Y	Y	N	50	13	13	25

	Study	Criterion																	Total %[$]			
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**Y**	**N**	**P**	**U**
	19	Y	N	Y	P	Y	U	NA	NA	Y	Y	NA	U	P	Y	Y	Y	N	57	14	14	14
	20	Y	N	Y	U	P	U	NA	NA	Y	U	NA	U	P	P	Y	Y	N	36	14	21	29
Total %[$]	**YES***	100	39	100	39	69	46	50	50	100	85	33	15	31	92	100	100	8				
	NO^	0	46	0	0	31	7	20	0	0	0	17	0	8	0	0	0	31				
	PARTLY[#]	0	15	0	23	0	7	10	0	0	0	33	15	61	8	0	0	61				
	UNCLEAR >	0	0	0	39	0	39	20	50	0	15	17	70	0	0	0	0	0				

Q1 = based on theory; Q2 = well defined research question; Q3 = appropriate methods; Q4 = appropriate recruitment; Q5 = adequate sample for stats; Q6 = measures to reduce bias; Q7 = equal group numbers; Q8 = groups well matched; Q9 = valid & reliable psychological health measure; Q10 = recommended use of psychological health measure; Q11 = recommended use of illness perception measure; Q12 = acceptable internal consistency; Q13 = adequate length of follow up; Q14 = appropriate quantitative analysis for hypothesis; Q15 = accurate interpretation of findings; Q16 = conclusions consistent with findings; Q17 = generalizable findings; * Items were judged to be evident within the study; ^ Items were judged to be absent from the study; # Items were partly described in the study but more detail would be required to make a definitive 'yes' judgement; > insufficient information had been provided with which to make a definitive judgement; $ Percentage calculated from applicable questions only

Appendix X – Review 2: Complete reporting quality ratings

Study	Criterion																Total %[$]		
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Y	N	P
8	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100	0	0
9	Y	Y	Y	Y	Y	Y	Y	P	N	Y	Y	Y	Y	Y	Y	N	81	13	6
10	Y	Y	N	Y	Y	NA	Y	Y	Y	Y	Y	Y	P	P	Y	Y	80	67	13
11	P	Y	N	Y	Y	N	N	Y	N	Y	Y	Y	Y	P	P	P	50	25	25
12	Y	Y	Y	Y	Y	Y	P	Y	N	Y	N	Y	Y	Y	Y	Y	81	13	6
13	Y	Y	P	Y	Y	Y	P	Y	Y	Y	Y	Y	Y	P	Y	N	75	6	19
14	Y	Y	Y	Y	N	P	Y	Y	N	Y	Y	N	P	N	Y	Y	63	25	12
15	Y	Y	Y	P	Y	P	Y	Y	N	Y	Y	Y	Y	N	Y	N	69	19	12
16	P	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	81	13	6
17	N	P	Y	Y	Y	N	Y	Y	N	P	P	P	P	N	Y	Y	44	25	31
18	N	P	Y	Y	Y	N	Y	Y	N	N	P	P	P	N	Y	Y	44	31	25

	Study	Criterion																Total %$		
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Y	N	P
	19	N	P	Y	Y	Y	NA	Y	Y	N	Y	Y	P	P	N	P	P	47	20	33
	20	N	P	P	N	Y	NA	N	N	N	Y	Y	Y	Y	N	Y	N	40	47	13
Total %$	YES*	54	69	69	84	92	40	69	84	31	84	77	69	62	31	77	54			
	NO^	31	0	15	8	8	40	15	8	69	8	8	8	0	46	8	31			
	PARTLY#	15	31	15	8	0	20	15	8	0	8	15	23	38	23	15	15			

Q1 = Clearly reported aims & objectives; Q2 = Clear description of sample; Q3 = Clear setting description; Q4 = Clear description of recruitment; Q5 = Clear description of intervention; Q6 = Clear description of control group(s); Q7 = Clear definition of psychological health measure; Q8 = Clear description of data collection; Q9 = Reliability of administered measures reported; Q10 = Clear description of data analysis; Q11 = Provision of attrition data; Q12 = Strengths and limitations discussed; Q13 = Problems with study design discussed; Q14 = Confounding factors reported; Q15 = Clinical relevance discussed; Q16 = Recommendations for clinical practice discussed; * Items were judged to be evident within the study; ^ Items were judged to be absent from the study; # Items were partly described in the study but more detail would be required to make a definitive 'yes' judgement; $Percentage calculated from applicable questions only