

THE UNIVERSITY OF HULL

The Role of Perceived Control in the Perception of
Breathlessness Severity in Heart Failure

being a Thesis submitted for the Degree of
Doctor of Clinical Psychology
at The University of Hull

by

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To the Clin Psych Massive, Class of 2011, thanks for keeping it foolish.

Finally, I would like to give love and special thanks to Carly, for keeping my head up and my feet moving forward.

Overview

This portfolio thesis is comprised of three parts; a systematic literature review, an empirical study and a set of appendices.

Part one is a systematic literature review of empirical papers examining the relationship between coping and outcomes of psychological wellbeing in heart failure. The review commences with an overview of literature relating to coping in health populations and psychological wellbeing, and a description of the rationale for the review. The systematic methodology used to identify and appraise relevant literature is described, as are the synthesised findings of the reviewed studies in relation to coping and the chosen domains of psychological wellbeing. These findings are discussed in relation to conceptual issues related to coping as a dimension, and how it is measured. The paper concludes with limitations of the review, suggestions for future research, clinical implications and a conclusion.

Part two is an empirical paper examining the role of health-related perceived control in the perception of breathlessness severity and distress for heart failure patients. An overview of the relevant literature, the rationale for the study, research questions and hypotheses are discussed. The paper describes the relevant aspects of the methodology including the study design, procedure, details of self-report measures, and the chosen approach to statistical analysis. Hypotheses of relationships between the main study variables based on previous research findings, and a recent model of distress in heart failure are tested using partial correlation analyses. Findings are discussed in relation to clinical implications, further research and study limitations.

Part Three comprises the appendices (including additional information and materials pertaining to the literature review and empirical paper), and a reflective statement documenting the journey taken through the research process.

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Word Counts

Systematic Review (excluding abstract, tables and references) **11497 words**

Empirical Paper (excluding tables and references) **5597 words**

Part One: Systematic Literature Review

The Relationship between Coping and Psychological Outcomes in Heart Failure:

A Systematic Review

**The Relationship between Coping and Psychological Outcomes in
Heart Failure: A Systematic Review**

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Abstract¹

Coping is acknowledged to be an important factor in the process of adjustment to illness, and which has consistently been related to outcomes in chronic health conditions such as heart failure (HF). Despite this, to date coping has been poorly conceptualised which has limited the clarity and usefulness of research findings. A systematic review was conducted to examine the relationship between ways of coping, and dimensions of psychological wellbeing as important health outcomes in the HF population. Electronic databases (CINAHL, Medline, PsychINFO, Scopus and Web of Science) were searched and articles selected based on systematic search, inclusion and exclusion criteria. Sixteen studies were included in the review utilising a variety of designs and measures. Study findings suggested that coping by ignoring, minimising or denying HF is related to poorer outcomes of psychological wellbeing. However, more illness focused ways of coping did not consistently relate to better outcomes. Consistent with research in other populations, the conceptualisation of coping in the reviewed studies was inconsistent. It is argued that coping should be considered within a wider framework of transition and adjustment to more meaningfully examine HF patients' experience following diagnosis and inform more appropriate psychological support strategies.

Keywords: *heart failure; coping; depression; quality of life;*

¹ Guidelines: One paragraph with no headings. 200 words or less (Word count: 195 words)

Introduction

Heart failure (HF) is a condition which is characterised by a distinct reduction in cardiac output due to physical damage or overactivity of the heart and is associated with a number of problematic symptoms including breathlessness, fatigue and swelling in the feet and ankles due to fluid retention (Scarborough et al, 2010). Like all chronic health conditions which impose significant limitations on physical functioning, HF significantly impacts on quality of life for patients (Hobbs et al, 2002).

HF is an important condition to consider due to its high prevalence, debilitating symptoms, high mortality and cost to health services. The prevalence of HF in the UK has been reported to represent 2% of the population, with an additional estimated 63,000 new cases each year (Scarborough et al, 2010). In the US, statistics indicate approximately six million individuals have a diagnosis of HF, with an estimated cost of over \$39 billion (Roger et al, 2011). Hospital burden is high, with up to 40% of patients being re-hospitalised within six months of an initial admission due to a cardiac event (Krumholz et al, 2002). Furthermore, the one year mortality rate is extremely high (one in five patients; Roger et al, 2011), and recently mortality rates have been suggested to strongly underestimate the number of deaths associated with HF (Engelfreit, Hoogenveen, Boshuizen & van Baal, 2011).

Furthermore, HF is highly comorbid with clinical distress. The prevalence of depression in HF is 15-36%, higher than the lifetime prevalence of major depression in the general population (Havranek, Ware & Lowes, 1999), and anxiety is also highly prevalent with 29-45% of HF patients experiencing anxiety (Jiang et al, 2004). This is particularly significant as depression has been associated with reduced quality of life, health decline, hospitalisation and death in HF (Havranek et al, 1999).

The Crisis Theory by Moos (Moos & Holahan, 2007; Appendix 3) formulates that health related outcomes such as quality of life and mood are influenced by the

psychosocial factor of coping in relation to adjustment² to illness. Indeed, evidence from research in other illness populations such as breast cancer and HIV/AIDS suggest that coping may significantly account for the development of negative mood states such as anxiety and depression (Carver et al, 1993; Stanton & Snider, 1993; Pakenham & Rinaldis, 2001). Coping has been defined as the ‘cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’ (Lazarus & Folkman, 1984 p.141). The research focusing on coping in relation to stress is extremely diverse in terms of theoretical conceptualisation, models and measures (Livneh, 1999). For example, coping has been theoretically formulated using trait models (McCrae & Costa, 1986), state models (Lazarus, 1993) and dimensional models (Carver & Scheier, 1981), and there are numerous widely used measures based on these different models. Trait models of coping originated from the psychoanalytic interest in defence mechanisms. These Freud inspired models suggest coping is a style and a stable fixed element of personality (McCrae & Costa, 1986).

Alternatively, state models of coping suggest coping strategies used by individuals in stressful situations change over time and are based on context. It is suggested coping strategies are not inherently positive or negative, but that the coping outcome is independent to the coping process and based on other factors, such as the appraisal of the stressor and the endurance of the stressor (Lazarus & Folkman, 1984). Folkman and Lazarus (1980) made a distinction between problem-focused coping, which is utilised when practical actions or strategies may be engaged in to reduce the impact of the stressor, and emotion-focused coping which involves focusing on management of the negative affect experienced when stress is enduring or chronic.

² Adjustment is defined as the functional and dynamic psychosocial response to a stressor such as a health condition, over time (Sharpe & Curran, 2006).

Finally, dimensional models of coping suggested from the development of self report measures such as the COPE³ (Carver, Scheier & Weintraub, 1989) have offered practically infinite ways of categorising coping. Factor analysis (FA) and Principle Component Analysis (PCA) methods have been widely used by researchers in order to formulate what scale items may relate to each other as independent categories of coping.

However, these different approaches to conceptualising and measuring coping has lead to a significant lack of consensus in the literature over how to categorise different ways of coping (Skinner, Edge, Altman & Sherwood, 2003). Skinner and colleagues (2003) found over 100 different coping category systems in the literature, with over 400 different individually labelled ways of coping. They argued that a hierarchical model of coping is required, with a distinction between lower order categories and higher order categories. Lower order categories are defined by clear, mutually exclusive and specific instances of coping behaviour, such as substance misuse, or denial of the health condition. On the other hand, higher order categories are super-ordinate categories of lower order coping arranged according to their adaptive functions, such as avoidant coping, which may contain several lower order categories such as mental disengagement, behavioural disengagement and denial (Skinner et al, 2003). Traditionally, there has been some confusion in the literature, with studies often not acknowledging these different levels and considering lower and higher order coping categories together. Furthermore, the ways in which higher order categories have been formulated have been inconsistent, as either based on the functions of coping, the topographical features, or the action type (Skinner et al, 2003). For example, problem-focused and emotion-focused coping, as already described (Folkman & Lazarus, 1980) are functional higher order coping categories, but several criticisms of these categories can be made. Firstly, it is argued there is no clear sense which lower order categories

³ A self-report measure of coping widely used in health research (described in Table 2)

should be included in either category. Secondly, the categories do not sufficiently cover all lower order categories. And thirdly, the two categories are not mutually exclusive as most ways of coping can serve either function and could be included in either category (Skinner et al, 2003). Similar critiques have been produced for other commonly used coping category dyads. These include adaptive versus maladaptive coping, in which coping approaches are considered inherently positive or negative in relation to a stressor and the experienced outcomes of the coping approach (Skinner et al, 2003), and active versus disengagement/avoidance coping (topological higher order categories), in which active coping refers to efforts made to practically address the stressor directly, and disengagement coping refers to attempts to avoid, deny, distract from and defend against the effects of the stressor or the emotional impact of the stressor (Livneh, 1999).

Considering the diffuse and confusing nature of the literature on coping, the significance of the effect of coping on mood and quality of life in HF, and the impact of these psychological wellbeing outcomes on illness trajectory and mortality, there is a clear rationale for a systematic narrative review. A previous review explored the relationship between coping and depression in HF (Allman, Berry & Nasir, 2009). However, due to the narrow inclusion criteria this review only included six studies and did not consider the relationships between coping and mood states other than depression, or health-related quality of life, all of which are widely used clinical outcomes in health settings (Moser, 2002). Furthermore, in the time since the review, further studies have been published with additional findings, which justify a more comprehensive review of this literature.

Therefore, the aim of the current review was to systematically examine published literature which has explored the relationship between coping, and outcomes of psychological wellbeing including mood and quality of life in a HF population. To meet this aim, the review questions were: (1) what models and categories of coping

have been applied to the HF population? (2) what relationships have been found between coping and outcomes of psychological wellbeing (mood and quality of life) in a HF population? (3) what are the themes of coping reported by HF patients and how do these relate to their psychological wellbeing?

Method

A systematic literature search was conducted using the electronic databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsycINFO, Scopus and Web of Science. These databases were selected in order to comprehensively search across both psychological and medical research domains.

Search terms:

“Heart failure” AND Cop* OR “dealing with illness” AND “quality of life” OR well-being OR emotion* OR psycho* OR distress OR affect OR depress* OR mood OR anxi*

Inclusion Criteria:

Research deemed eligible for inclusion in the review were required to:

- Use either a quantitative or qualitative methodology.
- Include only adult participants with a diagnosis of heart failure.
- Include measures of coping and psychological well-being in the form of affect or quality of life.
- Be published in a peer reviewed journal, before 13th March 2011. No initial publishing date restriction was chosen, due to the long history of research focussed on coping (Lazarus, 1993).

Exclusion Criteria:

Research was excluded from the review in cases where the research:

- Used a single case design
- Used participants with forms of cardiac disease other than heart failure

- Was not published in the English language
- Was not available from the British Library

Research Selection:

The titles of all research articles identified by the search terms were reviewed and those not meeting the inclusion criteria were dismissed. Additional articles were sourced from hand searching the references of the included articles. The full texts of the included articles were then reviewed against the inclusion and exclusion criteria.

Assessment of Quality:

The quality of each article employing a quantitative methodology was assessed using a customised checklist (Appendix 4.1) based on items from checklists developed by Downs and Black (1998), CONSORT (2010) and the National Institute of Clinical Excellence (2007). Existing checklists are predominantly used for assessing the quality of intervention studies and randomised controlled trials, therefore necessitating some adaptations for use with cross-sectional and non-intervention studies. Quality scores for quantitative studies were calculated using scores of one or zero for each checklist criterion, providing a total score out of 16 with a higher score indicating greater quality. The quality of studies employing qualitative methodology were assessed using the qualitative study methodology checklist produced by the National Institute for Health and Clinical Excellence (NICE, 2007; Appendix 4.2). Quality scores for qualitative studies were calculated using positive and negative symbols for each checklist criterion, with the predominant number of symbols indicating the overall quality of either very good (++), good (+) or poor (-). The quality of each study with either methodological approach was rated by two researchers for assessment of inter-rater reliability.

Data Extraction:

Data was extracted from each article using a pro forma (Appendix 5) based on a series of criteria regarding the reporting of specific research processes.

Data Analysis:

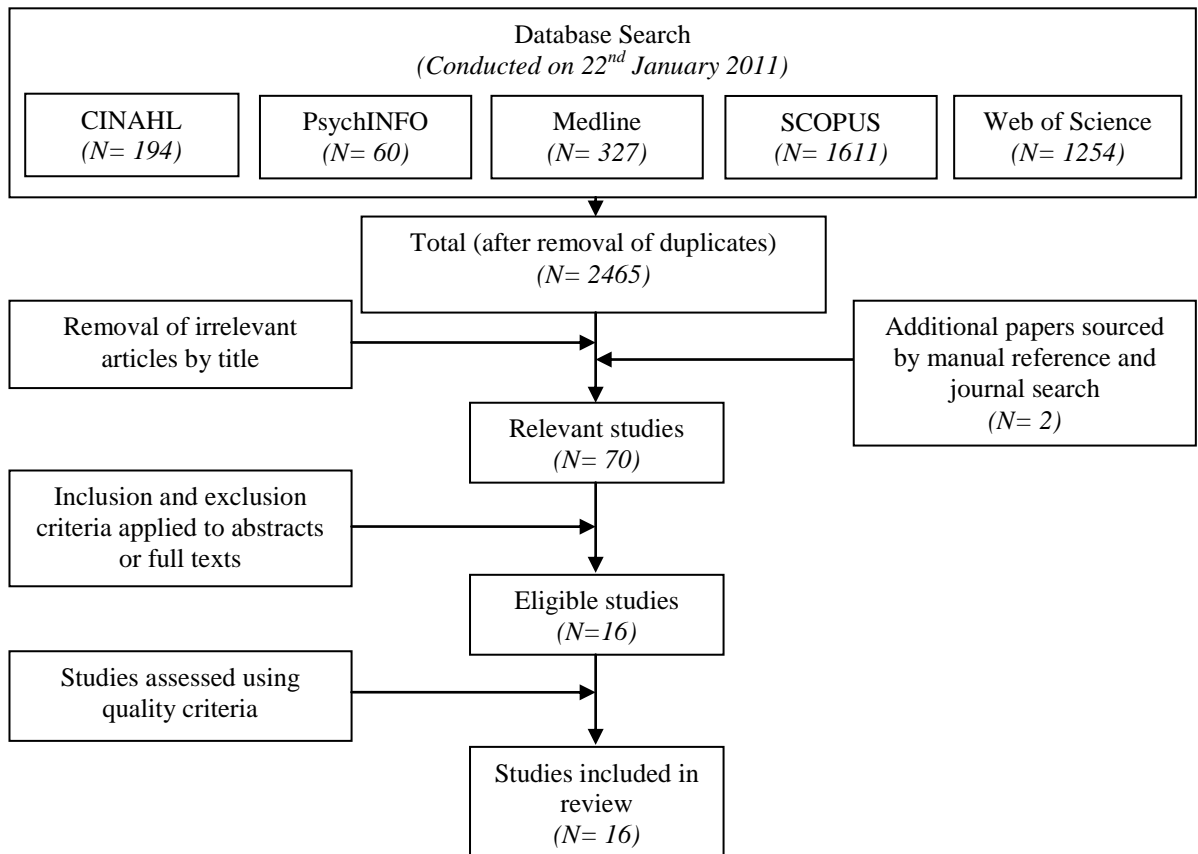
Extracted data from the reviewed studies were analysed using a narrative approach as opposed to a quantitative approach such as meta-analysis. This was due to the inclusion of studies utilising both a quantitative and qualitative methodology. Furthermore, studies utilised a variety of populations and inclusion and exclusion criteria, making direct quantitative comparisons impractical. However, quantitative data such as demographic details of participants and participant numbers were examined in relation to population statistics to indicate the generalisability of study findings.

Results

Article Selection:

Figure 1 describes the article selection strategy. Of the 2465 articles identified from the initial database searches, 2405 were excluded due to lack of relevance based on the article titles. Two further articles were identified by searching through remaining article reference sections and hand searching relevant journals. Following exclusion of studies based on availability and stated inclusion and exclusion criteria, 16 studies were included in the final review (references for excluded studies are recorded in Appendix 6).

Figure 1: Systematic Selection Strategy



Summaries of data extracted from the included research articles are provided in Tables 1 and 5. Thirteen studies utilised a quantitative methodology, and three studies employed a qualitative approach; these studies have been considered separately.

Quantitative studies:

Quality:

Included studies were of reasonable quality according to the specific quality assessment tool (Appendix 4.1), with each scoring between 10 and 15 of a maximum 16 points. All studies were included in the review regardless of quality. However, a theme in the quality assessment of the studies was a lack of explanation regarding how categories of ways of coping were chosen. An independent reviewer also rated a sample of six of the included articles to examine reliability of ratings. Kappa for the agreement

between the two raters had a mean value of 0.77 (SD= 0.26) which showed strong agreement (Landis & Koch (1977)).

Participants:

Of the thirteen studies using quantitative methodology included in the review, two studies shared the same original sample (Park, Fenster, Suresh & Bliss, 2006; Park, Malone, Suresh, Bliss & Rosen, 2008), but examined different findings which were both relevant to the review.

- *Sample size:*

Study sample sizes ranged from 35 (Jackson & Emery, 2011) to 291 (Scherer et al, 2007), with a mean sample size of 121.08 (SD= 74.60). This suggested good statistical power in the majority of studies, but with one exception, as declared by the study authors (Jackson & Emery, 2011).

- *Age:*

In two studies, only participants over the age of 60 were eligible for inclusion in the study (Paukert, Le Maire & Cully, 2009; Klein, Turvey & Pies, 2007) and in one study sample only participants over the age of 40 were eligible to participate (Park et al 2006; Park et al, 2008). The remaining studies included HF patients over the age of 18. All included study participant samples ranged in mean age from 48.6 (Hallas, Wray, Andreou & Banner, 2011) to 72.5 (Scherer et al, 2007) with a mean age across all studies of 63.37. Statistics indicate that heart failure is most prevalent in adults over the age of 75 in both the UK (BHF, 2010) and the US (Lloyd-Jones et al, 2009) which may indicate a general age mean discrepancy between study samples and the general HF population.

- *Gender:*

One of the studies (Jackson & Emery, 2011) included a sample of exclusively female HF patients. The remaining studies included male and female samples, with a

generally higher percentage of male participants to female participants. There is a distinctly higher prevalence of males with HF than females in the population (BHF, 2010) and the study samples predominantly reflect this.

- *Ethnicity:*

The ethnicity of participants was not reported in four studies (Carels, 2004; Murberg, Bru & Stephens, 2002; Nahlén & Saboonchi 2010; Scherer et al, 2007). In the remaining studies, the ethnicity of participants were categorised into Caucasian/White, African American, Hispanic and Other. In all but one of these studies, Caucasian participants contributed to over 50% of each total sample, with one study including 99% Caucasian participants (Klein et al, 2007). The study sample examined by Bean, Gibson, Flattery, Duncan and Hess (2009) was unique in that it included a sample comprising of approximately equal Caucasian and African American participants with some additional Hispanic participants. In the general population in the United States (the location where the majority of studies were carried out), HF is distinctly more prevalent in African American and Hispanic populations, related to hypertension and diabetes (Lloyd-Jones et al, 2009), but this prevalence is not reflected in the reviewed studies.

Table 1: Data from the quantitative studies included in the review.

Study #	Author/ Pub Date/ Country	Study Desig n	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well-being Outcomes and Measures Used	Findings	Quality Score (/16)
1	Bean, Gibson, Flattery, Duncan & Hess (2009) USA	C-S	93.5% completed the study	N= 100 Age= 53.0 (14.0) 67% male, 33% female 49.5% African-American, 47.4% Caucasian, 3.1% Hispanic	I & II= 53 III & IV= 44	Two factor model. Brief COPE	Depression and anxiety: HADS	Depression scores on the HADS associated with and predicted by an avoidant coping among other factors including social support and meaning in life. Anxiety associated with approach coping style in Caucasian participants only.	14
2	Carels (2004) USA	L	95.1% provided required data	N= 58 Age= 67.7 (11.8) 57% male, 43% female Ethnicity not reported	I= 2 II= 30 III= 23 IV= 3	Four factor model. Conceptualised as part of QoL. Brief COPE	Depression: BDI	Action/ acceptance coping scores on the brief COPE were significantly associated with lower BDI scores. Depressed HF patients reported significantly less action/ acceptance coping such as trying to accept their illness or taking action to make their symptoms better, than non-depressed patients.	13

Study #	Author/ Pub Date/ Country	Study Design	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well-being Outcomes and Measures Used	Findings	Quality Score (/16)
3	Doering et al (2004) USA	C-S	100%	N= 84 Age= 54.1 (10.8) 70.2% male, 29.8% female 70.2% Caucasian, 9.5% Hispanic, 8.3% African-American, 4.8% Other	I= 2 II= 18 III= 41 IV= 23	Three factor model. Dealing with Illness Checklist	Mood states: Profile of Mood States	Active behavioural coping style associated with lower fatigue and higher vigour scores on the Profile of Mood States. Avoidance coping associated with significantly higher anxiety, anger, depression, confusion and fatigue scores.	14
4	Hallas, Wray, Andreou & Banner (2011) UK	C-S	51% agreed to participate	N= 146 Age= 48.6 (9.45) 82.2% male, 17.8% female 88% Caucasian	Not stated	Focus on negative coping styles as results of illness perceptions. No model stated. COPE	Depression and anxiety: HADS	Depressed patients and anxious patients showed significantly greater maladaptive coping styles including denial, behavioural disengagement and venting emotions coping compared to non-depressed and non-anxious patients. Coping did not predict depression scores, but venting of emotions coping predicted the greatest variance in anxiety scores.	12

Study #	Author/ Pub Date/ Country	Study Design	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well-being Outcomes and Measures Used	Findings	Quality Score (/16)
5	Jackson & Emery (2011) USA	C-S	Not reported	N= 35 Age= 55.7 (14.5) 100% female, 0% male 60% Caucasian, 40% African-American	Not stated	Maladaptive coping/emotional expression. Three factors: AES, TAS-20, EEQ	Emotional QoL: CES-D, STAI Physical QoL: MLWHFQ & SF-36	Depressive symptoms were positively associated with anger-in and alexithymia, and negatively correlated with emotional expression. Anxiety symptoms were positively associated with anger in and alexithymia and negatively associated with emotional expression.	10
6	Klein, Turvey & Pies (2007) USA	C-S	49% of approached participated, then reduced by exclusion criteria	N= 80 Age= 69 (7) 48% male, 52% female 99% White	I= 4 II= 28 III= 47 IV= 1	Active and passive coping. Adaptive and maladaptive coping. Multidimensional. Brief COPE	QoL: KCCQ Depression: GDS	Adaptive coping not associated with outcome variables. Maladaptive coping (self distraction, denial, behavioural disengagement, venting and self blame) negatively associated with quality of life and depression. Denial strongly associated with lower quality of life and higher depression scores. Self distraction negatively associated with quality of life but not depression. Self-blame associated with lower quality of life and higher depression scores.	13

Study #	Author/ Pub Date/ Country	Study Design	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well-being Outcomes and Measures Used	Findings	Quality Score (/16)
7	Murberg, Bru & Stephens (2002) Norway	L (2 years)	60.29% agreed to participate from postal invitation.	N= 119 (T1) N= 83 (T2) Age= 67.5 (9.5) 51.5% male, 48.5% female	I= 2 II= 51 III= 29 IV= 1	Testing of trait model of coping styles against personality. COPE (Dispositional)	Depression: Zung SDS	Emotional support, restraint coping and mental disengagement poorly associated with depression. Behavioural disengagement strongly associated with depression. When demographics controlled, significant positive association between emotional support & mental and behavioural disengagement and depression. Coping accounted for 9.3% of variance of depression when personality controlled.	14
8	Nahlén & Saboonchi (2010) Sweden	C-S	85.1% completed all required data	N= 80 Age= 72.1 (10.5) 72.5% male, 27.5% female Ethnicity not reported	I= 0 II= 39 III= 39 IV= 2	Crisis Theory (Moos & Holahan, 2007) and state model of coping. Four factor model. Brief COPE	Positive and Negative Affect: PANAS	Active coping, positive reframing and emotional support correlated significantly with positive affect. Venting, behavioural disengagement, substance use and self-blame correlated significantly with negative affect. Problem focused coping significantly predicted positive affect but the total explained variance was 14%. Avoidant coping and socially supported coping significantly predicted negative affect and accounted for 31% of the total variance.	15

Study #	Author/ Pub Date/ Country	Study Design	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well-being Outcomes and Measures Used	Findings	Quality Score (/16)
9	Park, Fenster, Suresh & Bliss (2006) USA	L	81% (12% lost at follow-up and 7% died before T2)	N= 202 (T1) N= 163 (T2) Age= 65.2 (10.0) 95% male, 5% female 67.5% Caucasian, 30% African-American, 2.5% Hispanic/Other	Mean= 1.9 (SD= 0.7)	Four factor model (described by Carver et al, 1989). COPE	Depressed mood: CES-D	Percentage of active coping employed was prospectively associated with lower levels of depression. However, T1 active coping did not prospectively predict T2 depression. Coping which occurred between T1 and T2 was predictive of subsequent adjustment, but coping prior to T1 was not. Coping did not mediate the effect of social support and appraisals on depression, but exerted an independent effect.	14
10	Park, Malone, Suresh, Bliss & Rosen (2008) USA	L	Same sample and participant characteristics as Park et al (2006)			Five factor model (same as #6 with extra religious coping factor) COPE	Health Related QoL: SF-36	Disengagement and seeking social support associated with poorer HRQOL. No coping styles related to higher levels of HRQOL. Acceptance/positive reinterpretation and religious coping associated with increased life meaning at T2 and life meaning related to HRQOL so speculated a small indirect effect of coping on HRQOL via meaning in life.	14

Study #	Author/ Pub Date/ Country	Study Desig n	Response Rate	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping Model/ Measures Used	Psychological Well- being Outcomes and Measures Used	Findings	Quality Score (/16)
11	Paukert, Le Maire & Cully (2009) USA	C-S	81.9% provided required data	N= 104 Age= 71.7 (7.7) 99% male, 1% female 72% Caucasian, 17% African-American, 8% Hispanic	Not reported	Three factor model based on factor analysis Brief COPE	Depression: GDS Anxiety: GAI	Depressive symptoms were significantly associated with maladaptive coping. No predictive value of coping on depressive symptoms independent of the influence of other bivariate factors such as self efficacy. Coping was only generally associated with depressive symptoms.	15
12	Scherer et al (2007) Germany	L	33.2% met criteria. 19.8% drop out.	N= 363 (T1) N= 291 (T2) Age= 72.5 (9.2) 53.3% female, Ethnicity not reported	Total sample not recorded	Five factor model of coping. FKV	Depression and Anxiety: HADS	No predictive value of coping on experience of distress. Backwards elimination from logistic regression based on significance criterion.	13
13	Trivedi et al. (2009) USA	C-S	Not reported	N= 229 Age= 57.3 (12.5) 67% male, 33% female 49% White	I= 7 II= 130 III= 88 IV= 7	Multidimension al state model of coping. COPE	Depression: BDI	Increased depressive symptoms were associated with more avoidant coping styles. Higher BDI scores were associated with lower scores on acceptance, humour, planning, seeking emotional support and mental disengagement, and higher scores on behavioural disengagement, denial and venting.	14

Study Design: C-S: Cross-sectional; L: Longitudinal; T1= Time point 1, T2= Time point 2

NYHA Class: New York Heart Association Functional Classification. QoL: Quality of Life

Questionnaire Measures: AES, Anger Expression Scale; TAS-20, Toronto Alexithymia Scale; EEQ, Emotional Expressiveness Questionnaire; HADS, Hospital Anxiety and Depression Scale; BDI, Beck Depression Inventory; CES-D, The Centre for Epidemiological Studies Depression Inventory; STAI, State-Trait Anxiety Inventory (STAI); MLWHFQ, Minnesota Living With Heart Failure Questionnaire; KCCQ, Kansas City Cardiomyopathy Questionnaire; GAI, Geriatric Anxiety Inventory; GDS, Geriatric Depression Scale; Zung SDS, Zung Self-rating Depression Scale; FKV, Freiburg questionnaire for coping with illness; SF-36, Medical Outcomes Study Short Form

Health Status:

Studies varied considerably in the extent to which the HF diagnosis of study participants was established and defined. Two studies only reported that some documented evidence of a diagnosis of HF were present in the patients' notes, but no further details were reported (Bean et al, 2009; Paukert et al, 2009). In the remaining studies, left ventricular ejection fraction (LVEF), a key diagnostic indicator of heart failure (<40%; Zile, 2003) was discussed, and in several studies participants' LVEF were reported (Carels, 2004; Doering et al, 2004; Park et al, 2006; Park et al, 2008; Trivedi et al, 2009; Nahlén & Saboonchi, 2010; Jackson & Emery, 2011).

There was also considerable variability in health related inclusion and exclusion criteria. The majority of studies reported exclusion of patients based on cognitive impairment or dementia, with only two study samples not reporting this (Park et al, 2006; Park et al, 2008; Hallas et al, 2011). Four studies excluded patients with serious or life threatening comorbid physical illness (Scherer et al, 2007; Nalen & Saboonchi, 2010; Doering et al, 2004; Carels, 2004). Two studies included patients with comorbid health problems such as diabetes and asthma, but recorded these (Hallas et al, 2011; Jackson & Emery, 2011). Physical health comorbidity was not excluded or reported in five participant samples (Paukert et al, 2009; Klein et al, 2007; Park et al, 2006; Park et al, 2008; Murberg et al, 2002; Bean et al, 2009). Five studies excluded participants based on heart specific health characteristics such as duration since myocardial infarction or heart transplantation (Paukert et al, 2009; Trivedi et al, 2009; Nahlén & Saboonchi, 2010; Murberg et al, 2002; Carels et al, 2004), and two studies reported patients with pacemakers or pacemaker dependency as an exclusion criteria (Trivedi et al, 2009; Carels, 2004). Substance use and thought disorders were exclusion criteria in two studies (Paukert et al, 2009; Carels, 2004).

Furthermore, with regards to functional severity of heart failure, New York Heart Association (NYHA) functional classifications⁴ were reported in all but four studies (Hallas, 2011; Jackson & Emery, 2011; Paukert et al, 2009; Scherer et al, 2009). In the studies where NYHA Classification was reported, Classifications of II and III were most prevalent among participants.

Coping Measures:

Studies employed a variety of different self-report scales to measure coping (Table 2), with each scale including different subscales which are reported to indicate different coping styles or ways of coping. Literature on the two most prevalently used scales, the COPE (Carver, Scheier & Weintraub, 1989) and the brief COPE (Carver, 1997) offer techniques for reducing the number of subscales and items using Principle Component Analysis (PCA) and Factor Analysis (FA) as previously discussed. These techniques were used in three studies using the COPE (Park et al, 2006; Park et al, 2008; Nahlén & Saboonchi, 2006) and three studies using the brief COPE (Paukert et al, 2009; Bean et al, 2009; Carels, 2004). Three studies using the COPE (Hallas et al, 2011; Trivedi et al, 2009; Murberg et al, 2002) and one study using the brief COPE (Klein et al, 2007) did not use this technique, instead using the full measure or selected subscales. Three studies used alternative measures. Doering and colleagues (2004) used the Dealing with Illness Checklist (Namir et al, 1987), Jackson and Emery (2011) used the AES (Spielberger et al, 1985), TAS-20 (Bagby et al, 1994) and EEQ (King & Emmons, 1990), and Scherer and colleagues (2007) used the FKV (Muthny, 1989). See Table 2 for descriptions of the scales used in the reviewed studies.

⁴ NYHA Classification is described in Appendix 10

Table 2: Measures of coping used in the reviewed studies

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
COPE (Carver, Scheier & Weintraub, 1989)	60 item self-report questionnaire with 15 subscales measuring a wide range of coping dimensions. Conceptualised to broadly measure dimensions of three distinct coping style domains of problem-focused (active coping, suppression of competing activities, restraint coping, seeking social support for instrumental reasons), emotion-focused (positive reframing, acceptance, seeking social support for emotional reasons) and maladaptive coping styles (venting of emotions, denial, behavioural disengagement, mental disengagement), although the subscale dimension of 'turning to religion' is considered miscellaneous to these domains.	Hallas et al, 2011	Full scale used, only maladaptive coping subscales reported in results.	Subscales ranged from 0.84 to 0.91
		Murberg, Bru & Stephens, 2002	Dispositional version of 13 subscales of COPE used at T1. 7 subscales used at T2: active coping, use of instrumental support, positive reframing, acceptance, denial, mental disengagement, behavioural disengagement.	Not reported
		Park et al, 2006 & Park et al, 2008	Principle components analysis (PCA) used to reduce COPE to five factors (active coping, disengagement, seeking social support, acceptance/ positive reinterpretation, and religious coping).	Subscales ranged from 0.66 to 0.91
		Trivedi et al, 2009	Full 15 subscale COPE administered	All but one subscales 0.60 and greater (mental disengagement= 0.45)
Brief COPE (Carver, 1997)	A brief form of the original COPE measure (28 items). Removal of the suppression of competing activities and restraint coping subscales, and reduces each subscale to two items. Addition of subscale of self-blame, which described as an additional dimension of maladaptive coping (14 subscales).	Bean et al, 2009	PCA used to reduce number of coping items. Two factors retained: approach coping (use of religion, emotional support, instrumental support, planning, positive reframing, active coping and acceptance) and avoidant coping (self-blame, behavioural disengagement, venting, denial, use of humour, substance use and self distraction).	Avoidant coping= 0.72 Approach coping= 0.81

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
		Carels, 2004	Acceptance, active coping, mental disengagement and instrumental support subscales of brief COPE chosen based on previous research findings of association with depression and mortality in heart failure. Two additional items added by authors for "symptom related coping"	Not reported
		Klein, Turvey & Pies, 2007	Full Brief COPE used	Not reported
		Nahlén & Saboonchi, 2010	Full Brief COPE used	Not reported
		Paukert, Le Maire & Cully, 2009	PCA conducted and a three factor model of adaptive coping (active coping, planning, positive reframing, instrumental support, emotional support, self distraction and acceptance), maladaptive coping (behavioural disengagement, self-blame, denial and venting) and religion and substance use.	Adaptive coping= 0.92 Maladaptive coping= 0.80 Religion and substance use= 0.60
Dealing with Illness Checklist (Namir, Wolcott, Fwzy & Alumburgh, 1987)	50 item self-report measure which examines the use of three different coping styles: active behavioural (AB), active cognitive (AC), and avoidance coping (AV).	Doering et al, 2004	All three subscales used (full scale)	AB= 0.76 AC= 0.80 AV= 0.64

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
Anger Expression Scale (AES; Spielberger et al, 1985)	24 item self-report measure which measures tendencies to withhold or express anger, using two subscales of anger-in (withholding) and anger-out (external expression).	Jackson & Emery, 2011	Only the Anger-in subscale used	Anger-in subscale= 0.71
Toronto Alexithymia Scale (TAS-20; Bagby, Parker & Taylor, 1994)	20 item self-report questionnaire which measures self-expression and interpretation of emotions. Includes two subscales: difficulty identifying feelings (DIF) and difficulty describing feelings (DDF).	Jackson & Emery, 2011	Use of full scale score and both subtest scores	Full scale= 0.81 DIF= 0.78 DDF= 0.71
Emotional Expressiveness Questionnaire (EEQ; King & Emmons, 1990)	16 item self-report questionnaire which measures emotional expressiveness on three subscales of Positive Emotion, Negative Emotion and Intimacy.	Jackson & Emery, 2011	Scale used in full with no use of subscales	Full scale= 0.82
Freiburg Disease Coping Questionnaire (FKV; Muthny, 1989)	Self report questionnaire with five subscales each measuring a different coping dimension: depressive coping, active problem-focused coping, distraction and self-encouragement, religious faith and search for meaning, and minimisation and wishful thinking.	Scherer et al, 2007	Full scale with all five subscales used	Not reported

Design and Analysis Issues:

Eight of the reviewed studies employed cross-sectional methodology (Bean et al, 2009; Doering et al, 2004; Hallas et al, 2011; Jackson & Emery, 2011; Klein et al, 2007; Nahlén & Saboonchi, 2010; Paukert et al, 2009; Trivedi et al, 2009) which is limited by the inability to determine causal relationships between factors such as coping and outcomes of psychological wellbeing.

Five studies employed longitudinal designs (Carels, 2003; Murberg et al, 2002; Park et al, 2006; Park et al, 2008; Scherer et al, 2007), which includes scope for assessing the change in relationships between factors over time. One of the longitudinal studies obtained daily questionnaire data for participants over a two week period to provide more stable assessment of essentially cross-sectional data (Carels, 2003). The remaining longitudinal studies however, used a two time-point design, with times between baseline and follow-up of six months (Park et al, 2006; Park et al, 2008), nine months (Scherer et al, 2007), and two years (Murberg et al, 2002). It should be noted however, that comparison of two time-points does not allow determination of the potential ongoing fluctuations in the relationships between factors over time.

Whilst the majority of studies explored the relationships between factors as continuous variables, some studies included groupings of participants for analysis using dichotomised scores on particular factor measures. Two methods for determining score cut-offs were utilised. The more robust approach was used with mood scales which included published clinical cut-offs, with one study using the Hospital Anxiety and Depression Scale (HADS; Hallas et al, 2011) and another study, the Beck Depression Inventory (BDI; Trivedi et al, 2009). Longitudinally, Scherer and colleagues (2007) dichotomised distress scores as measured by the HADS to form four groups based on relationships between baseline and follow-up levels of distress. The second approach was used where measures were used without published norm data. A study included

formation of two groups based on a dichotomy of high and low coping using median score criteria (Doering et al, 2004). However, without discussion of the distribution of scores on this scale within the study, it is unclear as to whether this was an appropriate criteria to undertake this dichotomy.

With regards to approaches to statistical analysis, all reviewed studies utilised correlation analyses and comparison tests (t-tests and Mann-Whitney U tests) to establish the cross-sectional relationships between factors. However, only two studies discussed exploration of the normality of the distribution of scores on factors to determine the use of parametric or non-parametric analyses (Nahlén & Saboonchi, 2010; Hallas et al, 2011). With regards to further analysis, all but two studies utilised multivariate stepwise hierarchical regression (Jackson & Emery, 2011; Park et al, 2006). In addition, two studies utilised logistical regression (Scherer et al, 2007; Trivedi et al, 2009), and one study used structural equation modelling to form a statistical model of the longitudinal inter-relationships between factors (Park et al, 2006). Although the sample sizes of the reviewed studies were indications of sufficient power for multivariate analysis, only one study described a power calculation justifying the appropriateness of the analysis based on the sample size (Nahlén & Saboonchi, 2010).

Considering the quantity of data analyses each study conducted, the risk of Type I error was notable. However, only five studies made reference to this risk and discussed attempts to minimise the risk of this occurring. Two studies discussed use of Bonferroni corrected significance values (Doering et al, 2004; Hallas et al, 2011), one study limited the number of analyses conducted (Scherer et al, 2007), and a further study only included scale total scores in the analyses rather than multiple subtest scores. The final study cited the small sample size and risk of Type II error as a rationale for not altering the analysis procedure, which is suggestive of positive results bias (Jackson & Emery, 2011).

Ways of Coping:

Concurrent with the findings of Skinner et al (2003), the variation in use of categories of ways of coping employed in the reviewed studies was so extensive they could be considered idiosyncratic. The majority of studies used higher order category frameworks to organise lower order ways of coping and many studies shared descriptive labels for these categories, either based on topographical or functional criteria. However, the variation in the inclusion of different lower order coping categories within similarly labelled higher order categories was extensive. This review acknowledges these variations in order to establish more accurately what findings could be synthesised.

For example, the most prevalent pair of higher order coping categories identified were active and avoidant coping, both identified together in five studies (Park et al, 2008; Doering et al, 2004; Nahlén & Saboonchi, 2010; Trivedi et al, 2009; Bean et al, 2009). Each of these studies used a version of the COPE to measure ways of coping, with the exception of the study by Doering and colleagues (2004), where active coping was divided into behavioural and cognitive categories, based on whether a way of coping dealt with the stressor through action or appraisal. This distinction is not comparable to the category system used on the COPE or brief COPE so synthesising the findings of these studies together based exclusively on higher order categories would be inappropriate. Furthermore, the studies which used a version of the COPE with shared lower order category subscales also varied in the inclusion of these different subscales in different higher order categories. For example, Bean and colleagues (2009) defined active coping using the COPE subscales of religion, emotional support, instrumental support, planning, positive reframing, active and acceptance coping. However, Park and colleagues (2006) defined active coping with religion, instrumental support, positive reframing and active coping, but without emotional support, planning or acceptance. It

is therefore not appropriate to consider these two presentations of *active* coping as resemblant.

Much of this variation appeared to be due to the use of Principal Component Analysis (PCA) on the scales to form study specific coping factors. This variation could also have occurred based on whether the active and avoidant categories were the only categories used or whether additional categories were also produced through PCA. For example, Nahlén and Saboonchi (2010) used a four factor model of coping based on a previous study (Litman, 2006), which included active problem focused coping, avoidant coping, but also emotion-focused coping and socially supported coping. This provides a very different underlying structure to active or avoidant coping than a factor structure of only two factors. One study used only a percentage of active coping employed for structural equation modelling purposes during data analysis with no reference to further ways of coping (Park et al, 2006), and other studies used a two factor structure which included all subscales into either active or avoidant coping (Bean et al, 2009).

Variations in underlying components of higher order categories used in the studies was repeated in the remaining reviewed studies. Active coping was identified in two further studies which did not also identify disengagement/avoidant coping (Scherer et al, 2007; Carels, 2004). Distraction coping, a specific example of avoidant coping in some frameworks, was identified in two studies (Scherer et al, 2007; Carels, 2003) but described in relation to higher order categories. Adaptive and maladaptive coping styles were identified as higher order categories of coping in three studies (Paukert et al, 2009; Bean et al, 2009; Carels, 2004). Emotion focused coping was also identified in three studies (Nahlén & Saboonchi, 2010; Trivedi et al, 2009; Murberg et al, 2002). Three distinct coping styles were identified with a religious element, religion (Park et al, 2008), religious faith and search for meaning (Scherer et al, 2007), and religion and substance use (Paukert et al, 2009). Religion and substance use is an example of a

category which has been formed out of PCA but which has little meaning as a distinct mutually exclusive and comprehensive single factor, further suggesting the questionable usefulness of categorising coping in this way.

The remaining coping styles identified in the reviewed studies were lower order categories of coping not shared between studies and appeared to be reflections of scales which were unique to particular studies. Repression, anger-in and alexithymia were unique to one participant sample (Jackson & Emery, 2011) where specific scales for each domain were employed. Symptom focused coping (Carels, 2003) did not relate well to other categories of coping and were additional items added by the study authors. Minimisation and wishful thinking was also a specific and unique scale used in one study (Scherer et al, 2007).

Psychological Outcome Measures:

Mood:

Twelve studies used mood-focused self rating measures in relation to coping (described in Table 3). Of these, five studies used exclusively depression scales. The BDI (Beck, 1976) was used by two studies (Carels, 2004; Trivedi et al, 2009) and the Geriatric Depression Scale (GDS; Yesavage, 1982) by one study (Klein et al, 2007). The Centre for Epidemiological Studies Depression scale (CES-D; Radloff, 1977) was used in two studies, one in isolation of another measure of mood (Park et al, 2006) and one where anxiety was also measured (Jackson & Emery, 2011) using the State Trait Anxiety Inventory (STAI; Spielberger et al, 1970). Both depression and anxiety were also measured in four further studies. In one study (Paukert et al, 2009), the revised version of the GDS (Sheikh & Yesavage, 1986) and the Geriatric Anxiety Inventory (GAI; Pachana et al, 2007) were used, and in three studies (Bean et al, 2009; Hallas et al, 2011; Scherer et al, 2007) the HADS (Zigmond & Snaith, 1983) was used. One study

measured several categories of affect in addition to depression and anxiety (Doering et al, 2004), using the Profile of Mood States (POMS; McNair, Lorr & Dopleman, 1971). Finally, one study used a different conceptualisation of affect to the other studies (Nahlén & Saboonchi, 2010), using the Positive and Negative Affect Scale (PANAS; Watson, Clark & Tellegen, 1988).

Quality of Life:

Three studies included a measure of quality of life in relation to coping (described in Table 4). One study measured exclusively physical quality of life (Paukert et al, 2009), using the Kansas City Cardiomyopathy Questionnaire (Green et al, 2000). Medical Outcomes Study Short-form Health Status Questionnaire (SF-36; McHorney, Ware & Raczek, 1993) was used by two studies, one study using both the mental and physical subscales (Park et al, 2008) and the other using only the physical subscale (Jackson & Emery, 2011). However, this study also employed the Minnesota Living With Heart Failure Questionnaire (MLWHFQ; Rector et al, 1987) which measures quality of life in the domains of physical, mental emotional and social quality of life. One study (Carels, 2004) conceptualised coping as an aspect of quality of life and therefore did not measure the relationship between the two concepts.

Table 3: Measures of mood used in the reviewed studies

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)	14 item self-report questionnaire which measures psychological distress through examination of symptoms of anxiety (7 items) and depression (7 items) neglecting somatic symptoms comorbid with physical illness. Scores of 8-10 indicate borderline clinical levels of anxiety and depression, and 11 or greater suggest clinically significant anxiety or depression.	Bean et al, 2009	Subscales used individually as indicators of anxiety and depression.	Depression subscale= 0.83 Anxiety subscale= 0.85
		Hallas et al, 2011	Subscales used individually as indicators of anxiety and depression.	Depression subscale= 0.83 Anxiety subscale= 0.85
		Scherer et al, 2007	Anxiety and depression subscale scores were dichotomised at baseline and follow-up to indicate if depression or anxiety were present, dictated by a depression score of >8 or anxiety score of >10.	Not reported
Beck Depression Inventory (BDI; Beck, 1976)	21 item self report questionnaire scale used to assess the presence of depressive symptoms in the general population, with score ranges suggestive of different levels of severity: 0-9: absence or minimal, 10-18: mild to moderate, 19-29: moderate to severe and 30-63: severe depression.	Carels, 2004 Trivedi et al, 2009	Full BDI used and treated as a continuous variable Full BDI used	Not reported Not reported
Positive and Negative Affect Scale (PANAS; Watson, Clark & Tellegen, 1988)	20 item self report questionnaire, involving rating the frequency of experiencing different listed feelings and emotions. Contains two independent subscales of positive affect (PA) and negative affect (NA).	Nahlén & Saboonchi, 2010	Both PA and NA scales used as independent scales of affect.	PA= 0.86 NA= 0.85

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
Zung Self-rating Depression Scale (Zung SDS; Zung, 1965)	20 item self-rating scale used to assess depressive symptoms.	Murberg, Bru & Stephens, 2002	Full SDS used	Not reported
Profile of Mood States (McNair, Lorr & Droppleman, 1971)	65 item self report scale measuring primary mood states and includes 6 subscales of confusion, vigour, fatigue, anger, depression and anxiety.	Doering et al, 2004	Full scale used with each subscale analysed individually	Confusion= 0.66, Vigour= 0.85, Fatigue= 0.88, Anger= 0.82, Depression= 0.85 and Anxiety= 0.77
Geriatric Depression Scale (GDS; Yesavage, 1982)	30 item self report screening questionnaire measuring specifically the cognitive aspects of depression for older people in order to restrict the impact of medical illness and neurodegeneration on depression scores.	Klein, Turvey & Pies, 2007	Full scale used.	Not reported
Geriatric Depression Scale (Revised; Sheikh & Yesavage, 1986)	15 item self report measure. A shorter version of the original GDS, measuring the same aspects of depression for use with older adults.	Paukert, Le Maine & Cully, 2009	Full scale used. Administered via telephone. A cut-off score of >5 was used to determine the presence of clinically significant depressive symptoms.	Not reported
Geriatric Anxiety Inventory (GAI; Pachana et al, 2007)	20 item self report scale assessing anxiety designed for use with older adult populations.	Paukert, Le Maine & Cully, 2009	Full scale used. Administered by telephone. A cut-off score of >8 was used to determine the presence of clinically significant anxiety.	Not reported

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
Centre for Epidemiological Studies Depression Inventory (CES-D; Radloff, 1977)	20 item self report measure of the frequency of depressive symptoms during the preceding week. Scores of >16 indicative of possible clinically significant depression.	Jackson & Emery, 2011	Full scale used as a continuous variable. Used as a measure of 'emotional quality of life'.	0.91
		Park et al, 2006	Full scale used as a continuous variable	0.88 at T1 and T2
State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch & Lushene, 1970)	40 item self report questionnaire measure, with 20 items each measuring current levels of anxiety (state anxiety) and longitudinal anxiety (trait anxiety).	Jackson & Emery, 2011	Only state anxiety scale used	State subscale= 0.91

Table 4: Measures of quality of life used in the reviewed studies

Measure Name	Measure Description	Studies Which Used Measure	Details of Use of Measure in Study	Internal Consistency (Cronbach's α)
Minnesota Living with Heart Failure Questionnaire (MLWHFQ; Rector, Francis & Cohn, 1987)	21 item self-report questionnaire used to assess patients' perceptions of the impact of their heart failure condition on daily life functioning.	Jackson & Emery, 2011	Full	MLWHFQ= 0.96
Kansas City Cardiomyopathy Questionnaire (KCCQ; Green, Porter, Bresnahan & Spertus, 2000)	Self administered disease specific quality of life inventory, measuring quality of life in several domains: physical limitations, symptoms, self efficacy, quality of life and social limitations.	Paukert, Le Maire & Cully, 2009	Physical limitations scale used only (physical deficits associated with HF only).	Not reported
Medical Outcomes Study Short-form Health Status Questionnaire (SF-36; McHorney, Ware & Raczek, 1993)	36 item self-report questionnaire. Produces two summary scores of mental health (mental health component score, MCS) with subscales of vitality, social functioning, mental health and role emotional) and physical health (physical component score, PCS) with subscales of physical functioning, bodily pain, role-physical and general health.	Jackson & Emery, 2011 Park et al, 2008	PCS used only Both scales of PCS and MCS used.	PCS= 0.84 PCS= 0.74 MCS= 0.77

Coping and Psychological Outcomes:

Due to the idiosyncratic use of higher order categories of coping in the reviewed studies, relationships between ways of coping and psychological outcomes were examined at the lower order level where possible to ensure appropriate synthesis of the findings. This also allowed additional relationships to be considered which were masked by analysis of higher order categories. For example, Nahlén and Saboonchi (2010) included the venting and support subscales of the COPE together in a higher order category of socially supported coping. However, the relationship between these lower order categories and other psychological outcomes were opposing, with venting positively relating to negative affect and emotional support positively relating to positive affect. Socially supported coping as an overall category, related to negative affect, which is counterintuitive, and contradictory to the findings of other research. Indeed, the authors identified venting as a plausible cause of this finding in their study (Nahlén & Saboonchi, 2010). Therefore, the distinct outcomes associated with lower order categories were acknowledged, although in the majority of studies these relationships were only considered using correlation analysis.

Lower Order Categories of Coping:

Behavioural Disengagement:

Behavioural disengagement is defined as a reduction of the effort made to intervene with the impact of a stressor and a cessation of attempts to attain goals associated with it (Carver et al, 1989). Behavioural disengagement was examined in five studies, with consistent findings of its detrimental impact on wellbeing. Three studies reported a significant positive correlational relationship between behavioural disengagement and depression (Murberg et al, 2002; Hallas et al, 2011; Klein et al, 2007) and one study reported this relationship was supported using a multivariate linear

regression analysis (Trivedi et al, 2009). This study also reported using a logistic regression analysis, and when depression scores on the BDI were equal to or over 10, there was a 30% likelihood of behavioural disengagement being reported by participants. Further correlational findings indicated that behavioural disengagement is also positively related to negative affect as measured by the PANAS (Nahlén & Saboonchi, 2010), the anxiety subscale of the HADS (Hallas et al, 2011) and negatively related to quality of life (Klein et al, 2007). A longitudinal study reported a moderate correlation of scores on behavioural disengagement at two time-points two years apart, suggesting some stability of this over time for HF patients (Murberg et al, 2002).

Venting:

Venting is described as the potentially unhelpful focusing or fixating on distress one is experiencing in relation to a stressor (Carver et al, 1989). Five studies examined venting and there was similar consensus that venting related to negative outcomes of wellbeing. Two studies reported positive correlations between venting and depression (Hallas et al, 2011; Klein, 2007) and one study between venting and negative affect (Nahlén & Saboonchi, 2010). A multivariate linear regression indicated this relationship with depression, and a logistic regression analysis indicated 20% likelihood of venting being reported by participants with a score equal to or above 10 on the BDI (Trivedi et al, 2009). However, one study did not report any relationship between venting and depression (Murberg et al, 2002). Studies also found a positive correlation between venting and anxiety (Hallas et al, 2011) and a negative correlation with quality of life (Klein et al, 2007).

Denial:

Denial can be defined as denying the reality of the stressor and the impact it is having (Carver et al, 1989). Five studies also examined denial with mixed findings relating to outcomes. One study reported a positive correlation between denial and

depression (Klein et al, 2007). This was supported in another study by a linear regression analysis, which also found a 20% chance of depression scores of 10 and over equating to a participant reporting denial coping (Trivedi et al, 2009). However, whilst one study reported a positive correlation with anxiety, there was no significant relationship with depression (Hallas et al, 2011) and another reported a negative correlation with quality of life (Klein et al, 2007), two further studies found no relationship with either depression (Murberg et al, 2002) or positive or negative affect (Nahlén & Saboonchi, 2010) and a longitudinal study reported no significant relationship between denial scores at two time-points two years apart, suggesting no longitudinal consistency (Murberg et al, 2002).

Self-Blame:

Self-blame refers to taking personal responsibility for a stressor and its negative impacts. Two studies reported findings in relation to self-blame. Both studies reported negative outcomes, with self-blame correlating positively with depression (Klein et al, 2007) and negative affect (Nahlén & Saboonchi, 2010), and negatively correlating with quality of life (Klein et al, 2007).

Self-Distraction:

Self-distraction is the use of strategies to distract oneself from a stressor, therefore potentially avoiding the distress associated with it. Two studies examined self-distraction with mixed findings. One study reported a positive correlation with depression and a negative correlation with quality of life (Klein et al, 2007). However, another study found no significant relationships between self-distraction and dimensions of affect (Nahlén & Saboonchi, 2010).

Substance Misuse:

Substance misuse in relation to coping is the use of substances such as alcohol and illicit drugs in times of stress to mediate the distress experienced. Substance misuse

as a way of coping was measured in two studies. A non-parametric correlation indicated a small positive correlation with negative affect in one study (Nahlén & Saboonchi, 2010), but another study reported no significant relationships with depression (Trivedi et al, 2009).

Active Coping (Lower Order):

Active coping is taking an active approach to remove or neutralise the impact of a stressor (Carver et al, 1989). Active coping was measured in four studies. Whilst one study reported a significant positive relationship with positive affect (Nahlén & Saboonchi, 2010), the other three studies reported no relationship with depression (Murberg et al, 2002; Trivedi et al, 2009; Klein et al, 2007) or quality of life (Klein et al, 2007). Furthermore, no longitudinal consistency was found for this way of coping over time (Murberg et al, 2002).

Instrumental Support:

Instrumental support can be defined as seeking information, advice, or practical support from others (Carver et al, 1989). Of the four studies which included measurement of instrumental support coping, only one study reported a significant positive relationship, with quality of life (Klein et al, 2007). However, three studies reported no significant relationship with depression (Murberg et al, 2002; Trivedi et al, 2009) or positive and negative affect (Nahlén & Saboonchi, 2010). Moderate consistency over a two year period was indicated in one study (Murberg et al, 2002).

Acceptance and Planning:

Acceptance and planning refers to acknowledging fully the impact of a stressor and considering approaches to cope with it (Carver et al, 1989). Of the four studies which looked at acceptance coping and planning coping there was very little evidence of a relationship with outcomes. One study reported negative relationships with depression from a linear regression, but these findings were not significant in a logistic

regression analysis (Trivedi et al, 2009). Three studies reported no significant relationships with depression (Murberg et al, 2002; Klein et al, 2007), positive and negative affect (Nahlén & Saboonchi, 2010) and quality of life (Klein et al, 2007) for these two ways of coping. Acceptance coping scores were reported to correlate moderately between baseline and two-year follow up in one longitudinal study (Murberg et al, 2002).

Emotional Support:

Emotional support involves obtaining understanding and moral support from others (Carver et al, 1989). Five studies measured the relationship between emotional support coping and outcomes, with mixed and contrasting findings. Trivedi and colleagues (2009) reported linear regression findings of a negative relationship between scores of depression and emotional support. Furthermore, emotional support positively correlated with positive affect (Nahlén & Saboonchi, 2010), indicating emotional support is a beneficial way of coping. However, two studies reported a lack of significant relationship between emotional support and outcomes of depression (Hallas et al, 2011; Klein et al, 2007), anxiety (Hallas et al, 2011) and quality of life (Klein et al, 2007) and interestingly, one study reported a positive correlation with depression scores when demographic and illness variables were controlled for (Murberg et al, 2002).

Mental Disengagement:

Mental disengagement is defined as a variety of actions or behaviours which serve to distract an individual from thinking about the negative impacts of a stressor (Carver et al, 1989). Two studies measured mental disengagement coping, both finding a positive relationship with depression (Murberg et al, 2002; Trivedi et al, 2009). Furthermore, a logistic regression analysis indicated that 30% of participants with scores equal to or exceeding 10 on the BDI reported this way of coping (Trivedi et al,

2009). Mental disengagement scores at baseline and two year follow-up were moderately correlated (Murberg et al, 2002).

Positive Reframing:

Positive reframing involves reappraisal of the impact of a stressor which manages the distress associated with it rather than directly affecting the stressor itself (Lazarus & Folkman, 1984). Four studies reported findings in relation to positive reframing. Whilst one study reported a positive correlation with positive affect (Nahlén & Saboonchi, 2010), three studies reported no significant relationship with depression (Murberg et al, 2002; Klein et al, 2007; Trivedi et al, 2009) and one study reported no relationship with quality of life (Klein et al, 2007). Moderate stability over time was found between baseline and two year follow-up in one study (Murberg et al, 2002).

Humour:

Humour coping refers to a form of positive reappraisal which involves using humour in relation to a stressor to reduce distress. Three studies considered humour as a way of coping with mixed results. Trivedi and colleagues (2009) reported a negative relationship with depression using a linear regression, but this finding was not supported with a logistic regression. However, one study reported that humour correlated negatively with quality of life (Klein et al, 2007), indicating humour was used more by participants where quality of life was more impaired. The third study found no relationship between humour and positive or negative affect (Nahlén & Saboonchi, 2010).

Miscellaneous:

The remaining lower order categories of coping were reported in studies which used measures of coping unique to this review. Jackson and Emery (2011) measured specifically elements of emotional expression as indicators of ways of coping using three specific scales (as already discussed). Emotional expression is defined as the

amount to which experienced emotions are projected. Anger-in and alexithymia positively related to both depression and anxiety, whereas emotional expression was negatively related to these factors (Jackson & Emery, 2011). Similarly, Scherer and colleagues (2007) used the FKV to measure coping. Interestingly, no subscales of coping in their study were related to outcomes of depression and anxiety as measured by the HADS.

Higher Order Categories of Coping:

Finally, studies which only reported findings for higher order coping or reported additional findings in these categories are described.

Active Coping:

Active coping involves active steps to intervene with the stressor and the distress it causes (Carver et al, 1989). The findings on the impact of active coping on psychological outcomes were inconsistent. Active behavioural coping was associated with lower scores of fatigue and higher scores of vigour (Doering et al, 2004). Furthermore, the study by Carels (2004) also reported an association between increased coping scores and decreased depression scores, Nahlén and Saboonchi (2010) found a positive correlation between active problem-focused coping and positive affect. However, these indications of the positive impact of actively facing and problem solving in the light of stress or adversity were contradicted by other findings. In one study, active approach coping was related to HADS anxiety scores (Bean et al, 2009), which the authors speculated may have been due to over-use of active coping, maintaining participants' awareness of the threat of their HF at a significant level. However, this relationship was found only with Caucasian participants when results were stratified by ethnicity. There were also study findings which suggested no significant direct relationship between psychological outcomes related to depression

(Scherer et al, 2007; Murberg et al, 2002), anxiety (Scherer et al, 2007) and health related quality of life (Park et al, 2008). However, in the study by Park and colleagues (2008), active coping strategies were related to increased scores of meaning in life, which in turn were strongly associated with health-related quality of life. It was therefore speculated that active coping had contributed to increased quality of life by fostering meaning in life. Longitudinally, the study by Park and colleagues (2006) showed a negative relationship between active coping at baseline and follow-up, with depression at follow-up which suggested active coping was predictive of reduced distress and positive adjustment in HF. However, with regards to the stability of active coping over time, scores at baseline and follow-up were only moderately correlated.

Avoidant Coping:

Avoidant coping involves strategies to avoid both mental and behavioural focus on the stressor or the impact it causes (Carver et al, 1989). On the other hand, findings on the impact of avoidant coping on psychological outcomes were more consistent. Avoidant coping was significantly positively related to anxiety, anger, depression, confusion and fatigue scores in one study (Doering et al, 2004). Three further studies found a positive relationship between avoidant coping and depressive symptoms (Trivedi et al, 2009; Bean et al, 2009; Murberg et al, 2002) and another study reported this relationship with negative affect (Nahlén & Saboonchi, 2010). A study also indicated that avoidant coping was related to poorer scores of health related quality of life (Park et al, 2008). However, one study reported no significant relationship between avoidant coping and depression (Park et al, 2006).

Adaptive and Maladaptive Coping:

This coping dichotomy refers to whether a coping strategy has a beneficial impact on adjustment or overcoming of a stressor. Those studies which included preconceived categories of coping strategies as adaptive or maladaptive, reported

unanimous findings that maladaptive coping styles were related to increased scores of depression (Paukert et al, 2009; Klein et al, 2007; Hallas et al, 2011) and anxiety (Hallas et al, 2011), and decreased scores of quality of life (Klein et al, 2007). However, adaptive coping in these studies were not significantly related to psychological outcomes.

Emotion-focused Coping:

Emotion focused coping includes all ways of coping which relate to the distress associated with a stressor rather than directly with the stressor itself. The three studies which discussed emotion-focused coping found a positive relationship between emotional venting and distress, in the forms of increased depression scores (Trivedi et al, 2009), anxiety (Hallas et al, 2011) and negative affect (Nahlén & Saboonchi, 2010). Emotional support which was conceptualised independently of social support, was identified as relating negatively with depression (Trivedi et al, 2009) and positively with positive affect (Nahlén & Saboonchi, 2010).

Qualitative studies:

Extracted summary data from the reviewed qualitative studies are provided in Table 5.

Quality:

The three qualitative studies included in the review were of reasonable quality, with one study rated within the highest of the three bands of rating as described by NICE (2007), with most of the criteria satisfactorily fulfilled. The other studies fell within the second band of rating categories, with some of the criteria fulfilled (Buetow, Goodyear-Smith & Coster, 2001; Bosworth et al, 2004).

Participant Characteristics:

The three studies varied considerably in the number of participants, from 15 (Bosworth et al, 2004) to 62 (Buetow et al, 2001). Two studies reported participant demographic details. One of these studies included exclusively male participants who were predominantly Caucasian (Bosworth et al, 2004), whereas the other study included participants specifically from Pacific Island ethnic groups but both females and males were included, with more female than male participants (Kaholokula, Saito, Mau, Latimer & Seto, 2008). The final study did not report participant demographic details, citing the importance of the participants' experiences and insights over the representativeness of the sample in qualitative research (Buetow et al, 2001).

Table 5: Reviewed studies utilising a qualitative methodology

Study#	Author/ Pub Date/ Country	Study Design	Sample Size/ Age Mean (SD)/ Gender/ Ethnicity	Sample NYHA Class	Coping-related Themes	Findings	Quality Score (++/+/ -)
15	Bosworth et al (2004) USA	C-S Qualitative (Semi structured open ended protocol). Grounded Theory	N= 15 Age range= 47-82 100% males, 0% females 83% Caucasian, 17% African- American	I-II: 10 III-IV: 5	Coping and compensation (negative and positive): Preparation/ thinking of future Contribution to others' well-being Knowledge of disease Compliance with medical regimen Spirituality Loss of income Normalising symptoms Affective response: Denial	Coping included positive and negative mechanisms for present and future coping. Positive coping strategies described included making instrumental changes to activities, substitution of activities with new ones, and placing the experience of the illness in the wider context of meaning of life. The anxiety, depression and fear reported by patients lead to avoidance and denial of symptoms to the extent of hesitation to seek treatment in some cases.	+
16	Buetow, Goodyear- Smith & Coster (2001) New Zealand	Qualitative	N= 62 Age, gender and ethnicity not reported.	Not reported	Four coping strategies identified: Avoidance Disavowel (healthy denial) Denial Acceptance	Avoidance, disavowel and acceptance were all highly salient when physical QoL was moderate on the MLWHFQ. With more severe impairment shown on the MLWHFQ, avoidance and acceptance coping were only moderately salient, but disavowel was highly salient. Denial was not described by any patients interviewed. Heart failure patients may use disavowel as a coping strategy to palliate the emotional strain of heart failure and develop a sense of hope.	+

17	Kaholokula , Saito, Mau, Latimer & Seto (2008) USA	Qualitative	N= 36 Age= 55.3 (14.9) 75% female, 25% male 61.1% Hawaiian, 27.8% Samoan, 11.1% Other	Not reported	Heart failure beliefs and attitudes: Avoidance and denial of illness Hopelessness and despair Religious/spiritual faith	Avoidance and denial of illness described as occurring out of fear of having heart failure or a lack of understanding regarding the illness. Hopelessness and despair in having heart failure related to a sense of simply biding time for the inevitable. Use of spirituality and religious beliefs to deal with the uncertainty of the illness.	++
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Methodology:

All of the studies utilised transcribed data from semi-structured sessions with participants as the source of data, and employed a form of thematic analysis. Two studies utilised stratified focus groups in order to produce the required qualitative data, whilst the third study involved individual semi-structured interviews with each participant (Buetow et al, 2001). With regards to the approaches taken to analysing data and establishing themes, two studies used a priori theoretical frameworks from existing literature to interpret the qualitative data (Buetow et al, 2001; Kaholokula et al, 2008). In contrast, the third study involved a Grounded Theory (GT) orientated approach to establish themes exclusively from the transcribed data without a literature-based framework (Bosworth et al, 2004).

The literature-based framework chosen by Kaholokula and colleagues (2008) was based on the theoretical domains discussed in health behaviour change models including health beliefs and attitudes, health practices, and social and environmental factors. This framework was used to design the interview questions, and in the interpretation of the data. The a priori framework used by Buetow and colleagues (2001) was reported to be informed by psychoanalytic literature describing defensive processes underlying emotion focused coping. Interestingly, the data recording process in this study did not involve audio recording and transcribing, but use of handwritten notes from interview sessions due to concerns that elderly participants may perceive audio recording as threatening. This has implications on the nature of the data interpretation, as the a priori framework may have influenced the selection of aspects of the interviews to be recorded in note form by the interviewer. As such, the data may have been influenced by the study framework before as well as during data analysis, although this was not acknowledged by the authors.

Furthermore, whilst the other studies utilised a traditional exclusively qualitative approach, Buetow and colleagues (2001) elected for data analysis which resembled a quantitative approach. For example, in addition to the interviews, participants also completed the MLWHFQ, which was used to dichotomise participants into groups of mild or moderate to severe limitation on physical functioning. Following thematic analysis of the data and formation of identified coping, the salience (defined in the study as the ‘interpretation of the clarity, importance and plausibility in the description of a patient’s lived experience’ p.118) of each way of coping was related to these dichotomies to indicate relationships. As the research question in this instance appeared to focus more on examining the specific relationships, a purely quantitative methodology or two-stage mixed design may have been more appropriate.

The study by Bosworth and colleagues (2004) aimed to establish components of quality of life from the perspective of HF patients and used a constant comparisons approach of GT to find prevalent and recurrent themes, with the aid of qualitative analysis computer software. However, in many respects the approach discussed by the authors, involving the development of conceptual domains which were systematically collapsed down into broader quality of life categories, is similar to the thematic analysis approach taken in the other qualitative studies reviewed, albeit without an explicitly stated conceptual framework. Within the themes of quality of life discussed by participants in the focus groups, some themes pertaining to coping emerged.

Coping Themes:

Avoidance and Denial:

In all three of the studies reviewed, avoidance and denial were identified as coping strategies. In two studies, these coping styles were described by some participants (Bosworth et al, 2004; Kaholokula et al, 2008). However, the study which

used a framework involving psychoanalytic defensive processes underlying emotion focused coping including denial reported that no participants involved in the study engaged in denial coping (Buetow et al, 2001). This study did report high salience of avoidance coping in moderate quality of life scores, and moderate salience with severe quality of life scores, as measured using the MLWHFQ (Table 4).

In the studies which did identify avoidance and denial coping for participants, there was some discussion over the causation of these coping styles in relation to mood states. In one study, it was reported that depression, anxiety and fear experiences by participants in relation to their HF condition had lead to engagement in this type of coping (Bosworth et al, 2004). A similar finding was reported in another study in which it was stated that fear had caused avoidance and denial (Kaholokula et al, 2008).

Religious/ Spiritual Coping:

This refers to turning to religion and spirituality in both practice and thinking during stressful events. Two studies discussed participant experiences in relation to religious or spiritual coping. It was reported in one study that religious and spiritual coping neutralised hopelessness for participants (Bosworth et al, 2004), indicating religious coping is effective in combating depressive emotional and cognitive states. In another study, it was speculated that this type of coping also allowed participants to deal with uncertainty more effectively (Kaholokula et al, 2008), suggesting it may have beneficial effects on anxiety also.

Disavowal:

Disavowal coping, described as a healthy form of denial or minimisation in which the individual may 'register and acknowledge reality, but to palliate the emotional strain it produces...dissociate that awareness from its personal impact' (p.119), was identified in one study (Buetow et al, 2001). The authors described that this way of coping was particularly salient in relation to medical uncertainty, which may

suggest it is a protective approach against anxiety. However, this was not an explicit link made in the study.

Additional Coping Themes:

One study reported additional coping themes which were experienced as more overtly positive by participants. These included consideration and planning of the future, seeking and using illness knowledge, advice and treatment from medical professionals and normalising symptoms. There was also some evidence of participants using selection and compensation strategies, which are elements of a model of successful ageing in other literature (Baltes & Baltes, 1990).

Finally, one study described some participants coping as a resignation to the reality of their HF without positively reframing it, which the authors labelled as acceptance coping (Buetow et al, 2001). This appeared to involve some participants accepting a hopelessness regarding the chronicity of HF, whilst others showed dispassionate and emotionally stable personal strength. This suggests that acceptance itself may still involve some individual differences based on other psychosocial factors.

Discussion

Findings

The aims of the current review were to examine the relationships between ways of coping with HF and outcomes related to psychological wellbeing. This aim was addressed by reviewing studies which utilised both qualitative and quantitative methodologies.

With regards to the quantitative studies, the most robust findings were reported for lower order ways of coping (Skinner et al, 2003) due to their comparable nature. Consistent findings were for a relationship between negative mood and poor quality of life with behavioural disengagement, venting, self-blame and mental disengagement.

This is in many ways unsurprising as these *ways of coping* are clinically all symptoms of depression. Mixed results were found for other lower order coping categories, particularly categories involving support from others and ways of coping which would intuitively be considered positive approaches to coping.

Higher order categories of coping were predominantly considered in the reviewed studies, but as established the synthesis of these results should be considered tentatively due to the variation of the underlying factors. Avoidant and so-called ‘maladaptive’ coping strategies were consistently related to negative outcomes of psychological wellbeing, including depression, anxiety and quality of life. These findings are consistent however, with the findings of the relationships between the lower order ways of coping which constitute avoidant and maladaptive coping, and outcomes. Also consistent were the findings related to active and adaptive coping, in which findings were extremely mixed, ranging from a lack of negative outcomes, negative outcomes, or no observed relationship at all.

Of particular interest though, was the longitudinal finding which suggested active coping at baseline was predictive of better adjustment to HF (reduced depression scores at follow-up), which was in distinct contrast to the predominant cross-sectional findings that there was not a relationship. Additional longitudinal findings reported that coping was not strongly consistent between time points, supporting theory that coping is not a reflection of personality (Lazarus, 1993). These findings could indicate that intuitively negative approaches to coping are sufficient in producing negative psychological outcomes, whereas more intuitively positive approaches to coping may not be sufficient in combating negative outcomes, with additional psychosocial and environmental factors required to achieve this goal.

However, a more complex interplay between the factors may be involved. Skinner and colleagues (2003) theorised that all coping behaviour is positive and

adaptive and it is the inter-related use of multiple coping styles which allows positive overall coping and adjustment to take place. Indeed, the cross-sectional findings may suggest that participants were employing more adaptive coping styles in an attempt to improve quality of life or reduce depression in some way, but that this may have already begun to achieve its goal. Participants' wellbeing related outcomes could therefore have been simply a function of the length of time they had employed this coping. If coping is considered a fluctuating and dynamic process, two time-point longitudinal studies provide impoverished evidence for the change in relationship between coping and outcomes.

With regards to the findings of studies using a qualitative methodology, much of the same language in relation to ways of coping was used. Avoidance was discussed in relation to quality of life and distress, and themes of religious coping, acceptance, and healthy disavowal coping were all described as positive approaches to coping taken by participants. These studies also suggested that HF patients' perception of their own wellbeing was responsible for their engagement in particular coping, rather than coping leading to particular wellbeing related outcomes. This supports the conceptualisation of coping as more complex and dynamic than simply cause and effect between a limited number of behavioural and emotional factors.

In summary, the findings of the reviewed studies suggest a multitude of individual ways of coping as relating to outcomes of psychological wellbeing. However, many of these findings indicated that coping is not simply a precipitate of emotional wellbeing and quality of life, but mutually affected by emotional processes, fluid, dynamic and changeable. It may therefore be more appropriate to consider coping in the wider process it is involved in, adjustment, rather than in isolation. The transition model of adjustment by Hopson and Adams (1976) is described as a conceptual transition cycle, with seven phases which an individual must negotiate in relation to a crisis, such

as a chronic health diagnosis like HF. The descriptions of each of the phases resemble those of particular ways of coping investigated in the reviewed studies. For example, the second phase named ‘minimisation’ is described as a form of denial in response to the stressor, which is a similar description to that used in the reviewed studies for avoidant coping. Furthermore, following a phase of ‘depression’ followed by ‘acceptance of reality’, the fifth stage is ‘testing out’ of new behaviours to re-establish a sense of what is attainable and achievable. This description is similar to that of active ways of coping.

The similarity between the descriptions of ways of coping, and Hopson and Adams’ (1976) model is significant because the transition model describes how all of the phases are functional, and lead to the eventual adaptive adjustment to the stressor, much like that described by Skinner and colleagues (2003). It is therefore extremely significant to know at what phase an individual may be in, in their transition, in order to hypothesise their coping behaviours and emotional wellbeing, and without the conceptual framework of adjustment, the relationship between coping and psychological wellbeing may be meaningless. It is also often assumed that if an individual is coping, they should also be experiencing positive psychological wellbeing and vice versa. However, based on the transition model of Hopson and Adams (1976), all of the reviewed ways of coping and states of psychological wellbeing are implicated in the same linear process, albeit at different phases. Ways of coping are not simply ‘good’ or ‘bad’, or ‘adaptive’ or ‘maladaptive’, but indicators of where an individual is in their adjustment journey.

These issues related to the theorised distinctions between factors such as ‘coping’ and ‘adjustment’ raise a wider difficulty with the conceptualisation of process and outcome in health psychology research, which is whether they can be considered distinct. According to the model by Hopson and Adams (1976), phases involving coping behaviours are compatible with stages defined by emotional states such as

depression. Indeed, coping behaviours in the reviewed studies such as behavioural disengagement are also indicators of depression, not necessarily exclusively as associated coping behaviours, but as behavioural symptoms of the emotional state. Evidence for flexibility in the distinctions between factors as process or outcome is further available in the reviewed literature. For example, one study included coping as an element of quality of life (Carels, 2004). Whilst the current review theorised coping as process and emotional wellbeing as outcome based on the model by Moos and Holahan (2007), it should be acknowledged this approach was one of many, including considering coping as a behavioural consequence of states of psychological wellbeing, or considering mood, quality of life and coping as all outcomes of another process variable such as social relationships.

Limitations

An enduring difficulty in systematically reviewing literature is synthesising findings which have been gathered using different measurement scales. This was the case in the current review, with a wide range of self-report measures used in relation to coping. Skinner and colleagues (2003) have argued that the FA method used with measures of coping is problematic as it produces a lack of repeatable factors and categories of coping. This was supported by the current review, as the studies which used FA and PCA with the COPE and brief COPE did not produce consistent categories of coping, and also produced several anomalous categories (for example, religion and substance misuse).

Conceptually, a consistent limitation in the reviewed studies was the absence of a reported framework for categorising ways of coping. The approach taken in the majority of reviewed studies appeared to be considering the more widely known coping literature, but using categories established by the self report measure of coping used rather than measures which corresponded to the study's reviewed literature. This

maintained unanswered questions in the majority of studies regarding what coping is and what implications it has for HF patients and clinicians.

Reviewed studies were also subject to biases in terms of demographic characteristics of their samples. As described, substantial age, gender and ethnicity biases were evident in the majority of quantitative studies, where generalisability is a key element of the design rationale. In particular, the samples were distinctly younger than those which make up the HF population. It was plausible this was due to the need to restrict health-related comorbidity, which reduces the number of eligible older patients. However, this has significant implications due to documented cohort differences about behaviour, expectations and emotional expression. For example, the prevalence of depression is higher in younger patients with HF (Gottlieb et al, 2004) indicating a younger sample would present differently, preventing findings being meaningfully generalised to all HF patients.

A further sampling issue was the ethnic bias inherent in the exclusion criteria of the reviewed studies. Whilst a small number of studies deliberately included participants from a range of ethnic backgrounds or focussed on particular ethnic groups, the exclusion of non-English speaking participants was a consistent theme in the majority of studies. This was despite the majority of study samples being recruited and participating at cardiology outpatient clinics, where the need for verbal communication would have necessitated the use of interpretation or translation in some form. There are obviously practical and financial difficulties with this in ensuring present, consistent and accurate interpretation, but researchers should strive to be more inclusive in order to reduce the ethnic bias still inherent in health psychology research.

With regards to the methodology employed in the studies, the majority of studies used a cross-sectional design, which is limited by the inability to establish causality between factors. The studies utilising a longitudinal design only included two time-

points, and if coping is indeed a dynamic and fluid process, this would not provide a comprehensive insight into how coping changes over time and across situations. There was also some question over the methodology employed in studies with a qualitative design. The grounded theory approach used in the study by Bosworth and colleagues (2004) deviated from the traditional description of grounded theory and appeared to be essentially thematic analysis. Furthermore, the study by Buetow and colleagues (2001) used a qualitative design with a significant quantitative component, which attempted to establish relationships between themes and quality of life scores. A mixed design approach with individual quantitative and qualitative elements may have been more appropriate in this case.

Finally, in consideration of the large number of statistical analyses being performed in the majority of quantitative studies, the chance of Type I error was increased, making it an important factor to consider. However, this was not considered in the majority of studies, and the approaches used to minimise it in some of the remaining studies deviated from those which are statistically recommended.

Strengths

Despite these limitations, the reviewed studies had a number of strengths. The sample sizes were generally large and provided sufficient power for use of the statistical methods employed. A number of studies utilised hierarchical regression which allowed for robust controlling of confounding variables and a greater sense of the predictive relationships between variables. In addition structural equation modelling was used in some studies, which provides a particularly robust basis for modelling the inter-relationships between measured factors. The studies utilising a qualitative design used very comprehensive approaches to extracting data and establishing themes based on established theoretical frameworks. Furthermore, careful attempts were made to stratify

focus groups based on demographic, health and cultural criteria, where these were employed in the procedure.

Review Limitations

The current review is limited in a number of ways. Primarily, all quantitative studies were reviewed based on a quality checklist created specifically for the review (Appendix 4.1). Whilst this was based on a number of established quality assessment checklists, their primary purpose was assessment of the quality of intervention studies and controlled trials, and not cross-sectional studies exploring the relationship between different psychological factors. Therefore, the checklist used was equally based on details provided in the included studies and how comprehensively they were written, as it was on specific design or methodological issues.

Furthermore, the critique based on the exclusion of non-English speaking participants in the majority of reviewed studies is also applicable to the current review. Studies published in a language other than English were excluded due to time and financial limitations. Moreover, an eligible study was not included in the review as it was unobtainable. This limited the comprehensiveness of the review by potentially neglecting relevant research.

Review Strengths

The review process for included studies was successful in providing a detailed and thorough synthesis of the research findings regarding coping and psychological wellbeing in the HF population. Furthermore, a rigorous approach to assessing coping as a construct was applied to provide meaning to the findings beyond simply the relationships the studies had established. Another strength of the review was the inclusion of studies with both quantitative and qualitative methodologies, which provided a richer description of the research findings.

Clinical Implications

The main implication of the current review is the suggestion that coping should be more appropriately considered in a wider framework of adjustment and transition. This has clinical implications as it would allow the mapping of a HF patient's journey through their response and adaptation to the crisis of receiving a diagnosis of HF. Reviewed studies suggested a range of psychological interventions to assist patients in coping more effectively with their illness, such as cognitive reframing and behavioural modification (Doering et al, 2004), and mindfulness meditation (Jackson & Emery, 2011). These suggestions have a number of implications. From the perspective of adjustment, these interventions are clearly useful approaches, but the use of interventions should be based on an assessment of the stage of adjustment a patient is at, in order to inform the best intervention which will allow the individual to progress on to the next stage. Furthermore, it may be inappropriate to intervene at all, if the process of adjustment is a necessary linear process which resolves itself, and suggesting the need for psychological intervention may in fact be pathologising a natural process. In health psychology, there are not specific approaches targeted at the enhancement of coping, interventions operate at the level of enhancing meaning, understanding, and general functioning, which results in an individual 'coping' more effectively. As such, taking a wider perspective on coping to the level of adjustment may be more engaging clinically.

Future Research

The current review has highlighted some significant issues in the conceptualisation of coping used in the HF literature, despite the comprehensive review and critique on the subject of coping produced by Skinner and colleagues in 2003. Future research should attempt to address these issues, particularly in the creation and use of measurement scales of 'ways of coping', which currently include a mixture of higher and lower order coping strategies, and anomalous categories of coping

behaviours due to the use of FA and PCA to reduce scale items. Research using a longitudinal design and multiple time-points would allow for a better understanding of how coping changes over time, and whether it does indeed follow the linear transitional curve as described by Hopson and Adams (1976). This would also address an enduring question in the domain of coping research, whether the particular ways of coping an individual engages in inherently biases their decision to participate in research. By examining participation rates and drop-outs at various stages of a more comprehensive study, this may provide some insight, which would have implications on how best clinicians should engage with patients at different stages of their transition.

Conclusion

This review is, to date the most thorough and comprehensive systematic exploration of literature examining the relationship between coping and psychological wellbeing outcomes in the adult HF population, particularly with regards to a more rigorous examination of how coping is conceptualised and measured as a theoretical construct. There is evidence to suggest coping does relate to outcomes, although research investigating the causal relationship has been limited. Negative outcomes have been found to relate particularly to ways of coping which ignore or avoid the presence and functional limitations of HF, and more active and focused ways of coping may not be sufficient in protecting against negative outcomes. However, there is also evidence to suggest coping is a dynamic process which frequently changes based on situational and task specific factors. Therefore, future research should aim to consider coping in the context of the process of adjustment to HF.

References

- Allman, E., Berry, D., & Nasir, L. (2009). Depression and coping in heart failure patients: A review of the literature. *Journal of Cardiovascular Nursing*, 24(2), 106-117
- Bagby, R. M., Parker, J. D. A. & Taylor, G. J. (1994). The twenty-item Toronto Alexithymia Scale-I. Item selection and cross-validation of the factor structure. *Journal of Psychosomatic Research*, 38: 23-32.
- Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In: Baltes, P.B. & Baltes, M. M. (Eds.) *Successful aging: Perspectives from the behavioral sciences*. New York: Cambridge University Press.
- Bean, M. K., Gibson, D., Flattery, M., Duncan, A., & Hess, M. (2009). Psychosocial factors, quality of life, and psychological distress: ethnic differences in patients with heart failure. *Progress In Cardiovascular Nursing*, 24(4): 131-140.
- Beck, A.T. (1976/1979) *Cognitive Therapy and the Emotional Disorders*. New York: Penguin Books
- Bosworth, H. B., Steinhauser, K. E., Orr, M., Lindquist, J. H., Grambow, S. C., & Oddone, E. Z. (2004). Congestive heart failure patients' perceptions of quality of life: The integration of physical and psychosocial factors. *Aging & Mental Health*, 8(1): 83-91.

Buetow, S., Goodyear-Smith, F., & Coster, G. (2001). Coping strategies in the self-management of chronic heart failure. *Family Practice, 18*(2): 117-122.

Carels, R. A. (2004). The association between disease severity, functional status, depression and daily quality of life in congestive heart failure patients. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation, 13*(1): 63-72.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*: 92-100

Carver, C.S., Pozo, C., Harris, S.D., et al (1993). How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. *Journal of Personal and Social Psychology, 65*: 375-390.

Carver, C. S. & Scheier, M. F. (1981). *Attention and self-regulation: A control-theory approach to human behavior*. New York: Springer

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2): 267-283.

Doering, L. V., Dracup, K., Caldwell, M. A., Moser, D. K., Erickson, V. S., Fonarow, G., & Hamilton, M. (2004). Is coping style linked to emotional states in heart failure patients? *Journal Of Cardiac Failure, 10*(4): 344-349.

Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiological Community Health*, 52: 377-384

Engelfriet, P.M., Hoogenveen, R.T., Boshuizen, H.C. & van Baal, P.H.M. (2011). Is Heart Failure Underrepresented in National Mortality Statistics? *European Journal of Heart Failure*, 13(4): 377-383.

Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle-aged sample. *Journal of Health and Social Behaviour*, 21: 219-239

Gottlieb, S.S., Khatta, M., Friedmann, E. et al. (2004). The influence of age, gender, and race on the prevalence of depression in heart failure patients. *Journal of the American College of Cardiology*, 43(9): 1542-1549.

Green, C.P., Porter, C.B., Bresnahan, D.R. & Spertus, J.A. (2000). Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *Journal of the American College of Cardiology*, 35: 1245-1255.

Hallas, C.N., Wray, J., Andreou, P. & Banner, N.R. (2011). Depression and perceptions about heart failure predict quality of life in patients with advanced heart failure. *Heart Lung*. 40:111-121

Havranek, E.P., Ware, M.G. & Lowes, B.D. (1999) Prevalence of depression in congestive heart failure. *American Journal of Cardiology*,84(3): 348-350.

Hobbs, F.D.R., Kenkre, J.E., Roalfe, A.K., Davis, R.C., Hare, R. & Davies, M.K. (2002). Impact of heart failure and left ventricular systolic dysfunction on quality of life. *European Heart Journal*, 23: 1867-1876.

Hopson, B. & Adams, J. (1976) "Towards an Understanding: defining some boundaries of transition dynamics" In: Adams, J., Hayes, J. & Hopson, B. (Eds.) *Transition: understanding and managing personal change* London: Martin Robertson.

Jackson, J. L., & Emery, C. F. (2011). Illness knowledge moderates the influence of coping style on quality of life among women with congestive heart failure. *Heart and Lung*: 40(2):122-9

Jiang, W., Kuchibhatla, M., Cuffe, M.S., et al. (2004) Prognostic value of anxiety and depression in patients with chronic heart failure. *Circulation*, 110(22): 3452-3456.

Kaholokula, J. K. a., Saito, E., Mau, M. K., Latimer, R., & Seto, T. B. (2008). Pacific Islanders' perspectives on heart failure management. *Patient Education and Counseling*, 70(2): 281-291.

King, L.A. & Emmons, R.A. (1990). Conflict over emotional expression: psychological and physical correlates, *Journal of Personality and Social Psychology*, 58: 864–877

Klein, D. M., Turvey, C. L., & Pies, C. J. (2007). Relationship of coping styles with quality of life and depressive symptoms in older heart failure patients. *Journal of Aging & Health, 19*(1): 22-38.

Krumholz, H.M., Amatruda, J., Smith, G.L., Mattera, J.A., Roumanis, S.A., Radford, M.J. et al. (2002). Randomised trial of an education and support intervention to prevent readmission of patients with heart failure. *Journal of the American College of Cardiology, 39*: 83-9.

Landis, J.R.; & Koch, G.G. (1977). "The measurement of observer agreement for categorical data". *Biometrics 33* (1): 159–174

Lazarus, R.S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine, 55*: 234-247.

Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer

Litman, J.A. (2006). The COPE inventory: Dimensionality and relationships with approach- and avoidance- motives and positive and negative traits. *Personality and Individual Differences, 41*: 273-284.

Livneh, H. (1999). Psychosocial Adaptation to Heart Diseases: The Role of Coping Strategies. *The Journal of Rehabilitation, 65*(3): 24-27.

Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson TB, Flegal K, et al. (2009) Heart disease and stroke statistics--2009 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*, 119(3): 480-6.

McCrae, R.R. & Costa, P.T. (1986). Personality, coping, and coping effectiveness in an adult sample. *Journal of Personality*, 54: 385-405.

McHorney CA, Ware JE, Raczek AE. (1993) The MOS 36-Item Short-Form Health Survey (*SF-36*): II psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care*, 31(3): 247-63.

McNair D, Lorr M, Droppleman L (1972). *Profile of Mood States*. San Diego: Educational and Industrial Testing Service

Moos, R.H. & Holahan, C.J. (2007). Adaptive tasks and methods of coping with illness and disability. In: Martz, E. & Livneh, H. (Eds.). *Coping with Chronic Illness and Disability*. New York: Springer

Moser, D.K. (2002). Psychosocial factors and their association with clinical outcomes in patients with heart failure: why clinicians do not seem to care. *European Journal of Cardiovascular Nursing*, 1: 183-188.

Murberg, T. A., Bru, E., & Stephens, P. (2002). Personality and coping among congestive heart failure patients. *Personality and Individual Differences*, 32(5): 775-784.

Muthny, F.A. (1989). *Freiburger Fragebogen zur Krankheitsverarbeitung*. Göttingen: Hogrefe.

Nahlén, C., & Saboonchi, F. (2010). Coping, sense of coherence and the dimensions of affect in patients with chronic heart failure. *European Journal Of Cardiovascular Nursing: Journal Of The Working Group On Cardiovascular Nursing Of The European Society Of Cardiology*, 9(2): 118-125.

Namir, S., Wolcott, D. L., Fawzy, F. I. and Alumbaugh, M. J. (1987), Coping with AIDS: Psychological and Health Implications. *Journal of Applied Social Psychology*, 17: 309–328

National Institute for Health and Clinical Excellence (2007). Appendix H Methodology Checklist: Qualitative Studies. In: NICE. The Guidelines Manual, 150-187.

Pachana, N., Byrne, G., Siddle, H., Koloski, N., Harley, E., & Arnold, E. (2007). Development and validation of the Geriatric Anxiety Inventory. *International Psychogeriatrics*, 19: 103-114

Pakenham, K.I. & Rinaldis, M. (2001). The role of illness, resources, appraisal, and coping strategies in adjustment to HIV/AIDS. *AIDS Care*, 8: 15-31.

Park, C. L., Fenster, J. R., Suresh, D. P., & Bliss, D. E. (2006). Social support, appraisals, and coping as predictors of depression in congestive heart failure patients. *Psychology & Health*, 21(6): 773-789.

Park, C. L., Malone, M. R., Suresh, D. P., Bliss, D., & Rosen, R. I. (2008). Coping, meaning in life, and quality of life in congestive heart failure patients. *Quality Of Life Research: An International Journal Of Quality Of Life Aspects Of Treatment, Care And Rehabilitation*, 17(1): 21-26.

Paukert, A. L., Lemaire, A., & Cully, J. A. (2009). Predictors of depressive symptoms in older veterans with heart failure. *Aging and Mental Health*, 13(4): 601-610.

Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1: 385-401

Rector, T.S., Kubo, S.H. & Cohn, J.N. (1987). Patients' self assessment of their congestive heart failure: II. Content, reliability and validity of a new measure-the Minnesota Living with Heart Failure questionnaire, *Heart Failure*, 3: 198–209

Roger, V.L., Go, A.S., Lloyd-Jones, D.M. et al. (2011) Heart Disease and Stroke Statistics - 2011 Update: A Report From the American Heart Association. *Circulation*, 123: e18-e209

Scarborough, P., Bhatnagar, P., Wickramasinghe, K., Smolina, K., Mitchell, C. & Rayner, M. (2010). *Coronary Heart Disease Statistics: 2010 Edition*. Loughborough: British Heart Foundation.

Scherer, M., Himmel, W., Stanske, B., Scherer, F., Koschack, J., Kochen, M. M., & Herrmann-Lingen, C. (2007). Psychological distress in primary care patients with heart failure: a longitudinal study. *British Journal of General Practice*, 57(543): 801-807.

Schulz, K.F., Altman, D.G. & Moher, D. For the CONSORT Group (2010). CONSORT Statement: Updated Guidelines for Reporting Parallel Group Randomised Trials. *Journal of Pharmacology & Pharmacotherapeutics*, 1(2): 100-107.

Sharpe, L. & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science Medicine*, 62(5): 1153-1166.

Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In: Brink, T.L. (Ed.), *Clinical Gerontology: A Guide to Assessment and Intervention* NY: The Haworth Press

Skinner, E.A., Edge, K., Altman, J. & Sherwood, H. (2003) Searching for the structure of coping: a review and critique of category systems for classifying ways of coping. *Psychology Bulletin*, 129: 216-269

Spielberger, C.D., Gorsuch, R.L., & Lushene, R.E. (1970). *The State-Trait Anxiety Inventory: Test manual*. Palo Alto, California: Consulting Psychologist Press.

Spielberger, C. D., Johnson, E. H., Russell, S. F., Crane, R. J., Jacobs, G. A., & Worden, T. I. (1985). The experience and expression of anger: Construction and validation of an anger expression scale. In M. A. Chesney & R. H. Rosenman (Eds.),

Anger and hostility in cardiovascular and behavioral disorders. Hemisphere: McGraw-Hill.

Stanton, A.L. & Snider, P.R. (1993). Coping with a breast cancer diagnosis: a prospective study. *Health Psychology*, 12: 16-23.

Trivedi, R. B., Blumenthal, J. A., O'Connor, C., Adams, K., Hinderliter, A., Dupree, C. & Sherwood, A. (2009). Coping styles in heart failure patients with depressive symptoms. *Journal of Psychosomatic Research*, 67(4): 339-346.

Watson, D., Clark, L. A., & Carey, G. (1988). Positive and Negative Affectivity and their relation to anxiety and depressive disorders. *Journal of Abnormal Psychology*, 97: 346-353

Yesavage, J. A., T. L. Brink, et al. (1982). Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of Psychiatric Research* 17(1): 37-49.

Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67: 361-370

Zile, M.R. (2003). Heart failure with preserved ejection fraction: is this diastolic heart failure? *Journal of the American College of Cardiology*, 41: 1519-1522.

Zung, W.W.K. (1965). A self-rating depression scale. *Archives of General Psychiatry*, 12: 63-70

Part Two: Empirical Research

The Role of Perceived Control in the Perception of
Breathlessness Severity in Heart Failure

The role of perceived control in the perception of
breathlessness severity in heart failure

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This paper is written in the format for submission to the British Journal of Health Psychology. See Appendix 7 for the Author Guidelines. Word count (exc. figures/tables): 5000 words

Abstract⁵

Objectives:

To investigate the relationship between important factors (health-related perceived control, distress, and the subjective perception of breathlessness severity) for heart failure (HF) patients in the experience of their condition.

Design:

A cross-sectional correlational design was employed, involving quantitative self-report recording of perceived control, perceived breathlessness and distress.

Methods:

Adult HF patients with symptoms of breathlessness (N=54) completed the Control Attitudes Scale- Revised, The Modified Borg Scale and the Hospital Anxiety and Depression Scale, and provided additional demographic information. Clinician determined HF severity (NYHA classification) and date of diagnosis of HF from echocardiogram was also recorded.

Results:

Partial correlations indicated a significant relationship between perceived control and perceived breathlessness when controlling for other factors. However, whilst perceived control significantly correlated with anxiety, perceived breathlessness did not significantly correlate with scores of anxiety. Only perceived breathlessness correlated with depression when other factors were controlled.

Conclusions:

Study findings were related to a cognitive model of distress in HF, in which control was described in terms of hopelessness rather than anxiety. Perceived control was implicated

⁵ Guidelines: Use of headings (as included). 250 words or less (word count: 222 words)

in the perception of breathlessness severity and it is suggested low cost and short term psychological interventions which enhance perceived control are developed, and used with patients even in the absence of mood disorder. Future research should seek to examine the relationship between perceived control and distress in HF. Limitations of the study are discussed.

Keywords: *heart failure; breathlessness; control; depression; anxiety*

Introduction

Chronic heart failure (HF) is an extremely debilitating condition, with an ever increasing prevalence, high mortality and poorly controlled symptoms (Edmonds et al, 2005). Furthermore, HF represents an extremely significant issue in terms of healthcare expenditure, currently constituting 2% of total healthcare expenditure in the UK (Hobbs, 2009). Among the physical symptoms of HF, breathlessness is the most commonly reported (Nordgren & Sørensen, 2003; Appendix 8.2). This represents a significant issue in the management of HF patients, who frequently present at hospital worried that their severe symptoms of breathlessness are an indication of an acute threat to life, due to the existential terror cognitions episodes of breathlessness can awaken (Edmonds et al, 2005). Breathlessness, or ‘dyspnoea’, is defined as a symptom of disordered breathing, which involves complex interactions between physical, psychological and functional factors (O’Driscoll, Corner & Bailey, 1999). Much of the literature uses the term ‘breathlessness’ interchangeably with dyspnoea (Chartered Society of Physiotherapy, 2002). However, the two can be conceptualised as distinct if dyspnoea is defined as difficult or laboured breathing which is externally observable by another, and breathlessness is considered the “subjective feeling of laboured breathing with and without dyspnoea and/or abnormal pulmonary functions” (West & Popkess-Vawter, 1994, p.622). For the purpose of this study the term ‘perceived breathlessness’ will be used, but with the assumption that the subjective experience of laboured breathing is a consequence of dyspnoea through organic heart dysfunction.

Proposed models of breathlessness emphasise the shared importance of psychological and physiological factors. Corner and colleagues (1995) described an integrated model that aims to facilitate a holistic understanding of breathlessness in the context of the individual’s life, illness experience and its meaning. As such, the emotional experience of breathlessness is considered inseparable from the physical

experience. Similarly, Gift (1990) proposed a multidimensional model of breathlessness which includes consideration of sensation, perception, distress, behavioural response and reporting symptoms and distress to others as components.

One of the major consequences of breathlessness is distress, concurrent with feelings of anxiety, fear and panic over the onset of breathlessness as a result of physical activity, and depression over the functional limitations it causes (Brendin et al, 1999). This relationship between breathlessness and distress has been examined in a range of health populations where breathlessness is a prevalent and distressing symptom, particularly in the advanced stages of many respiratory diseases including asthma, chronic obstructive pulmonary disease (COPD) and lung cancer (Bausewein et al, 2008). In all of these cases, it is consistently reported that distress is strongly related to the experience of breathlessness and reporting of symptoms, but not related to objective measures of breathlessness severity (Janson, Björnsson, Hetta & Boman, 2004; Van Peski-Oosterbaan et al, 1996; Martinez-Moragón et al, 2003). In a review of the literature in the domain of distress and breathlessness, Cameron, Leventhal and Love (1998) commented “...anxiety-related traits are not associated with poorer health or increased susceptibility to disease; instead, they are associated with biases in somatic perception and tendencies to over report symptoms.” (p.459). Indeed, within the large quantity of more recent research examining psychosocial factors which impact on breathlessness, this finding of a discrepancy between the personal appraisal of breathlessness, and the underlying physiological event has been consistently shown, with the influence of various psychological processes most commonly stated (De Peuter et al, 2004).

Many studies have examined different characteristics as potential variables that may impact on perceptual accuracy of breathlessness severity. Demographic characteristics such as age and gender have been examined with conflicting reports of

either an effect on perceptual accuracy (Tetzlaff et al, 1999), or none at all (Bijl-Hofland et al, 1999). However, competition between internal and external cues, learning, past experiences, and schemata have all been implicated in mediating the perceptual accuracy of breathlessness symptoms (De Peuter et al, 2004). For example, research has reported a functional relationship between breathlessness perception and previous experiences of breathlessness (Wilson & Jones, 1990).

A general model of illness representation which may be applicable to the perception of breathlessness severity in HF was described by Leventhal and colleagues (1992). This 'Common-sense' model of chronic illness (Appendix 8.1) suggests cognitions and affect are major determinants of health-related behaviour (Leventhal, Nerenz & Steele, 1984). Among the illness representation (belief) categories described in the model is the concept of perceived control (controllability). 'Health-related perceived control' can be defined as a measure of patients' beliefs about their ability to control their disease (Calfee et al, 2006). In the current study, it refers to the subjective assessment of the ability to determine or influence the outcome of symptoms of heart failure.

Dracup and colleagues (2003) investigated the impact of perceived control on emotional stress in HF patients. Their findings indicated perceived control significantly impacted on distress, with individuals with high perceived control experiencing less distress. Furthermore, individuals with high levels of perceived control were observed to perform significantly better on exercise tests in terms of distance, after controlling for factors such as demographic and health status, which indicated a superior functional status for these individuals. Furthermore, research has demonstrated a relationship between perceived control and health-related quality of life in HF (Heo et al, 2009). These findings suggest perceived control may be an important factor in the appraisal of illness symptoms such as breathlessness in HF.

Research has not explicitly explored the relationship between perceived control, distress and perceived breathlessness in the cardiac population, although some research has alluded to its potential importance. For example, in a qualitative investigation of HF patients' perceptions of breathlessness, Edmonds and colleagues (2005) found that the narratives of these patients suggested three particular experiences of breathlessness; "everyday", "worsening", and "uncontrollable". Whilst everyday breathlessness was not considered unmanageable, worsening breathlessness was reported to lead to hospital admission, and uncontrollable breathlessness was considered a difficulty even for medical professionals. The narratives recorded in this study did make some reference to control, anxiety and panic, but without further exploration. Furthermore, in a study conducted by Van Diest and colleagues (2005), it was suggested that for individuals with a pronounced tendency to experience negative affect, there may be confusion between the interpretation of the physiological processes of breathlessness and the psychological process of anxiety. For example, the same language is often used to describe symptoms in both cases, such as 'suffocating feeling' or 'fatigue'. Additionally, Johnson and Morse (1990) reported in their research that perceived control is a fundamental predictor of adaptation to cardiovascular conditions.

Perceived control has been recognised as an important factor in aetiology and maintenance of mood disorders (Chapman, Kertz & Woodruff-Brown, 2009). In particular, perceived control has been significantly associated with physiological symptoms in specific anxiety disorders including panic disorder suffocation fear, and agoraphobia (Sanderson, Rapee & Barlow, 1989; Zvolensky, Lejuez & Eifert, 1998; Appendix 8.3), and learned helplessness in depression (Seligman, 1975; Burger & Arkin, 1980). Much of this research has focused on the relationships between control, physical sensations and distress in acute stress situations. Conversely, chronic health problems such as HF involve enduring states of distress and limiting physical

symptoms, which is distinct from acute distress. Therefore, it may be more important to establish the relationships between these factors over time and across situations which may then better inform intervention and adjustment strategies for HF patients. However, mood disorders and cognitive behaviour therapy (CBT) literature base includes a wealth of information on the nature of perceived control, its relationship with distress, and how it can be cognitively challenged (for example, Wells, 1997).

Recently, a cognitive model of anxiety and depression applied to HF was published (Hallas, Wray, Andreou & Banner, 2011; Appendix 8.4), based on a study exploring coping strategies used by HF patients. This model is the product of several other cognitive models, including the common sense model of illness representations (Leventhal, Nerenz & Steele, 1984), a cognitive model of health anxiety (Salkovskis, 1996), Beck's work on depression (1967) and continued work exploring depression and anxiety by Clark and Steer (1996). According to the model, the appraisal processes which contribute to produce an anxious cognitive state include perception of threat severity, heightened sense of threat severity, a perceived lack of coping ability, and attention paid to the negative consequences of having HF. These appraisals are moderated by coping appraisals and behaviours. It is formulated that depression in HF is often a comorbid product of anxiety, physically and emotionally limiting the individual resulting in negative cognitions regarding loss, failure which lead to a sense of hopelessness. Beliefs which develop from this depressive state, and from the chronic symptoms of heart failure are formulated to include a sense of loss of control regarding symptoms, role, function and well-being, and a perception that symptoms and the ongoing development of HF are unpredictable and constantly changing. Such beliefs increase the negative emotional states of anxiety and depression, and encourage the use of ways of coping which avoid focus on the stressor including behavioural disengagement and avoidance. Safety behaviours and cognitive biases are described as

perpetuating the state of negative affect. This model has significant relevance to the current study as it implicates perceived control, biased appraisal of physical symptoms, and comorbid depression and anxiety in the experience of HF for patients. However, the model requires further empirical investigation.

In summary, there is literature to suggest the importance of perceived control in the perception of physical symptoms such as breathlessness, and the experience of distress in HF. However, there has been limited research to date. Furthermore, there is a reliance on pharmacological interventions to reduce breathlessness, which can be expensive, time-consuming, and invasive (Cubbon & Witte, 2009; Zareba, Piotrowicz, McNitt & Moss, 2005). The aim of this study was to investigate the relationship between health-related perceived control, distress, and the subjective perception of breathlessness severity for HF patients. The research question for the current study was: what are the relationships between health-related perceived control, perceived breathlessness, distress and clinician determined disease functional classification in HF? It was hypothesised that anxiety and depression would positively relate with perceived breathlessness, and these factors would negatively relate to perceived control, based on Hallas and colleagues' (2011) model. A hypothesised model of breathlessness in HF is shown in Figure 2. It was also hypothesised that clinician determined illness severity would have a weak positive relationship with perceived breathlessness and distress, and no relationship with perceived control, based on the findings of Dracup and colleagues (2003).

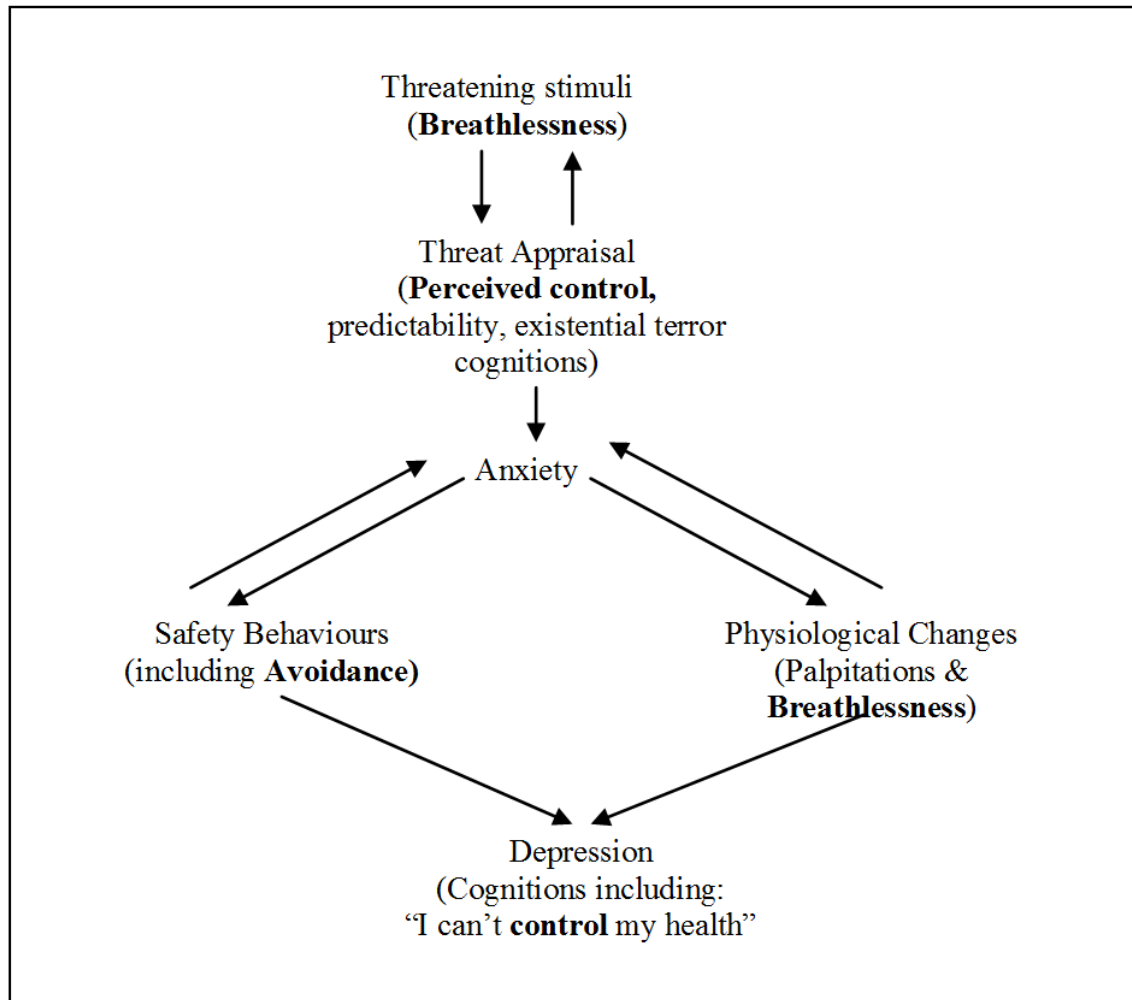


Figure 2: Hypothesised model of breathlessness in HF (based on Hallas et al, 2011)

Method

Design

A cross-sectional non-experimental correlational design was employed, using data from self-report questionnaire measures and additional clinical information provided by participants' clinicians.

Participant Criteria & Recruitment

Participants were recruited through a Community HF Nursing Team between March and May 2011. Potential participants were identified by Community HF Specialist Nurses by examining case loads against study inclusion and exclusion criteria

(Table 6). Potential participants were approached about the study by the nurses, or the researcher during routine home visits.

The primary research question was to examine the relationship between perceived control and perceived breathlessness, controlling for a total of seven confounding variables by partial correlation. No research to date has investigated this so there was limited data to base a power calculation on. It was therefore hypothesised that a correlation or effect size of 0.4 would be present. Assuming this effect size for a marginal correlation, a total sample size of 46 would give 80% power for a statistically significant relationship using a 5% significance level (G*Power; Buchner, A., Erdfelder, E., Faul, F, & Lang, 2009). For a partial correlation, the number of control variables need to be added to this sample size (Algina & Olejnik, 2003), leading to a required sample size of 53.

Table 6: Inclusion and exclusion criteria for participation in the current study (Appendix 9 describes criteria rationale)

Inclusion Criteria	Exclusion Criteria
Aged 18 and over	Congenital HF
A clinical diagnosis of HF made by a cardiologist and evidence of an echocardiogram showing left ventricular systolic dysfunction	Respiratory comorbidity (e.g. Chronic Obstructive Pulmonary Disease) – determined from patient’s medical records by patient’s clinician
New York Heart Association Functional (NYHA) Classification II-IV - determined by patient’s clinician (explained in Appendix 10)	NYHA Classification I Too ill to participate
Ability to give informed consent	Unable to provide informed consent (e.g. cognitive impairment) Undertaken implantation procedure such as cardiac defibrillator

Of the 59 patients approached to participate in the study, 2 were unable to provide informed consent due to cognitive impairment impeding capacity, 2 declined due to lack of interest and 1 declined due to the additional appointment time required to complete the measures. Overall, 54 patients participated in the study reflecting a response rate of 91.5%, and providing sufficient statistical power.

Measures

Demographics

Demographic details of age, gender and ethnicity were recorded by participants. In addition, participants consented to their clinician providing details of their NYHA classification (Appendix 10) and date of HF diagnosis.

Perceived Breathlessness

Perceived breathlessness was measured using the Modified Borg Scale (Borg, 1982), which has been widely used to measure the intensity of the sensation of breathlessness. The scale is a category scale spanning from zero to ten, with participants required to rate their level of breathlessness based on categorical descriptions with zero described as ‘no breathlessness at all’, five as ‘severe breathlessness’, and ten as ‘maximum breathlessness’. However, the scale also has ratio properties which allow statistical calculations (Molen, 1995). Whilst traditionally the Borg Scale has been used in conjunction with an exercise test as a measure of breathlessness being experienced in the moment, exercise testing of participants was not viable in the experimental procedure due to service limitations. Consequently, the Borg Scale was used by patients to rate perception of breathlessness in four different circumstances: their breathlessness in the moment of completing the questionnaire measures and their estimation of their breathlessness when it is at its best, its worst, and on average. The accumulative score of the four numerical ratings was used as a representation of the participants’ relative

breathlessness severity. The internal consistency of the Borg ratings in the current study had a Cronbach's alpha value of 0.73.

Health-Related Perceived Control

The Control Attitudes Scale-Revised (CAS-R) is an 8-item self-report questionnaire, designed to measure the level of perception of control specifically for individuals with cardiac disease, originally created by Moser and Dracup (1995). With scores ranging from 8 to 40, a higher score indicates greater perceived control. Each item is scored from one (totally disagree) to five (totally agree). In the current study, scale items referred to HF symptoms generally rather than exclusively symptoms of breathlessness to optimise the distinction between perceived control and perceived breathlessness severity. Previous research using a HF population reported a Cronbach's alpha of 0.76 and one factor analysis using principal component analyses was conducted and accounted for 39% of the total variance, with all items showing loadings greater than 0.40 (Moser et al, 2009). In the current study, a Cronbach's alpha of 0.86 was calculated.

Distress

The Hospital Anxiety and Depression Scale (HADS; Zigmund & Snaith, 1983) is a 14-item self report questionnaire used to examine symptoms of anxiety and depression in non-psychiatric hospital patients. The HADS excludes reference to somatic symptoms in order to avoid confounding caused by comorbid health problems (Snaith & Zigmund, 1994). The HADS includes independent anxiety and depression scales and each scale can be interpreted in the score ranges of normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). Research has concluded the HADS is a valid measure of anxiety and depression in the HF population, albeit with lower score cut-offs

to indicate clinically significant cases of four and above for the depression scale and seven and above for anxiety (Haworth, Moniz-Cook, Clark, Wang & Cleland, 2007).

The psychometric properties of the HADS within a cardiac population was assessed by Martin, Lewin and Thompson (2003), using patients who had experienced a myocardial infarction (MI⁶). Reliability for the overall HADS score, and individual anxiety and depression scales were investigated at three different time points after the MI event at 1 week, 6 weeks, and 6 months. Across these time points, the Cronbach's alpha value ranged from 0.87 and 0.90 for the overall HADS score, 0.83-0.86 for the anxiety scale, and 0.76-0.81 for the depression scale. Cronbach's alpha values in the current study were 0.81 for the total scale, 0.81 for the anxiety subscale and 0.69 for the depression subscale.

Procedure

Approval for the study was granted by a local NHS Research Ethics Committee (Appendix 11) and the Research and Development Department of the participating Trust (Appendix 12). Potential participants were approached and recruited during routine home visits undertaken by Community HF Specialist Nursing staff and accompanied by the researcher between April and May 2011. All participants were provided with written and verbal information regarding the study (Appendix 13) and if willing to participate provided written informed consent (Appendix 14). After consenting, participants were required to complete the four questionnaire measures and the HF Nurse conducting the visit recorded the patient's NYHA Classification and date of diagnosis from medical records. A schematic representing the experimental procedure is provided in Appendix 17.

⁶ MI refers to the sudden reduction of blood flow to the heart, commonly called a heart attack (Scarborough et al, 2010)

Data Analysis

Data was analysed using PASW v18.0 (SPSS Inc., 2009) for Windows. Pearson's and Spearman's correlations were conducted to identify the nature of relationships between distress, perceived control and perceived breathlessness. Independent t-tests and Mann Whitney U tests were used to identify differences between scores on these factors in different NYHA classifications. Finally, partial correlations were conducted to examine the relationships between the factors, controlling for demographic details. A total of nine variables were included in the partial correlations, with the effect of seven being controlled for in each analysis. The nine included variables in each partial correlation analysis were: age, gender, ethnicity, illness duration, clinician determined illness severity, perceived control, perceived breathlessness, anxiety and depression. Partial correlation analysis was chosen rather than regression analysis, as conceptually perceived control, perceived breathlessness and distress could be considered independent variables or outcome variables and a linear hierarchy could not be established based on past research.

Results

Descriptive Statistics

The mean age of participants (72.7 years) was somewhat lower than the population average age of diagnosis of HF in the UK (76 years) indicated by statistics (National Institute of Clinical Excellence, 2010). There were more male participants than females (55.6% males), which is reflective of the HF population nationally (Scarborough et al, 2010). The study sample included little ethnic diversity, with 90.7% Caucasian participants. The majority of participants were classified as NYHA II (57.4%) by the HF clinician involved in their care, with the remaining participants

classified as NYHA III (42.6%). Patients with NYHA IV were included in the study criteria, but no patients with this classification participated. The mean known duration of illness from diagnosis date was just over one year (13.02 months), although this varied widely from less than one month to five years nine months.

Details of scores obtained on the different self-report measures used in the study are provided in Table 7. Based on the range of scores on the Borg Scale, all participants reported some experience of breathlessness, consistent with their NYHA Classifications.

Based on the reduced cut-offs for clinically significant HADS scores in the HF population (Haworth et al, 2007), there was a high prevalence of clinically significant distress in the sample, with 55.8% of participants having clinically significant depression scores, 34.6% clinically significant anxiety scores, and 23.1% significant depression and anxiety scores.

Table 7: Scores obtained on self-report measures

Scale	Min. Score	Max. Score	Mean	SD
Borg Scale Total	1.5	29	9.53	5.79
CAS-R	12	40	31.76	7.11
HADS Anxiety	0	15	5.76	4.22
HADS Depression	0	12	5.39	3.27

Self-report measure scores were examined for departure from normality, and significant departure from normality was indicated by a value of skewness more than twice the value of the standard error (Coolican, 2004). CAS-R (skewness= -1.07, SE= 0.33) and Borg scale scores (skewness= 1.30, SE= 0.33) showed a significant negative skew and positive skew, respectively, indicating the use of nonparametric tests for these variables.

Measure Scores and Demographic Variables

Relationships between measure scores and demographic variables were examined, using correlation analyses for continuous demographic variables, and t-tests and Mann Whitney U tests where variables were categorical. Interestingly, there was a statistically significant moderate negative nonparametric correlation between participant age and Borg scale scores ($\rho = -0.31$, $N = 54$, $p = 0.03$), indicating perceptions of breathlessness reduced with increasing age. No other scores related to age, and gender, ethnicity and known duration of illness were not significantly related to any self-report measure scores.

Measure Scores and NYHA Classification

A Mann Whitney U-test showed that perceived breathlessness scores were significantly higher for participants with NYHA Classification III than for NYHA II ($U = (31, 23) = 218.5$, $p = 0.016$). An independent samples t-test indicated that HADS depression scores for participants with NYHA Classification III (mean = 6.78, SD = 2.91) were significantly higher ($t = -2.88$, $df = 52$, $p < 0.01$) than participants with NYHA Classification II (mean = 4.35, SD = 3.17). However, NYHA Classification did not relate significantly to HADS anxiety scores or CAS-R scores.

Perceived Breathlessness, Perceived Control, Anxiety and Depression

Scores on the Borg, CAS-R and HADS anxiety and depression scales were examined using both parametric and nonparametric correlation analyses to establish the best fit of the relationships. A moderate positive parametric correlation was found between HADS anxiety and depression scores ($r = 0.38$, $N = 54$, $p < 0.01$). Strong positive nonparametric correlations were found between scores on the Borg Scale and HADS

anxiety ($\rho = 0.43$, $N = 54$, $p < 0.01$) and HADS depression subscales ($\rho = 0.48$, $N = 54$, $p < 0.01$). In addition, strong negative nonparametric correlations were observed between scores on the CAS-R and HADS anxiety subscale ($\rho = -0.55$, $N = 54$, $p < 0.01$), HADS depression subscale ($\rho = -0.43$, $N = 54$, $p < 0.01$) and the Borg Scale ($\rho = -0.57$, $N = 54$, $p < 0.01$).

Parametric partial correlations were conducted between the measure scores, and nonparametric partial correlations were conducted using ranks of the data. In each case, demographic variables of age, gender and known duration of HF, NYHA Classification, and the measure scores not included in the correlation were controlled. When other variables were controlled for, there was no longer a significant relationship between HADS anxiety and depression scores ($r = 0.20$, $N = 54$, $p = \text{ns}$), Borg Scale scores and HADS anxiety scores ($r = 0.08$, $N = 54$, $p = \text{ns}$), and Borg Scale scores and HADS depression scores ($r = 0.19$, $N = 54$, $p = \text{ns}$). Furthermore, the correlation between CAS-R and HADS depression scores ($r = -0.14$, $N = 54$, $p = \text{ns}$) was no longer significant. Conversely, the strong negative correlation between CAS-R and Borg Scale scores remained significant ($r = -0.42$, $N = 54$, $p < 0.01$), and CAS-R and HADS anxiety scores maintained a moderate negative correlation after controlling for all other measured variables ($r = -0.39$, $N = 54$, $p < 0.01$).

Summary of Results

In summary, the study results indicated several significant relationships between perceived control, perceived breathlessness, distress and clinician determined illness severity. Perceived breathlessness and depression significantly increased with an increase in clinician determined HF functional severity. Perceived control and perceived breathlessness were strongly negatively correlated when controlling for other factors, and perceived control was moderately negatively correlated with anxiety. However,

perceived control was not related to depression when other variables were controlled, and perceived breathlessness was not related to depression or anxiety when controlling for other variables.

Discussion

Findings

This study aimed to investigate the relationship between health-related perceived control, distress, and the subjective perception of breathlessness severity in HF.

Perceived Breathlessness and Perceived Control

Perceived control and perceived breathlessness strongly correlated when controlling for confounding variables, with increased breathlessness severity related to reduced perceptions of health related perceived control. This is consistent with the cognitive model described by Hallas and colleagues (2011; Appendix 8.4). It is also conceptually plausible, as both are cognitive appraisals relating to HF. Whilst it could be asserted the close predictive relationship between these factors is evidence to suggest they are simply both examples of a single broader 'severity of illness' appraisal, it is evident the two appraisals are distinct. Firstly, perceived breathlessness is focused on a physiologically evident experience for the individual and the other is a less tangible psychosocial factor. Secondly, NYHA was significantly related to perceived breathlessness but not perceived control when controlling for other factors, which is reasonable, as the perception of breathlessness should at least be partly based on HF severity.

Perceived Control and Anxiety

The finding that perceived control was negatively correlated with anxiety was consistent with the hypothesis, and findings of past research (Dracup et al, 2003; Appendix 8.3). Hallas and colleagues' (2011) model proposes a direct relationship

between cognitive appraisal process such as perceived control and anxiety as early mechanisms in the maintenance cycle. The findings of the current study of a moderate correlation between anxiety and perceived control support the assertion that other appraisal mechanisms such as coping and self-efficacy also have a role in the anxiety response in HF. Future research should investigate the relative role of these factors in the experience of anxiety.

Perceived Control and Depression

However, the findings of the current study did not indicate a relationship between perceived control and depression when other factors were controlled for. Whilst perceived control is formulated as a component of the initial appraisal of the stressor related to anxiety in Hallas and colleagues' (2011) model, perceived loss of control is included separately as a cognitive component of a depressive state. The relationship between control and depression is conceptually logical, based on the theory of planned behaviour (Ajzen, 1991): With a lack of perceived control, motivation to attempt behaviours to avoid or mediate negative outcomes may be minimal, leading to apathy and helplessness (Bryant, 1989). Therefore the related personal appraisal factor of self-efficacy may also be involved which may account for the lack of relationship between control and depression found in the current study. This link between control, depression and behaviour is significant in the context of HF because a central goal of clinicians is to foster motivation in patients to mobilise their own coping resources to improve quality of life.

The study used a basic and unitary conceptualisation of perceived control to consider the relationships between the measured variables. In order to identify differences between perceived control which relates to anxiety and perceived control which relates to depression, more sophisticated models of perceived control need to be investigated. Research has demonstrated through factor analysis that perceived control

is a unitary factor (Ajzen, 2002). However, the role of different factors including self-efficacy, locus of control and mastery may all have different competing or complimentary roles in relation to perceived control (Ajzen, 2002) and distress and it may be these alternative factors which differentiate the relationship between perceived control and anxiety, and perceived control and depression.

Perceived Breathlessness and Distress

The study findings indicated no direct relationship between perceived breathlessness and depression or anxiety. The shared relationships of perceived breathlessness and anxiety with perceived control indicated an indirect relationship between perceived breathlessness and anxiety, which was consistent with the model by Hallas and colleagues (2011). However, an indirect relationship between breathlessness and depression was not indicated by the study findings. Although breathlessness is a chronic symptom in HF, its presentation and impact fluctuate significantly based on physical activity. However, other more consistent physical symptoms of HF such as oedema may be more applicable to depression. The study was based on an assumption that breathlessness is a severe and under-researched symptom in HF (Johnson, Oxberry, Cleland & Clark, 2010). In reality isolating the impact of specific symptoms on emotional wellbeing is not possible, but the overall relationship between HF and depression is well documented in the literature (Havranek, Ware & Lowes, 1999).

Depression and Anxiety

The model by Hallas and colleagues (2011) emphasised the comorbidity of depression and anxiety in HF based on the complex relationships between cognitive, emotional and behavioural factors. The current study sample included high rates of depression, anxiety, and indeed a high rate of comorbidity of these dimensions of distress in HF. However, the study did not find a significant direct relationship between depression and anxiety when other factors were controlled. This indicates that

depression and anxiety are more independent than suggested in the model by Hallas and colleagues (2011), and potentially involve distinct onset and maintenance mechanisms.

Perceived Breathlessness and Age

An intriguing finding which did not relate to the experimental hypothesis was the decrease in perception of breathlessness severity with age, which in many ways is counterintuitive. It can be postulated this finding reflected wider cohort related factors which were not inherently considered in the current study. For example, this finding may indicate older HF patients are more perceptually accurate (Tetzlaff et al, 1999), have on average had longer to adjust to their illness, or have lower expectations for their own physical activity levels. In contrast, younger HF patients may have additional difficulties adjusting to HF based on contrasts with life stage expectations and additional physical demands. It is recommended further research examines this finding further in relation to cohort factors and expectations.

Limitations

A major limitation was the use of NYHA classification as an indicator of HF illness severity. Whilst NYHA Classification is based on clinical indicators of functioning such as pulse oximetry, LVEF⁷ and blood pressure, clinician ratings of HF are unavoidably subjective and as indicated in this study, are bi-directionally related to distress. More severe HF would plausibly increase levels of distress, but distress itself may lead to a decrease in general functioning and quality of life, and increased reporting of symptoms, leading to a higher clinician rating of HF severity. As the study procedure aimed to limit intrusiveness into patients' medical information, no objective data was collected regarding clinically determined cardiac pathology, and it is suggested future research includes this.

⁷ Left ventricular ejection fraction (LVEF) refers to the unit quantity of blood pumped from the left ventricle of the heart per heart beat.

In addition, the study used a modified version of the Borg scale as an assessment of perceived breathlessness severity, in the absence of an exercise test which was not possible due to service limitations. This Borg scale was not validated for use in the altered form, and the study would have been greatly improved with the use of a validated self-report measure of perceived breathlessness severity, or use of the Borg in response to an exercise test.

The study was also limited due to the lack of participants with NYHA Class IV. Consequently, the sample did not include those most impaired and potentially distressed by their HF condition. This limited the generalisability of the study considerably, as it is unknown whether more severe HF has a qualitatively different relationship to the factors of perceived control, perceived breathlessness and distress than mild and moderate HF impairment. The study was also limited by a relatively small sample size and a cross-sectional design. As such, causal relationships between factors could not be established or suggested as being representative of the larger HF population. Future research should seek to explore the experimental variables in a broader sample, preferably employing a longitudinal design to establish relationships between factors over time.

Strengths

As far as possible, the study included a homogenous sample of adult HF patients, which provided a reasonably robust sense of the relationship between the measured variables. Hence, the study successfully highlighted breathlessness as a significant symptom for HF patients, something which is neglected in research on the HF population compared to illness populations where respiratory difficulties are more overt, such as lung cancer and COPD. The study was also innovative in synthesising research findings from chronic health population literature, and psychological research

in mood disorders regarding the role of health related perceived control in psychological and emotional functioning.

Further Research

This study highlighted several viable areas of future study, many of which have been discussed in relation to ambiguous findings or study limitations. In particular, investigating the causal relationships between the measured factors using a longitudinal design and clinical indicators of HF severity would provide a greater insight into the validity of the model provided by Hallas and colleagues (2011). There still remain questions about the relationship between perceived control and distress and in particular the role of perceived control in depression. With regards to exploring the acute impact of a lack of perceived control related to extreme breathlessness in HF, another more specific paradigm would be needed, potentially utilising an exercise test as a means of evoking more panic related control cognitions. The current study demonstrated relationships between emotions, cognitions and physiology in HF. However, further research should strive to explore the impact of the relationships between these domains on behaviour, considering the importance of health related behaviour in coping and quality of life.

Implications

Health-related perceived control was implicated in the experience of breathlessness, therefore reinforcing the need for low cost non-pharmacological interventions to enhance low perceived control, and ultimately reduce perceived breathlessness severity for HF patients. Such interventions may be in addition to or as an alternative to pharmacological treatments. Furthermore, the wealth of research on control as a cognitive factor involved in the formulation of distress in the CBT literature potentially indicates clinical health psychology can play a major role in informing and

implementing appropriate psychosocial interventions to address breathlessness with HF and other patient groups.

Conclusion

In conclusion, the current research provides evidence that health related perceived control may be an important factor in the perception of breathlessness severity and experience of anxiety in HF. Interventions focused at fostering an enhanced sense of control are recommended for reducing HF patients' experience of breathlessness severity and anxiety, and the functional limitations associated with these factors. In addition, the study indicated more complex relationships between perceived control, perceived breathlessness and depression, which should be explored in further research.

References

- Ajzen, I. (1991). The theory of planned behaviour. *Organizational Behaviour and Human Decision Processes*, 50: 179-211
- Ajzen, I. (2002). Perceived behavioral control, self efficacy, locus of control, and the theory of planned behaviour. *Journal of Applied Social Psychology*, 32(4): 665-683.
- Algina, J. & Olejnik, S. (2003) Generalized Eta and Omega Squared Statistics: Measures of Effect size for some common research designs. *Psychological Methods*, 8: 434-447
- Bausewein, C., Booth, S., Marjolein, G. & Higginson, I.J. (2008). Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. *Cochrane Database of Systematic Reviews: Reviews (2)*. John Wiley & Sons
- Beck, A.T. (1967). Depression: clinical, experimental and theoretical aspects. New York: Harper Row
- Bijl-Hofland, I.D., Cloosterman, S.G.M., Folgering, H.Th,M., Akkermans, R.P. & van Schayck, C.P. (1999). Relation of the perception of airway obstruction to the severity of asthma. *Thorax*, 54: 15-19.
- Borg, G.A.V. (1982). Psycho-physical bases of perceived exertion. *Medical Science Sports Exercise*, 14: 377-381.

- Bredin, M., Corner, J., Krishnasamy, M., Plant, H., Bailey, C. & A'Hern, R. (1999). Multicentre randomised controlled trial of nursing interventions for breathlessness in patients with lung cancer. *British Medical Journal*, 318(7188): 901-904
- Bryant, F.B. (1989). A four-factor model of perceived control: avoiding, coping, obtaining and savouring. *Journal of Personality*, 57(4): 773-797.
- Buchner, A., Erdfelder, E., Faul, F., & Lang, A. (2009). G*Power (Version 3.1.2) [Computer program]. <http://www.psych.uni-duesseldorf.de/aap/projects/gpower/>
- Burger, J.M. & Arkin, R.M. (1988). Prediction, control, and learned helplessness. *Journal of Personality and Social Psychology*, 38(3): 482-491.
- Calfee, C.S., Katz, P.P., Yelin, E.H., Iribarren, C. & Eisner, M.D. (2006). The influence of perceived control of asthma on health outcomes. *Chest*, 130(5): 1312-1318
- Cameron, L.D., Leventhal, H. & Love, R.R. (1998) Trait anxiety, symptom perceptions, and illness-related responses among women with breast cancer in remission during a tamoxifen trial. *Health Psychology*, 17: 459-469.
- Chapman, L.K., Kertz, S.J. & Woodruff-Borden, J. (2009). A structural equation model analysis of perceived control and psychological distress on worry among African American and European American young adults, *Journal of Anxiety Disorders*, 23: 69–

Chartered Society of Physiotherapy (2002). *Priorities for Physiotherapy Research in the UK: Topics prioritised by the cardiorespiratory expert panel [Annex 1]: Topic CR4: Breathing Exercises and the Breathless Patient*. London: Chartered Society of Physiotherapy.

Clark, D.A. & Steer, R.A. (1996). Empirical status of the cognitive model of anxiety and depression. In: Salkovskis, P.M. (Ed.) *Frontiers of cognitive therapy*. New York: Guildford Press

Coolican, H. (2004) *Research Methods and Statistics in Psychology (4th edition)*. London: Hodder & Stoughton.

Corner, J., Plant, H. & Warner, L (1995). Developing a nursing approach to managing dyspnoea in lung cancer. *International Journal of Palliative Nursing*, 1: 5-11.

Cubbon, R.M. & Witte, K.K.A. (2009). Cardiac Resynchronisation Therapy for Chronic Heart Failure. *British Medical Journal*, 338: 1064-1069.

De Peuter, S., Van Diest, I., Lemaigre, V., Verleden, G., Demedts, M. & Van den Bergh, O. (2004) Dyspnoea: The role of psychological processes. *Clinical Psychology Review*, 24: 557-581.

Dracup, K., Westlake, C., Erickson, V.S., Moser, D.K., Caldwell, M.L. & Hamilton, M.A. (2003). Perceived control reduced emotional stress in patients with heart failure. *The Journal of Heart and Lung Transplantation*, 22(1): 90-93

Edmonds, P.M., Rogers, A., Addington-Hall, J.M., McCoy, A., Andrew, J.S., Coats, J. & Gibbs, S.R. (2005). Patient descriptions of breathlessness in heart failure.

International Journal of Cardiology. 98: 61-66

Gift, A.G. (1990). Dyspnea. *Nursing Clinics of North America*, 25(4): 955-965.

Hallas, C.N., Wray, J., Andreou, P. & Banner, N.R. (2011). Depression and perceptions about heart failure predict quality of life in patients with advanced heart failure. *Heart Lung*. 40:111-121

Havranek, E.P., Ware, M.G. & Lowes, B.D. (1999) Prevalence of depression in congestive heart failure. *American Journal of Cardiology*,84(3): 348-350.

Haworth, J.E., Moniz-Cook, E., Clark, A.L., Wang, M. & Cleland, J.G.F. (2007). An evaluation of two self-report screening measures for mood in an out-patient chronic heart failure population. *International Journal of Geriatric Psychiatry*, 22(11): 1147-1153.

Heo, S., Moser, D.K., Lennie, T.A., Chung, M.L., Pressler, S.J., Arbor, A. & Dunbar, S.B. (2009). Factors associated with perceived control in patients with heart failure. *Heart & Lung*, 38(3): 262-263

Hobbs, R.F.D. (2009). Delivering quality and value in heart failure. *British Medical Journal*, 338: 1286.

Janson, C., Björnsson, E., Hetta, J. & Boman, G. (1994) Anxiety and depression in relation to respiratory symptoms in asthma. *American Journal of Respiratory and Critical Care Medicine*, 158: 1134-1141.

Johnson J.L. & Morse J.M. (1990) Regaining control: the process of adjustment after myocardial infarction. *Heart & Lung*, 19(2):126-135.

Johnson, M.J., Oxberry, S.G., Cleland, J.G.F. & Clark, A.L. (2010). Measurement of breathlessness in clinical trials in patients with chronic heart failure: the need for a standardized approach: a systematic review. *European Journal of Heart Failure*, 12: 137-147

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representation and coping with health threats. In Baum, A., Taylor, S. E. & Singer, J. E. (Eds.), *Handbook of Psychology and Health*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Martin, C.R., Lewin, R.J.P. & Thompson, D.R. (2003). A confirmatory factor analysis of the Hospital Anxiety and Depression Scale in coronary care patients following acute myocardial infarction. *Psychiatry Research*, 120: 85-94.

Martinez-Moragón, E., Perpiñá, M., Belloch, A., de Diego, A. & Martínez-Francés, M. (2003) Determinants of dyspnoea in patients with different grades of stable asthma. *Journal of Asthma*, 40: 375-382.

Molen, B. (1995). Dyspnoea: a study of measurement instruments for the assessment of dyspnoea and their application for patients with advanced cancer. *Journal of Advanced Nursing*, 22(5): 948-956.

Moser, D.K. & Dracup, K. (1995). Psychosocial recovery from a cardiac event: The influence of perceived control. *Heart & Lung*, 24(4): 273-280.

Moser, D.K., Riegel, B., McKinley, S., Doering, L.V., Meischke, H., Heo, S., Lennie, T.A. & Dracup, K. (2009). The Control Attitudes Scale-Revised: Psychometric Evaluation in Three Groups of Patients with Cardiac Illness. *Nursing Research*, 58(1): 42-51.

National Institute for Health and Clinical Excellence. (2010). *Chronic Heart Failure. [CG108]*. London: National Institute for Health and Clinical Excellence.

Nordgren, L. & Sörensen, S. (2003). Symptoms experienced in the last six months of life in patients with end-stage heart failure. *European Journal of Cardiovascular Nursing*. 2: 213-217

O'Driscoll, M., Corner, J. & Bailey, C. (1999). The experience of breathlessness in lung cancer. *European Journal of Cancer Care*. 8: 37-43

Salkovskis, P.M. (1996). The cognitive approach to anxiety: threat beliefs, safety-seeking behaviour and the special case of health anxiety and obsessions. In: Salkovskis, P.M. (Ed.) *Frontiers of cognitive therapy*. New York: Guildford Press

Sanderson, W. C., Rapee, R. M., & Barlow, D. H. (1989). The influence of an illusion of control on panic attacks induced via inhalation of 5.5% carbon dioxide-enriched air. *Archives of General Psychiatry*, 46: 157-162.

Scarborough, P., Bhatnagar, P., Wickramasinghe, K., Smolina, K., Mitchell, C. & Rayner, M. (2010). *Coronary Heart Disease Statistics: 2010 Edition*. Loughborough: British Heart Foundation.

Seligman, M. E. P. (1975). *Helplessness: On depression, development, and death*. San Francisco: Freeman.

Snaith, R.P., Zigmond, A.S. (1994). *The Hospital Anxiety and Depression Scale Manual*. NFER, Windsor: Nelson.

SPSS for Windows. Version 18.0 (2009) [Computer Program] Chicago: SPSS Inc.

Tetzlaff, K., Lепlow, B., ten Thoren, C. & Dahme, B. (1999). Perception of dyspnea during histamine- and metacholine- induced bronchoconstriction. *Respiration*, 66: 427-433.

Van Diest, I., De Peuter, S., Eertmans, A., Bogaerts, K., Victoir, A., & Van den Bergh, O. (2005) Negative affectivity and enhanced symptom reports: Differentiating between symptoms in men and women. *Social Science & Medicine*, 61, 1835–1845.

Van Peski-Oosterbaan, A.S., Spinhoven, P., Van der Does, A.J.W., Willems, L.N.A. & Sterk, P.J. (1996). Is there a specific relationship between asthma and panic disorder? *Behaviour Research and Therapy*, 34: 333-340.

Wells, A. (1997). *Cognitive Therapy of Anxiety Disorders: A Practice Manual and Conceptual Guide*. Chichester: John Wiley & Sons

West, N. & Popkess-Vawter, S. (1994). The subjective and psychosocial nature of breathlessness. *Journal of Advanced Nursing*, 20(4): 622-626.

Wilson, R.C. & Jones, P.W. (1990). Influence of prior ventilatory experience on the estimation of breathlessness during exercise. *Clinical Science*, 78: 149–153

Zareba, W., Piotrowicz, K., McNitt, S. & Moss, A.J., MADIT II Investigators (2005). Implantable cardioverter-defibrillator efficacy in patients with heart failure and left ventricular dysfunction (from the MADIT II population). *American Journal of Cardiology*, 95(12): 1487-1491.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67: 361–370.

Zvolensky, M. J., Lejuez, C. W., & Eifert, G. E. (1998). The role of offset control in anxious responding: An experimental test using repeated administrations of 20% carbon-dioxide-enriched air. *Behavior Therapy*, 29, 193-209.

PART Three: Appendices

Appendix 1: Reflective Statement

Introduction:

In this reflective statement, I aim to describe the journey I have taken through the process of undertaking my doctoral research. In reflecting on the process of my research, many parallel themes have emerged between the conceptualisation of my research and the experiences of the heart failure patients I met during data collection, and my own experience of the research process. In particular, themes about control, adjustment and adaptation were extremely apparent.

Removed for hard binding

Figure 3: The transition cycle - a template for human responses to change
(Adams, Hayes & Hopson, 1976)

Research Planning:

Excitement

Fresh from completion of a degree in Psychology, and acceptance onto the doctoral degree of Clinical Psychology, I was extremely excited to engage with all of the challenges of clinical training, including the clinical research element. I had relished my previous experience of research from my undergraduate studies, particularly completion of my dissertation. The entire process of taking a research question and hypothesis through testing, analysis and write up had provided a real sense of

achievement and self contained learning. However, my interest in research had always been in the value and use of the findings to the real world. Conducting a piece of clinical research gave me this opportunity and I was keen to begin the process.

Very early in the process of considering a research topic I decided on health psychology research. For me, the role psychological processes have in the experience and impact of physical conditions has been an enduring fascination of mine. A particular idea for a thesis project was presented by a member of staff involving a breathlessness intervention for individuals with heart failure. The prospect of an intervention study, although daunting fulfilled my interest in researching something overtly meaningful for patients. After discussing the study with my research supervisor, I began working on developing a sound psychological background for the study.

Despair

However, several months into the research process, after a great deal of literature reviewing and planning, I was informed the project was not appropriate for doctoral thesis. Up to this stage I had felt very much in control of the process of my research. However, the sudden realisation of the illusion of this control left me feeling shocked and angry over this decision, and I despaired at the prospect of starting the research process from the beginning again. Initially, I convinced myself that this decision would change and I would be able to continue the project as planned. For some time I found it difficult to consider other possible studies, ruminating on the loss of the study I had not considered would fail and struggling to shift focus from an intervention design to a cross-sectional correlational design. However, on reflection this is a common and necessary process in research; accepting some things are not possible and working within the confines of the context of the research.

After some time, with the pressure of departmental deadlines for peer review increasing, I developed a proposal for a new study with the same conceptual focus.

Whether my experience of losing control over the research had some impact on my choice of new research topic is unclear, but the potential role of perceived control in both breathlessness and anxiety had some clinical interest for me from cognitive behavioural models of anxiety and panic. As the proposal was created with limited time and was in many ways quite raw, the process of peer review was extremely beneficial in raising potential issues with the study. In particular, I was preoccupied with smaller details regarding the design of the project, and review of the proposal by peers provided me with a broader sense of how the relationships between the factors might be conceptualised using more of a process of formulation. However, at this stage of the research, early in my second year of training, I still felt my roles as trainee psychologist and researcher were distinct, and I feel I did not exploit my clinical experience and knowledge to improve the conceptual basis of the project as much as I could have done. However, by this stage, a study design and procedure had been formulated and I was ready to take the project forward.

Ethical Approval

Minimisation

Obtaining ethical approval for my study I believed was a particularly stress-free stage in the research process. At the time of applying for NHS Research Ethics Committee (REC) approval for the study, the majority of my peers had already completed the process and so peer anxiety about submission to REC had significantly reduced, and I was able to negotiate the sense of unknown about the process with the benefit of advice and guidance from my peers. I was being avoidant of the pressure to catch up with my peers and make up for some of the lost time spent on the first study proposal, which I justified to myself based on the demands of other course commitments. I have learned that time management is incredibly important on longer

scale research and without it, it is easy to become lost in the process without a specific aim. Again, this is key to therapeutic work and I had not begun to use my clinical knowledge for the benefit of the research. Furthermore, my study was ethically very low impact, which further reduced my concerns over the process. A study involving more vulnerable participants or a more complex procedure would have required a great deal more input at the stage of gaining ethical approval. I did not attend the REC meeting, but my study was approved first time with some conditions to be addressed for Research and Development (R&D) approval.

Setting up the Research

Uncertainty

Of the entire research process, the stage of setting up the research felt the most unknown, in terms of the etiquette of approaching clinicians, procedures and protocols, and the integration of conducting research into clinical practice. In fact, I did not know where to start. Unlike the process of REC approval which is very structured, concrete and time limited, setting up the research felt diffuse and intangible, and I had a sense of a lack of progress. Much of the reason for this was not being able to source a clinician in the field to co-supervise my research. In hindsight, I was possessive and overly protective of the project design, due to my previous experience of having to change the proposed research. It is plausible this may have impeded my motivation to seek a field supervisor, for fear of loss of control over the study. Consequently, my research design remained unchanged from my initial proposal, involving very specific requirements for the assessment of patients as part of data collection, including exercise testing and measurement of oxygen saturation. This was despite the service limitations regarding these requirements (the cardiology departments in the local trusts significantly reducing the use of these assessments or not using them at all). However, only after consulting

professionals in four trusts did I consider altering the study design. On reflection, this was further evidence of the lack of integration between my roles as researcher and psychologist. A key feature of clinical therapeutic work is collaboration. However, I had neglected this approach setting up the research, preferring to hold on to a rigid vision of the research despite the practical difficulties of implementation.

During this time I was also beginning work on the systematic literature review. The systematic process involved in systematic review provided escape from the uncertainty of the empirical study and producing written work felt rewarding. However, at some stage it became apparent I had underestimated the review as a piece of work, due to having no previous experience of the process. The level of rigour involved in deconstructing the reviewed studies required the development of new or underdeveloped skills in critical analysis and appraisal. This process allowed me to engage closely with the research and I felt immersed in the conceptual issues and experimental findings being discussed. The review process also significantly contributed to my sense of the empirical study and I felt a shift from viewing the two papers as distinct to acknowledging a strong sense of continuity between the two.

Losing Confidence

Eventually I accepted the need to change the proposed study, and using field consultation from a number of clinicians altered the design. This change also involved an application for a substantial amendment from the REC, which although approved, gave me a sense of the significance of the ethical process, and the importance of formulating a clear research design before going to ethics. Throughout the process of developing an alternative design I was deflated, and lacked the ambition to carry the project forward. It took time to accept the new changes and I held on to a feeling of hopelessness, preoccupied with the belief the design had been significantly weakened by the changes. Despite this however, I submitted the proposed study for R&D approval

and after receiving their approval, prepared to begin the data collection phase of the research.

Data Collection

Crisis

Data was collected in a very short period of time due to the generosity of clinicians based in the trust where I collected data allowing me to accompany them on several home visits a day and I learned that careful planning of the data collection phase resulted in very efficient use of time. However, at this stage I was several months behind schedule for completion of the thesis. At times the process of the research felt overwhelming. I was collecting data, writing my systematic review, discussing data analysis and beginning to write my empirical paper. There was no linear path to navigate or unpick. In an ideal world a good research plan with time frames would have assisted this issue, but I equally acknowledge it should be expected that a crisis stage is reached in all research before the write up process allows integration of theory and experience through analysis of data.

I have clear recollections of sessions with my research supervisor at this time. I felt de-motivated and unreceptive to discussion about conceptual aspects of the research, maintaining my concerns on more concrete issues such as the number of participants I required for statistical power. I felt short periods of re-established drive to get onto the write-up phase after meetings with my supervisor, who provided constructive reflective space as well as guidance on the research itself. However, the positive effect this had on productivity and clarity of thought faded after some time. In reflection with my supervisor, we questioned whether this could be formulated as a parallel process of the experience of patients who are feeling helpless and overwhelmed, attending an appointment with their clinician in which a sense of hope, optimism and

forward movement are fostered, only for this feeling to deplete in the days following the appointment.

Acceptance

It was during time spent with patients collecting data that I feel I resolved the crisis I experienced with my research. During the data collection process, I had many opportunities to speak to participants about the concepts I was measuring. Although my study used a quantitative methodology, at times I regretted this decision due to how important patient's experiences felt to understanding the factors I was measuring. These accounts were useful in bridging the relationship between the raw data I was collecting, and the lived experiences of patients, a process I acknowledge to be critical in drawing successful and meaningful conclusions about the data. Contact with patients awakened the clinical skills I had collected over the course of training. Understanding the factors in a real sense rather than simply conceptually allowed me to progress beyond the sense of uncertainty regarding the research design and procedure, to a state in which I was driven to formulate the relationships between these factors, and how they were impacting on the lives of the participants.

Writing up

Exploring and Testing

The writing up stage of the research was experienced with mixed feelings. On the one hand, finally producing the final document was incredibly rewarding, and an opportunity to make vague and intangible ideas more concrete. In contrast, in addition to the usual stress related to the need to produce a significant quantity of written work at a high standard, there was something frustrating about having to reduce the big expansive ideas about a topic that has been in your head for a considerable period of time, into text. Once again, not having control, over the format of the paper and the word count exacerbated these frustrations. The simplicity of the chosen design also did

not allow for the level of descriptive discussion I was compelled to produce, again indicating to me a potential interest in qualitative research, something I had little experience of. Furthermore, the necessity of consultation from a medical statistician is something I will never learn to take for granted!

Choice of Journals

Health Psychology Review was chosen for submission of the systematic literature review because of the broad implications relating to coping research discussed in the review having significance beyond the scope of just the heart failure population. The British Journal of Health Psychology was chosen for submission of the empirical paper, because the findings were based on a British sample, but again the conceptual implications for the research felt like they extended beyond the heart failure population, and may have been more relevant to individuals working in health psychology than exclusively heart failure specialist clinicians.

Viva

New Confidence & Transformation...?

Summary

With the intention not to invalidate the distressing experiences of patients attempting to adjust to the new realities of having a chronic heart condition, reflection on the research process has allowed me to acknowledge a particular transitional journey I have undertaken over the past three years as a trainee psychologist and a researcher, which strongly resembles the journey of a patient following diagnosis of heart failure. Furthermore, the theme of a need to feel in control, and the negative consequences when this perception was taken away was a consistent feature in my research journey. However, I have learned a great deal about the research process, in particular the

process of research in the context of clinical practice. I also recognise the utility of clinical skills in the process of research, such as collaboration, formulation, evaluation, reflection, supervision and consultation. I hope to exploit my clinical skills and expertise to better effect in the process of research in the future, and now having almost finished my clinical training I feel these roles have finally converged.

Reference:

Adams, J., Hayes, J. & Hopson, B.(1976). *Transition: Understanding and Managing Personal Change* London: Martin Robinson

Appendix 2: Author Guidelines for Health Psychology Review

Instructions for Authors

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Introduction

Submission of a paper to *Health Psychology Review* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of the editor and publisher.

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Submission process

Manuscripts must be submitted by one of the authors of the manuscript. The submitting author is responsible for the article during the submission and peer review process.

To facilitate the review process *Health Psychology Review* accepts only online submissions. All submissions should be made online at *Health Psychology Review's* ScholarOne Manuscripts site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Preparation of manuscripts

Currently, *Health Psychology Review* can only accept manuscripts written in English. Manuscripts should be double-spaced and should be prepared in accordance with the format and style specified in the Publication Manual of the American Psychological Association (APA), Sixth Edition. Pages should be numbered consecutively and organized as follows:

The Title Page (p. 1) should contain the article title, authors' names and affiliations. It should also include an author note with authors' full affiliations and the address for manuscript correspondence (including e-mail, address and telephone and fax numbers). In accordance with the APA Publication Manual (6th Ed.). No information that would indicate authors' identity or affiliation should be contained in the manuscript itself, all such information should be included on the title page only.

The Abstract (p. 2) must be a single paragraph that summarizes the main findings of the paper in fewer than 200 words. After the abstract a list of up to six keywords that will be useful for indexing or searching should be included.

Manuscript length

There is no formal word limit for manuscripts. Submissions should, however, be as long as necessary and authors of submissions of excessive length which do not convey ideas and points succinctly and concisely will be asked to truncate their manuscript. We also draw authors' attention to the Health Psychology Review online repository of supplemental materials that provides a permanently accessible resource of materials that are too long for the print version of the journal (e.g., oversized tables, intervention

protocols, questionnaires etc.) but to which authors of articles appearing in Health Psychology Review wish readers to have access.

Style guidelines

The manuscript should follow the guidelines of the APA Publication Manual, Sixth Edition.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Figures should be in a finished form suitable for publication and should be numbered consecutively with Arabic numbers in order of appearance in the text.

Tables should be numbered consecutively with Arabic numbers in order of appearance in the text. Type each table double-spaced on a separate page, with a short descriptive title typed directly above and with essential footnotes below.

Competing interests

A competing interest exists when your interpretation or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors should disclose all financial and non-financial competing interests.

Authors are required to complete a declaration of competing interests and submit it together with the manuscript. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'. Please consider the following questions:

Financial competing interests

In the past five years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this

manuscript, either now or in the future? Is such an organization financing this manuscript? If so, please specify.

Do you hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? If so, please specify.

Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.

Do you have any other financial competing interests? If so, please specify.

If you are unsure as to whether you, or one of your co-authors, has a competing interest please discuss it with the editorial office.

Authors' contributions

All authors are expected to have made substantive intellectual contributions to, and to have been involved in drafting or revising the manuscript. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship. With the submission of a manuscript, it is assumed that all authors have read and approved the final manuscript.

Acknowledgements

All contributors who do not meet the above criteria for authorship, should be listed in an acknowledgements section in accordance with the APA guidelines. The acknowledgements should be contained on the title page of the manuscript as making acknowledgements available to reviewers will compromise the masked peer-review process. Examples of those who might be acknowledged include those who provided

general, technical, or writing assistance. Acknowledgement of funding/grants are also included in this section.

Proofs

The manuscript will be edited according to the style of the journal, and PDF proofs will be e-mailed to the corresponding author for final review. To avoid delay in publication, only necessary changes should be made, and corrections should be returned promptly.

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Appendix 3: Supplemental Conceptual Information for Systematic Review

Figure 4: Health Crisis Model (Moos & Holahan, 2007):

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The health crisis model formulated by Moos and Holahan (2007) conceptualises coping skills within a broader framework informed by crisis theory, in order to describe the determinants of adaptation to chronic illness. According to the model (Figure 3), five distinct factors are involved in the selection of a given coping strategy. Health-related factors such as the onset and severity of the health condition, personal resources including past experience and demographic factors, and the social and physical context the individual is in dictate the appraisal of the health crisis. This appraisal influences the choice of adaptive tasks employed such as acceptance of an altered self identity, which further informs the selection of particular coping strategies. The model formulates that the outcomes related to this process of coping are health-related outcomes, such as quality of life, and mental health.

Reference:

Moos, R.H. & Holahan, C.J. (2007). Adaptive tasks and methods of coping with illness and disability. In: Martz, E. & Livneh, H. (Eds.). *Coping with Chronic Illness and Disability*. New York: Springer

Appendix 4: Study Quality Assessment Checklists

4.1 – Studies with a Quantitative Design

Research Quality Assessment Checklist	
Title:	
Author(s):	
Date:	
Journal:	
Criteria:	Score: Yes= 1 No or unable to establish= 0
1) Is the hypothesis/ aim/ objective of the study clearly described?	
2) Are the main factors to be measured clearly described in the Introduction or Method section?	
3) Is the conceptualisation/ model/ definition of ‘coping’ clearly established and outlined in the Introduction or Method section?	
4) Are the sample characteristics (age, gender, ethnicity, diagnosis duration etc) clearly defined?	
5) Have the inclusion and exclusion criteria been clearly described?	
6) Is the sample representative of the entire population from which they are recruited (heart failure population)? If no, is any sampling bias explained or accounted for?	
7) Are figures for drop-out rates and non-consent stated? Have reasons for drop-outs been identified and clearly stated?	
8) Are the questionnaire measures/ scales used clearly described?	
9) Are the main outcome measures justified as appropriate (validity and reliability)?	
10) Has the strategy of statistical analysis been clearly stated?	
11) Is the statistical analysis strategy used to analyse the main outcomes appropriate?	
12) Are the findings of the study clearly described?	
13) Have actual probabilities/ confidence intervals been reported for the main outcomes? E.g. 0.035 rather than <0.05, except for probability values <0.001	
14) Is the aim/ objective of the study clearly referred to/ answered in the Conclusion?	
15) Are limitations identified in the Discussion?	
16) Are implications identified and described in the Discussion/ Conclusion?	

Customised checklist based on Downs and Black (1998), CONSORT (2010) and NICE (2007).

4.2 – Studies with a Qualitative Design (NICE, 2007)

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References:

Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiological Community Health*, 52: 377-384

National Institute for Health and Clinical Excellence (2007). Appendix H Methodology Checklist: Qualitative Studies. In: NICE. The Guidelines Manual, 150-187.

Scarborough, P., Bhatnagar, P., Wickramasinghe, K., Smolina, K., Mitchell, C. & Rayner, M. (2010). *Coronary Heart Disease Statistics: 2010 Edition*. Loughborough: British Heart Foundation.

Schulz, K.F., Altman, D.G. & Moher, D. For the CONSORT Group (2010). CONSORT Statement: Updated Guidelines for Reporting Parallel Group Randomised Trials. *Journal of Pharmacology & Pharmacotherapeutics*, 1(2): 100-107.

Appendix 5: Study Data Extraction Pro Forma

Data	Information
Title name	
Year	
Author	
Country of origin	
Design	
Aim	
Models of coping used	
Sample size	
Response rates/drop outs	
Participant demographics (age/gender etc)	
Type of HF, severity/duration of illness etc	
Measures used	
Main results	
Main conclusions	

Appendix 6: Excluded Studies at Review of Full Article Stage

- Allman, E., Berry, D., & Nasir, L. (2009). Depression and coping in heart failure patients: a review of the literature. *Journal of Cardiovascular Nursing*, 24(2), 106-117.
- Albert, N. M., & Zeller, R. (2009). Depressed patients understand heart failure prognosis but not how to control it. *Heart and Lung: Journal of Acute and Critical Care*, 38(5), 382-391.
- Arnold, R., Ranchor, A. V., Koëter, G. H., De Jongste, M. J. L., & Sanderman, R. (2005). Consequences of chronic obstructive pulmonary disease and chronic heart failure: The relationship between objective and subjective health. *Social Science and Medicine*, 61(10), 2144-2154.
- Barremo, A., Bruce, E., Salander, M., & Sundin, K. (2008). Persons' experiences of living with congestive heart failure -- a systematic literature review [Norwegian]. *Nordic Journal of Nursing Research & Clinical Studies / Vård i Norden*, 28(3), 34-38.
- Bennett, S. J., Pressler, M. L., Hays, L., Firestine, L. A., & Huster, G. A. (1997). Psychosocial variables and hospitalization in persons with chronic heart failure. *Progress in Cardiovascular Nursing*, 12(4), 4-11.
- Brummett, B. H., Babyak, M. A., Mark, D. B., Clapp-Channing, N. E., Siegler, I. C., & Barefoot, J. C. (2004). Prospective Study of Perceived Stress in Cardiac Patients. *Annals of Behavioral Medicine*, 27(1), 22-30.
- Carels, R. A., Musher-Eizenman, D., Cacciapaglia, H., Perez-Benitez, C. I., Christie, S., & O'Brien, W. (2004). Psychosocial functioning and physical symptoms in heart failure patients - A within-individual approach. *Journal of Psychosomatic Research*, 56(1), 95-101.

Caroci, A. D. S., & Lareau, S. C. (2004). Descriptors of dyspnea by patients with chronic obstructive pulmonary disease versus congestive heart failure. *Heart & Lung*, 33(2), 102-110.

Dekker, R. L., Peden, A. R., Lennie, T. A., Schooler, M. P., & Moser, D. K. (2009). Living with depressive symptoms: patients with heart failure. *American Journal of Critical Care*, 18(4), 310-318.

Dougherty, C. M., Pyper, G. P., Au, D. H., Levy, W. C., & Sullivan, M. D. (2007). Drifting in a shrinking future: Living with advanced heart failure. *Journal of Cardiovascular Nursing*, 22(6), 480-487.

Edmonds, P. M., Rogers, A., Addington-Hall, J. M., McCoy, A., Coats, A. J. S., & Gibbs, J. S. R. (2005). Patient descriptions of breathlessness in heart failure. *International Journal of Cardiology*, 98(1), 61-66.

Gustavsson, A., & Bräänholm, I.-B. (2003). Experienced health, life satisfaction, sense of coherence, and coping resources in individuals living with heart failure. *Scandinavian Journal of Occupational Therapy*, 10(3), 138-143.

Joekes, K., Van Elderen, T., & Schreurs, K. (2007). Self-efficacy and overprotection are related to quality of life, psychological well-being and self-management in cardiac patients. *Journal of Health Psychology*, 12(1), 4-16.

Johnson, M. J., & Oxberry, S. G. (2010). The management of dyspnoea in chronic heart failure. *Current Opinions in Supportive Palliative Care*, 4(2), 63-68.

Karapolat, H., Eyigor, S., Atasever, A., Zoghi, M., Nalbantgil, S., & Durmaz, B. (2008). Effect of dyspnea and clinical variables on the quality of life and functional capacity in patients with chronic obstructive pulmonary disease and congestive heart failure. *Chinese Medical Journal*, 121(7), 592-596.

Kent, L. K., & Shapiro, P. A. (2009). Depression and related psychological factors in heart disease. *Harvard Review of Psychiatry*, 17(6), 377-388.

Koenig, H. G. (2006). Differences between depressed patients with heart failure and those with pulmonary disease. *American Journal of Geriatric Psychiatry*, 14(3), 211-219.

Koenig, H. G. (2007). Recognition of depression in medical patients with heart failure. *Psychosomatics*, 48(4), 338-347.

Koenig, H. G., Vandermeer, J., Chambers, A., Burr-Crutchfield, L., & Johnson, J. L. (2006a). Comparison of major and minor depression in older medical inpatients with chronic heart and pulmonary disease. *Psychosomatics*, 47(4), 296-303.

Koenig, H. G., Vandermeer, J., Chambers, A., Burr-Crutchfield, L., & Johnson, J. L. (2006b). Minor depression and physical outcome trajectories in heart failure and pulmonary disease. *Journal of Nervous and Mental Disease*, 194(3), 209-217.

Konstam, V., Moser, D. K., & De Jong, M. J. (2005). Depression and anxiety in heart failure. *Journal of Cardiac Failure*, 11(6), 455-463.

Lesman-Leegte, I., Jaarsma, T., Sanderman, R., Hillege, H. L., & van Veldhuisen, D. J. (2008). Determinants of depressive symptoms in hospitalised men and women with heart failure. *European Journal of Cardiovascular Nursing*, 7(2), 121-126.

Linden, W. (2002). Review: no definite conclusions can be drawn as to the effect of psychological factors in congestive heart failure. *Evidence-Based Mental Health*, 5(4), 124-124.

Moser, D. K., & Worster, P. L. (2000). Effect of psychosocial factors on physiologic outcomes in patients with heart failure. *Journal of Cardiovascular Nursing*, 14(4), 106-115.

Murberg, T. A., & Bru, E. (2001). Coping and mortality among patients with congestive heart failure. *International Journal of Behavioral Medicine*, 8(1), 66-79.

Murberg, T. A., Furze, G., & Bru, E. (2004). Avoidance coping styles predict mortality among patients with congestive heart failure: a 6-year follow-up study. *Personality and Individual Differences*, 36(4), 757-766.

Norra, C., Skobel, E. C., Arndt, M., & Schauerte, P. (2008). High impact of depression in heart failure: Early diagnosis and treatment options. *International Journal Of Cardiology*, 125(2), 220-231.

O'Hea, E., Houseman, J., Bedek, K., & Sposato, R. (2009). The use of cognitive behavioral therapy in the treatment of depression for individuals with CHF. *Heart Failure Reviews*, 14(1), 13-20.

Pattenden, J. F., Roberts, H., & Lewin, R. J. P. (2007). Living with heart failure; patient and carer perspectives. *European Journal of Cardiovascular Nursing*, 6(4), 273-279.

Ramasamy, R., Hildebrandt, T., O'Hea, E., Patel, M., Clemow, L., Freudenberger, R., & Skotzko, C. (2006). Psychological and social factors that correlate with dyspnea in heart failure. *Psychosomatics*, 47(5), 430-434.

Riedinger, M., & Singh, D. (2006). A range of factors influence health-related quality of life in people with heart failure. *Evidence-based Cardiovascular Medicine*, 10(2), 108-109.

Rohrbaugh, M. J., Cranford, J. A., Shoham, V., Nicklas, J. M., Sonnega, J. S., & Coyne, J. C. (2002). Couples coping with congestive heart failure: Role and gender differences in psychological distress. *Journal of Family Psychology*, 16(1), 3-13.

Rohrbaugh, M. J., Mehl, M. R., Shoham, V., Reilly, E. S., & Ewy, G. A. (2008). Prognostic significance of spouse we talk in couples coping with heart failure. *Journal of Consulting and Clinical Psychology*, 76(5), 781-789.

Rohrbaugh, M. J., Shoham, V., Cleary, A. A., Berman, J. S., & Ewy, G. A. (2009). Health consequences of partner distress in couples coping with heart failure. *Heart & Lung*, 38(4), 298-305.

Russell, C. K., Geraci, T., Hooper, A., Shull, L., & Gregory, D. M. (1998). Patients' explanatory models for heart failure and COPD exacerbations. *Clinical Nursing Research, 7*(2), 164-188.

Rustoen, T., Stubhaug, A., Eidsmo, I., Westheim, A., Paul, S. M., & Miaskowski, C. (2008). Pain and quality of life in hospitalized patients with heart failure. *Journal of Pain & Symptom Management, 36*(5), 497-504.

Ryan, M., & Farrelly, M. (2009). Living with an unfixable heart: a qualitative study exploring the experience of living with advanced heart failure. *European Journal of Cardiovascular Nursing, 8*(3), 223-231.

Scherer, M., Himmel, W., Stanske, B., Scherer, F., Koschack, J., Kochen, M. M., & Herrmann-Lingen, C. (2007). Psychological distress in primary care patients with heart failure: a longitudinal study. *British Journal of General Practice, 57*(543), 801-807.

Scherer, M., Stanske, B., Wetzel, D., Koschack, J., Kochen, M. M., & Herrmann-Lingen, C. (2006). Psychosocial co-symptoms in primary care patients with heart failure. *Herz, 31*(4), 347-354.

Schiffer, A. A., Pelle, A. J., Smith, O. R. F., Widdershoven, J. W., Hendriks, E. H., & Pedersen, S. S. (2009). Somatic versus cognitive symptoms of depression as predictors of all-cause mortality and health status in chronic heart failure. *Journal of Clinical Psychiatry, 70*(12), 1667-1673.

Selman, L., Beynon, T., Higginson, I. J., & Harding, R. (2007). Psychological, social and spiritual distress at the end of life in heart failure patients. *Current Opinion In Supportive And Palliative Care*, 1(4), 260-266.

Sherwood, A., O'Connor, C. M., Routledge, F. S., Hinderliter, A. L., Watkins, L. L., Babyak, M. A., Blumenthal, J. A. (2011). Coping Effectively With Heart Failure (COPE-HF): Design and Rationale of a Telephone-Based Coping Skills Intervention. *Journal of Cardiac Failure*, 17(3), 201-207.

Shimizu, Y., Yamada, S., Suzuki, M., Miyoshi, H., Kono, Y., Izawa, H., Murohara, T. (2010). Development of the Performance Measure for Activities of Daily Living-8 for Patients with Congestive Heart Failure: A Preliminary Study. *Gerontology*, 56(5), 459-466.

Turvey, C. L., Klein, D. M., Pies, C. J., & Arndt, S. (2003). Attitudes about impairment and depression in elders suffering from chronic heart failure. *International Journal of Psychiatry in Medicine*, 33(2), 117-132.

Vollman, M. W. (2003). Personal and situational factors influencing coping and depression in adults with heart failure. *Ph.D.*, Vanderbilt University. Retrieved from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2005035745&site=ehost-live> Available from EBSCOhost rzh database.

Vollman, M. W., Hepworth, J. T., & LaMontagne, L. L. (2004). Psychosocial factors and functional status predict depression in adults with heart failure. *Circulation*, 110(17), 1967.

Vollman, M. W., LaMontagne, L. L., & Hepworth, J. T. (2007). Coping and depressive symptoms in adults living with heart failure. *Journal of Cardiovascular Nursing*, 22(2), 125-130.

Vollman, M. W., LaMontagne, L. L., & Wallston, K. A. (2009). Existential well-being predicts perceived control in adults with heart failure. *Applied Nursing Research*, 22(3), 198-203.

Wallis, M., Boxer, E., Chaboyer, W., Grant, S., Bardsley, K., Carlson, M., & Lindqvist, R. (2006). Health related quality of life and coping in chronic illness: a pilot study. *Nursing Monograph*, 9-15.

Worcester, M. U. C., & le Grande, M. R. (2008). The role of cardiac rehabilitation in influencing psychological outcomes. *Stress and Health*, 24(3), 267-277.

Yeh, P., & Bull, M. (2009). Influences of spiritual well-being and coping on mental health of family caregivers for elders. *Research in Gerontological Nursing*, 2(3), 173-181.

Yu, D. S. F., Lee, D. T. F., Woo, J., & Thompson, D. R. (2004). Correlates of psychological distress in elderly patients with congestive heart failure. *Journal of Psychosomatic Research*, 57(6), 573-581.

Zambroski, C. H. (2003). Qualitative analysis of living with heart failure. *Heart & Lung*, 32(1), 32-40.

Zipfel, S., Lowe, B., Schneider, A., Herzog, W., & Bergmann, G. (1999). Quality of life, depression, and coping in patients awaiting heart transplantation. *Psychotherapie Psychosomatik Medizinische Psychologie*, 49(6), 187-194.

Appendix 7: Author Guidelines for the British Journal of Health Psychology

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond

this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review.

In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via <http://www.editorialmanager.com/bjhp/>. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper.

5. Manuscript requirement

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

6. Supporting Information

BJHP is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format

and is not copyedited or typeset. Further information about this service can be found at <http://authorservices.wiley.com/bauthor/suppmat.asp>

7. Copyright

Authors will be required to assign copyright to The British Psychological Society. Copyright assignment is a condition of publication and papers will not be passed to the publisher for production unless copyright has been assigned. To assist authors an appropriate copyright assignment form will be supplied by the editorial office and is also available on the journal's website at http://www.blackwellpublishing.com/pdf/CTA_BPS.pdf. Government employees in both the US and the UK need to complete the Author Warranty sections, although copyright in such cases does not need to be assigned.

8. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded here.

9. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

10. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit <http://authorservices.wiley.com/bauthor/> for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

11. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. The proof can be downloaded as a PDF (portable document format) file from this site.

Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site:

<http://www.adobe.com/products/acrobat/readstep2.html>. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Hard copy proofs will be posted if no e-mail address is available. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

12. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View

articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

Appendix 8: Supplemental Conceptual Information for Empirical Paper

8.1 - Common-Sense Model of Illness Representation

Figure 5: The Common-Sense Model of Illness Representation

(Leventhal, Nerenz & Steele, 1984)

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The model displayed in Figure 4 theorises that in the event of an acknowledgement of a somatic sensation such as a physiological limitation of breathing, the individual begins a parallel process of considering the perceived reality of the health threat using cognitive mechanisms, and emotional reactions to this threat. In such a situation, the individual actively problem solves by seeking information from various sources such as past experience and the immediate environment (interpersonal feedback for example), and actively tests semantic hypotheses about the sensation in order to form an appraisal. The illness representation is the cognitive construct responsible for coping-based decision making. Consequently, such representations are extremely

individual and subjective when compared to medically ascertained symptoms and their objective severity.

8.2 - Physiological Basis of Breathlessness in Heart Failure

The physiological basis of breathlessness as a physical symptom in heart failure is not fully understood, and some debate still exists in the literature regarding the exact cause (Witte & Clark, 2007). However, in general breathlessness in heart failure is caused by the impact of decreased heart functioning, both directly and indirectly to lung functioning. Two main causal explanations exist. The first explanation proposes that the requirement for increased left ventricular filling pressure in the heart to maintain cardiac output leads to inflexible lungs. This makes the muscular mechanism of breathing more difficult (Witte & Clark, 2007). The other explanation which has more empirical support is focused on the disruption of fluid homeostasis due to additional pulmonary fluid which causes an obstruction in the lungs, making absorption of oxygen through the alveoli less efficient. Fluid retention in heart failure occurs due to attempted compensation for reduction in the efficiency of the heart. Hormones are released which stimulate fluid retention in the kidneys to increase blood volume. This fluid become obstructive and enters the lungs and other tissue areas (Witte & Clark, 2007).

8.3 - Perceived Control in Mood Disorders

Perceived control has been implicated in the experience of physiological symptoms of anxiety in studies which have examined control processes in anxiety disorders. Experimental studies which have given participants the illusion of control in breathing carbon dioxide enriched air have shown that participants who believe they can control whether the air is carbon dioxide enriched report less anxiety related symptoms and less perceived breathlessness. These findings have been found for participants with

panic disorder and agoraphobia (Sanderson, Rapee & Barlow, 1989) and replicated in a normal population of participants which reported high levels of suffocation fear (Zvolensky, Lejuez & Eifert, 1998). Furthermore, Zvolensky and colleagues (2001) reported that participants who perceived less control over anxiety related events showed greater interpretive biases in relation to ambiguous stimuli compared to controls.

Perceived control of a stressor has also been implicated in the experience of depression, through the theory of learned helplessness (Seligman, 1975). This assertion has been supported empirically in different populations, that a lack of perceived control produces a state of learned helplessness and symptoms consistent with a depressive state (Weisz, 1979; Burger & Arkin, 1980).

8.4 - Cognitive Model of Anxiety and Depression for Heart Failure

Figure 6. Cognitive model of anxiety and depression applied to heart failure
(Hallas, Wray, Andreou & Banner, 2011)

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References

Beck, A.T. (1967). *Depression: clinical, experimental and theoretical aspects*. New York: Harper Row

Burger, J.M. & Arkin, R.M. (1980). Prediction, Control and Learned Helplessness. *Journal of Personality and Social Psychology*, 38(3): 482-491.

Clark, D.A. & Steer, R.A. (1996). Empirical status of the cognitive model of anxiety and depression. In: Salkovskis, P.M. (Ed.) *Frontiers of cognitive therapy*. New York: Guildford Press

Hallas, C.N., Wray, J., Andreou, P. & Banner, N.R. (2011). Depression and perceptions about heart failure predict quality of life in patients with advanced heart failure. *Heart Lung*. 40:111-121

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representation and coping with health threats. In Baum, A., Taylor, S. E. & Singer, J. E. (Eds.), *Handbook of Psychology and Health*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Rapee, R. M., Craske, M. G., Brown, T. A., & Barlow, D. H. (1996). Measurement of perceived control over anxiety-related events. *Behavior Therapy*, 27, 279-293

Salkovskis, P.M. (1996). The cognitive approach to anxiety: threat beliefs, safety-seeking behaviour and the special case of health anxiety and obsessions. In: Salkovskis, P.M. (Ed.) *Frontiers of cognitive therapy*. New York: Guildford Press

Sanderson, W. C., Rapee, R. M., & Barlow, D. H. (1989). The influence of an illusion of control on panic attacks induced via inhalation of 5.5% carbon dioxide-enriched air. *Archives of General Psychiatry*, 46, 157-162.

Seligman, M. E. P. (1975). *Helplessness: On depression, development, and death*. San Francisco: Freeman.

Weisz, J.R. (1979). Perceived control and learned helplessness among mentally retarded and nonretarded children: a developmental analysis. *Developmental Psychology*, 15(3): 311-319.

Witte, K.K. & Clark, A.L. (2007). Why does chronic heart failure cause breathlessness and fatigue? *Progress in Cardiovascular Diseases*, 49(5): 366-384.

Zvolensky, M. J., Heffner, M., Eifert, G. E., Spira, A. P., Feldner, M. T., & Brown, R. A. (2001). Incremental validity of perceived control dimensions in the differential prediction of interpretive biases for threat. *Journal of Psychopathology and Behavioral Assessment*, 23, 75-83.

Zvolensky, M. J., Lejuez, C. W., & Eifert, G. E. (1998). The role of offset control in anxious responding: An experimental test using repeated administrations of 20% carbon-dioxide-enriched air. *Behavior Therapy*, 29, 193-209.

Appendix 9: Rationale for Participant Inclusion and Exclusion Criteria (Table 8)

Inclusion Criteria	Rationale
<ul style="list-style-type: none"> • Aged 18 and over 	<ul style="list-style-type: none"> • Focus on the research was adults with HF only (for ethical reasons)
<ul style="list-style-type: none"> • A clinical diagnosis of HF made by a cardiologist and evidence of an echocardiogram showing left ventricular systolic dysfunction 	<ul style="list-style-type: none"> • To increase the reliability of the HF sample being homogeneous.
<ul style="list-style-type: none"> • New York Heart Association Functional (NYHA) Classification II-IV (mild to severe limitation of physical activity) - determined by patient's clinician 	<ul style="list-style-type: none"> • Classifications II-IV include physical limitations consistent with experience of breathlessness during the normal range of physical activity.
<ul style="list-style-type: none"> • Ability to give informed consent 	<ul style="list-style-type: none"> • An essential ethical criterion.
Exclusion Criteria	Rationale
<ul style="list-style-type: none"> • Congenital HF 	<ul style="list-style-type: none"> • Physiologically, this form of HF is qualitatively different from acquired HF.
<ul style="list-style-type: none"> • Respiratory comorbidity (e.g. Chronic Obstructive Pulmonary Disease) – determined from patient's medical records by patient's clinician 	<ul style="list-style-type: none"> • Respiratory comorbidity would not allow findings to be related exclusively to HF.
<ul style="list-style-type: none"> • NYHA Classification I 	<ul style="list-style-type: none"> • This classification refers to no functional limitations. Ordinary physical activity does not cause breathlessness which was a requirement for participation.
<ul style="list-style-type: none"> • Too ill to participate 	<ul style="list-style-type: none"> • An essential ethical criterion to not do harm or increase distress unless necessary.
<ul style="list-style-type: none"> • Unable to provide informed consent (e.g. cognitive impairment) 	<ul style="list-style-type: none"> • An essential ethical criterion.
<ul style="list-style-type: none"> • Undertaken implantation procedure such as cardiac defibrillator 	<ul style="list-style-type: none"> • This would confound the underlying physiological status of HF, and impact on the experience of breathlessness.

Appendix 10: New York Heart Association (NYHA) Functional Classification

Figure 7: NYHA Classification criteria (Criteria Committee for the NYHA, 1964)

Class	Limitations on Physical Activity	Symptoms with Physical Activity	Findings at Rest
I	None	None	Comfortable at rest
II	Slight	Symptomatic with greater than ordinary activities	Comfortable at rest
III	Marked	Symptomatic with ordinary activities	Comfortable at rest
IV	Any activity increases symptoms	Symptomatic at less than ordinary levels of activity	May or may not be symptomatic at rest

NYHA Classification is a four category system for categorising patients based on the extent to which they experience functional limitation during physical exertion, and clinical indicators of symptom severity (Criteria Committee for the NYHA, 1964). It is designed for ease of use by clinicians, and although subjective has been shown empirically to predict morbidity and mortality in HF patients (Witte & Clark, 2007).

References:

The Criteria Committee for the New York Heart Association (1964). *Nomenclature and Criteria for Disease Sixth Edition*. New York: Little Brown and Company

Witte, K.K. & Clark, A.L. (2007). Why does chronic heart failure cause breathlessness and fatigue? *Progress in Cardiovascular Diseases*, 49(5): 366-384.

Appendix 11: NHS Research Ethics Committee Approval Documentation



National Research Ethics Service

Sheffield Research Ethics Committee

Yorkshire and Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Telephone: 0113 3050127

09 September 2010

Mr J D Hyman
Trainee Clinical Psychologist
Humber Mental Health Foundation Trust
Hertford Building
The University of Hull
HU6 7RX

Dear Mr Hyman

Study Title: The Role of Health-Related Perceived Control in the Perception of Breathlessness Severity and Affect in Heart Failure
REC reference number: 10/H1308/58

The Research Ethics Committee reviewed the above application at the meeting held on 06 September 2010.

Ethical opinion

During the Committee meeting members noted that the results of the walk test will be written on the bottom of the anonymised form, but the participant could be identified by you through the consent form. The Committee suggested that if a participant wishes to withdraw from the study, then you would need to know who that participant is.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in Yorkshire

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

1. You ensure that the personal computers used in the study will be password protected and only used to analyse anonymised data.
2. That the PIS is presented on headed paper.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		
Protocol		01 January 2010
Confirmation of application booked through yorkshire and humber REC local allocation system	1	28 October 2009
REC application		03 August 2010
Questionnaire: Hospital Anxiety and Depression Scale questionnaire		
Participant Information Sheet	1.0	12 June 2010
Participant Consent Form	1	12 June 2010
Questionnaire: Control attitudes scale revised		
Questionnaire: Demographic Questionnaire		
Questionnaire: The borg scale		
Supervisors CV Dr Dorothy.J. Frizelle		
Research Protocol summary diagram		
Peer review forms		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1308/58

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Mr N Sykes
Vice Chair

Email: Nicola.mallender-ward@leedspft.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

*Copy to: Stephen Walker, Humber NHS Foundation Trust
Humber Mental Health Foundation Trust
Research & Development Department
Trust Headquarters
Willerby Hill
HU10 6ED*

Sheffield Research Ethics Committee

Attendance at Committee meeting on 06 September 2010

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Miss Lauren Baxter		Yes	
Dr J Burr	Lecturer in Foundations of Medicine and Ethics	No	
Dr Mary Cooke	Lecturer in Midwifery and Nursing	Yes	
Dr N D Edwards	Consultant Anaesthetist	No	
Dr N Hoggard	Consultant Vascular Radiologist	Yes	
Miss Pamela Kingman	Retired Care Home Manager	Yes	
Mr J Kirkland	Deputy Ward Manager	Yes	
Professor R M Loynes	Retired Professor of Statistics	No	
Mrs Jennifer Martin	Pharmacist	Yes	
Mr Ian Potter	Senior Operating Department Practitioner	No	
Dr Basil Sharrack	Consultant Neurologist	Yes	
Dr S Song	Consultant Diabetologist	No	
Mr N Sykes	Engineering Company Director/Owner	Yes	
Dr Angela Tod	Senior Research Fellow	No	
Mr Mark Wilkinson	Consultant Orthopaedic Surgeon	Yes	

Written comments received from:

<i>Name</i>	<i>Position</i>
Mr Ian Potter	Senior Operating Department Practitioner
Dr Angela Tod	Senior Research Fellow

In attendance:

Mrs Nicola Mallender-Ward

Ms Ann Tunley



National Research Ethics Service

Sheffield Research Ethics Committee

Yorkshire and the Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Tel: 0113 3050160

07 December 2010

Mr J D Hyman
Trainee Clinical Psychologist
Humber Mental Health Foundation Trust
Trainee Clinical Psychologist
Hertford Building
The University of Hull
HU6 7RX

Dear Mr Hyman

Study title: The Role of Health-Related Perceived Control in the Perception of Breathlessness Severity and Affect in Heart Failure
REC reference: 10/H1308/58
Amendment number:
Amendment date: 12 November 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 03 December 2010 by the Sub-Committee in correspondence.

Ethical opinion

There were no ethical issues.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Revised IRAS Form		22 November 2010
Summary/Synopsis		22 November 2010
Participant Consent Form	2	14 October 2010
Participant Information Sheet	3	09 November 2010

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Protocol	3	01 November 2010
Notice of Substantial Amendment (non-CTIMPs)		12 November 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H1308/58:	Please quote this number on all correspondence
---------------------	---

Yours sincerely



Mr John Robinson
Committee Co-ordinator

E-mail: john.robinson@leedspft.nhs.uk

Enclosures: List of names and professions of members who took part in the review

*Copy to: Stephen Walker
Humber NHS Foundation Trust
Research and Development Department
Trust Headquarters
Willerby Hill
Beverley Road
Willerby
Hull
HU106ED*

Sheffield Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 03 December 2010

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Dr Ruth Stirton	Lecturer in Law	Lay
Mr Neil Sykes	Retired	Lay
Mr Ian Potter	Senior Operating Department Practitioner	Expert

Appendix 12: NHS Trust Research and Development Department Approval

Documentation



NHS Bradford and Airedale
Research management and governance support team
Clinical Quality
Level 2
Douglas Mill, Bowling Old Lane
Bradford BD5 7JR

OurRef://RMG/Approval/approval_letter_version_3

Tuesday, 1st March 2011

Mr James D Hyman
Department of Clinical Psychology and Psychological Therapies
The Hertford Building
The University of Hull
Hull
HU6 7RX

Re: The Role Of Perceived Control In Breathlessness In Heart Failure

Ref no: 001_01_03_11_0000

Thank you for your recent submission to NHS Bradford and Airedale research management and governance support team.

Following consideration of your submission I am pleased to confirm that research management and governance approval has been granted by NHS Bradford and Airedale for the above research to take place as described in your completed application and accompanying documentation.

Conditions of approval

You should be aware that approval is granted subject to the conditions specified below:

- You must obtain an honorary contract and Letter of Access from NHS Bradford and Airedale prior to commencing your study
- All Global Governance checks must be completed on CSP ReDA
- All Local Governance must be completed on CSP ReDA
- Throughout the course of the study, all research activity should comply with relevant, current governance and regulatory requirements including (but not limited to)
 - The Research Governance Framework for Health and Social Care, 2nd Ed (2005)
 - The Medicines for Human Use (Clinical Trials) Regulations (2004) and subsequent amendments
 - The Mental Capacity Act (2005)
 - The Ionising Radiation (Medical Exposure) (Amendment) Regulations (2006)
 - The Medical Devices Regulations (2002) (Statutory Instrument 2002/618)

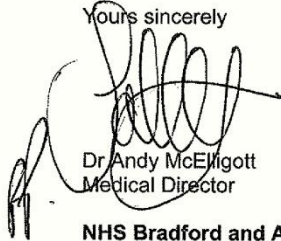
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Quality\Research\MASTER_RM_&_G\Approvals\10_11\001_01_03_11_0000_Hyman.doc

- o The Human Tissue Act (2004)
- o The Data Protection Act (1998)
- Consent for NHS Bradford and Airedale to audit your project, which is implicit in your acceptance of approval.
- Where any amendments, substantial or non substantial are made throughout the course of the study these should be notified to NHS Bradford and Airedale on the relevant form (available from <http://myresearchproject.org>)
- A copy of the final study report should be forwarded to NHS Bradford and Airedale on the relevant form (available from <http://myresearchproject.org>) no later than 3 months following study completion
- Should any serious adverse event(s) occur throughout the course of the study these should be notified to NHS Bradford and Airedale using the contact details set out above

Should you require any clarification regarding any of the points raised above, or have any further queries in relation to approvals and post approval study management process then please do not hesitate to contact me on 01274 237397.

Finally, may I take this opportunity to wish you well with your study and look forward to hearing about your progress in due course.

Yours sincerely



Dr Andy McEligott
Medical Director

NHS Bradford and Airedale

Ms Claire Seymour
Assistant Director – Medical Directorate

NHS Bradford and Airedale

Encs.

CC:

Appendix 13: Empirical Study Participant Information Sheet



Participant Information Sheet, v.3.2, 10.01.11

Health Related Perceived Control, Mood and Breathlessness in Heart Failure

I would like to invite you to take part in my research study. Before you agree to participate, I would like you to understand why the research is being done, and what it would involve for you. I will go through the information sheet with you, and answer any questions that you might have. Please talk to others about the study if you wish.

Purpose/aim of the research

This research is being conducted as part of the doctorate in Clinical Psychology programme at the University of Hull. The aim of my research is to provide a greater understanding of what impact a person's beliefs about their health has on their mood, and how much they experience breathlessness as part of heart failure. At the moment, this has not been looked at in heart failure research, but has been found to be a key issue for people suffering from other health problems, and has helped in the development of useful management strategies for people with these problems.

How the research will be carried out

During this research, I will be asking patients with heart failure who are attending a cardiology clinic appointment or are being visited at home by a heart failure nurse, to complete a questionnaire looking at health-related perceived control, and also a questionnaire looking at demographic details (age, gender, ethnicity etc). This can be done during the appointment, or after the appointment at home and sent back to clinic. To ensure confidentiality, identifying details like your name or initials will not appear on any of these questionnaires.

In addition to these questionnaires, some of the information the clinic staff will often be routinely collecting during the appointment will also be used for the research. This will be the scores recorded on the mood rating scale called the HADS, and a breathlessness rating. There are also some questions on the demographic questionnaire about when you were diagnosed and a medical classification of your heart failure which you may not remember, and so the clinician conducting your appointment can answer these if you agree.

Why have I been asked?

You have been invited to take part as someone who has a diagnosis of heart failure and experiences some breathlessness because of this. You have been identified as a potential participant by community heart failure nurse specialists, and have received this information as initial information about the study before considering taking part. However, it is completely up to you to decide to participate in the study. If you do not, no details of you will be made available to me and you will not receive any further contact from me.

What will happen?

On attending your clinic appointment or during your home visit you will be asked whether you have received and read the information, and are interested in participating in the study. This information sheet will be presented, and the information discussed with you so you can ask any questions you may have, or check any concerns. If you would still like to be involved I will ask you to sign a consent form.

Once this happens, you will complete the four questionnaires required for the research which will be made available to me. You will also complete your Cardiology clinic appointment or home visit as routine.

I will not have direct access to your medical notes; the information collected during your appointment will be provided to me directly on the forms they have been recorded on, with no identifiable information making them anonymous.

You are free to decide not to continue the research at any time, without giving a reason. At this point all information you have given for the research would be destroyed. This would not affect the standard of care you receive.

How the research will be used

As stated, the research is being conducted to fulfil a course requirement on the doctorate in Clinical Psychology programme. This means that the research will be submitted for assessment to the Department of Clinical Psychology and Psychological Therapies at Hull University. When the research is written up, only the questionnaire results and answers will be included, and confidentiality and anonymity will be maintained at all times.

You will be free to withdraw your data from the research up until the time it is submitted. In addition to submission to the university, it is likely that the research will be submitted for wider publication, for example in a peer-reviewed journal. This means that anybody else who is interested in this research will be able to access it. If you are interested in receiving a summary of the research you can request this from the cardiology team.

Potential disadvantages/advantages of participation

It is not expected that completion of the questionnaires will be distressing. However, if you do become distressed or have any concerns during or after completion of the questionnaires, these issues can be addressed by me or the visiting clinician during your appointment, or if any issues arise following the appointment, included with this information sheet is a list of my contact details for further consultation. The main disadvantage to participating in the research is the additional time completing the questionnaires will take, and this is expected to take no more than 15 minutes.

Whilst participating in the research may not provide you with any direct benefits, you will be contributing to valuable information about the experiences of heart failure patients with breathlessness, and it is hoped this will allow more effective interventions to be developed in the future.

What if there is a problem?

If you have a concern about any aspect of this study, I will do my best to answer your questions (contact details below). If you remain unhappy and wish to complain formally, you can do this by contacting the local NHS Patient Advice and Liaison Service (PALS). Their contact details are listed at the bottom of the sheet.

Who is funding this research?

The Humber Mental Health Foundation Trust is sponsoring this research. The research forms part of a course of study and is funded through that.

Who is reviewing this research?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Sheffield Research Ethics Committee.

Further information and contact details

Should you wish to obtain further information on this research please do not hesitate to contact me via the details below:

James Hyman
Department of Clinical Psychology and Psychological Therapies
Hertford Building, University of Hull
Cottingham Road,
Hull,
HU6 7RX
Tel: 07972139882
Email: j.hyman@2005.hull.ac.uk

If you wish to make a complaint regarding the research:

Bradford and Airedale PCT Patient Advice & Liaison Service (no stamp required)
FREEPOST RLZH-XTUZ-YAZK
Douglas Mill
Bowling Old Lane
Bradford
BD5 7JR
Tel: 01274 237555
Email: pals@bradford.nhs.uk

Appendix 14: Empirical Study Participant Consent Form



Consent Sheet, v.3.2, 10.01.11



CONSENT FORM

Title of Project:

The Role of Health-Related Perceived Control in the Perception of Breathlessness Severity and Affect in Heart Failure

Name of Researcher:

James Hyman

PLEASE INITIAL BOX

1. I confirm that I have read and understand the information sheet dated 10th January 2011 (version 3.2) for the above study. I have had the opportunity to consider the information, and if I have had any questions, these have been answered satisfactorily.

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

3. I understand that the following information recorded during my clinic appointment or home visit will be provided by Cardiology Department staff:
 - Control-Attitudes Scale-Revised (perceived control questionnaire)
 - Demographic Questionnaire
 - Score on the HADS (mood scale rating)
 - Borg Scale Rating (perceived breathlessness score)
 - Walk test and pulse oximetry data (where routinely collected)

4. I agree to my GP being informed of my participation in the study **IF** any concerns regarding my wellbeing arise. This will be discussed with me before any action is taken.

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

Name of Patient _____

Signature _____

Date _____

Name of Person taking consent _____

Signature _____

Date _____