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**Men Waiting for Heart Transplant:
An Interpretative Phenomenological Analysis (IPA)
and
Clinical Research Portfolio**

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BSc Honours in Applied Psychology

Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

Institute of Health and Wellbeing
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Chapter 1: Systematic Review:

What is the relationship between illness perceptions and outcomes in heart failure patients?

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ABSTRACT

Aim

There are known negative health outcomes associated with heart failure. Research has shown that illness perceptions, as conceptualised by the common-sense model of illness, are associated with health outcomes in chronic illness. This systematic review examines the role of illness perceptions in heart failure (HF) outcomes.

Methods

A systematic literature search was conducted in April 2018 on the databases Medline, Embase, CINAHL, PsychINFO and Web of Science using key words and subject headings. Articles were assessed against eligibility criteria. Included studies were quality assessed using an adaption of the AXIS tool (Downes, Brennan, Williams, & Dean, 2016). Individual study results were compared using narrative synthesis.

Results

Two longitudinal and eight cross-sectional studies were included. The most commonly measured outcomes were anxiety and depression symptoms. Results across studies were inconsistent. There was limited preliminary support for a relationship between 1) perceived consequences of HF and illness outcomes and 2) relationships between illness perceptions and anxiety and depression symptoms.

Conclusions

The differences in illness severity amongst participants, the application of outcome measures and the adjustment for covariates may partly account for the inconsistent results. The studies also lacked statistical power. Longitudinal designs and adjustment for co-variates are recommended for future studies.

INTRODUCTION

What is heart failure?

Heart failure (HF) occurs when the heart's ability to circulate blood around the body becomes impaired. It affects approximately 900,000 people in the UK (NICE, 2014). Average age at diagnosis is 77 years (Conrad et al., 2017). Prognosis following diagnosis is poor, with mortality at 36-38% within a year (Bleumink et al., 2004; Cowie et al., 2000). The New York Heart Association (NYHA) classifies severity from mild to severe: minimal symptoms are classified NYHA I; slight limitations to physical activity are classified NYHA II; symptoms whilst walking on the flat are classified NYHA III and patients whose functioning is severely limited are classified as NYHA IV (Mosterd & Hoes, 2007).

Role of illness perceptions

According to the common-sense model of illness perceptions, these are the representations individuals construct in response to a health threat (Leventhal, Meyer, & Nerenz, 1980). Following a diagnosis of heart failure, individuals will develop perceptions of what HF means to them, based on information obtained during diagnosis and from past experience (Leventhal, Phillips, & Burns, 2016; Weinman & Petrie, 1997). Research investigating the role of illness perceptions in acute and chronic health conditions has increased (Petrie, Jago, & Devcich, 2007) and associations have been found with numerous outcomes, including psychological wellbeing and quality of life (Hagger & Orbell, 2003).

Illness perceptions involve several key dimensions. Early research identified five dimensions: *control/cure* - the extent a person believes they can control or cure the illness; *consequences* - the anticipated outcomes of illness; *identity* - the symptoms perceived as part of the illness; *timeline* - the illness's expected duration; and *cause* (Weinman, Petrie, Moss-Morris, & Horne, 1996). Later research divided the control/cure dimension into *personal control* and *treatment control* - the extent a person believes either themselves, or their treatment can control the illness. A *cyclical timeline* dimension was also incorporated and measured perceptions regarding the changeability of symptoms (Moss-Morris et al., 2002). Several questionnaires have been developed to measure these dimensions in accordance with the common sense model of

illness: the Illness Perceptions Questionnaire (IPQ) (Weinman et al., 1996); the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) and the Brief Illness Perception Questionnaire (B-IPQ) (Broadbent, Petrie, Main, & Weinman, 2006). Differences in these questionnaires are detailed in Appendix 1b.

Illness perceptions in Heart Failure

Heart failure patients' negative outcomes include a higher prevalence of anxiety and depression than in the general population (Delville & McDougall, 2008; Konstam, Moser, & De Jong, 2005), poorer quality of life when compared to other chronic illnesses (Hobbs et al., 2002) and below optimal medical and lifestyle compliance (Van Der Wal et al., 2005). A meta-analytic study across a range of health conditions highlighted the importance of illness perceptions, particularly perceived consequences and symptoms, in determining illness outcomes (Hagger & Orbell, 2003). No studies with heart failure patients were included. Subsequent studies have investigated the role of illness perceptions in heart failure outcomes and there is some evidence for a role of illness perceptions in determining psychological distress (Hallas, Wray, Andreou, & Banner, 2011), quality of life (Mulligan et al., 2012) and medical adherence (Molloy et al., 2009). Interventions designed to target maladaptive illness perceptions have offered preliminary evidence for improved health outcomes (O'Rourke & Hampson, 1999; Petrie, Cameron, Ellis, Buick, & Weinman, 2002). A systematic review of the role of illness perceptions in heart failure outcomes therefore has the potential to inform clinical interventions.

Aim

This systematic review aims to provide a synthesis of the evidence concerning the relationships between illness perceptions, as defined by the common sense model of illness, and health outcomes in heart failure, such as psychological distress, health related quality of life and medication adherence.

METHODS

Search strategy

Scoping searches identified relevant studies and the indexing Medical Subject Headings (MeSH) and keywords. This informed the final syntax used to conduct the systematic literature search on the 12th April 2018 (Appendix 1c). The following databases were searched: Medline, Embase, CINAHL, PsychINFO and Web of Science. Results were limited to publications in English and from 1980, the year the common-sense model of illness was developed. The references of included studies were manually searched to identify additional relevant articles.

Eligibility criteria

Studies were included if: (1) participants were aged 18 years or over with a HF diagnosis; (2) illness perceptions were measured in line with the common sense model of illness using the IPQ, IPQ-R or B-IPQ; (3) outcomes were measured physiologically or with a standardised tool and (4) the relationship between illness perceptions and outcomes were reported. Studies were excluded if: (1) they utilised a qualitative or mixed methods design and (2) were non-peer reviewed (i.e. editorials, conference articles or dissertations).

Data selection

Data selection followed the process outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (Moher, Liberati, Tetzlaff, Altman 2009). Studies identified from the search strategy were screened and duplicates removed by the primary reviewer using reference management software. The primary reviewer screened the title and abstracts and excluded those not eligible. Where eligibility was unclear, the article was included for full text review. Potential articles were retrieved and independently assessed against the eligibility criteria by the primary reviewer. Those deemed suitable were included for data extraction and quality review.

Data extraction

Key data from each article was extracted into a Microsoft Excel spreadsheet and used to complete the table of results. This included inclusion and exclusion criteria, study recruitment, sample size and characteristics, IPQ and outcome measurement, IPQ dimensions reported, statistical analysis, correlation and regression results. Where applicable, adjustment for confounding variables, time from baseline to follow-up and numbers lost to follow-up were also included.

Quality assessment

The quality of included studies was assessed using a modified version of the AXIS tool as developed and documented for cross-sectional studies by Downes et al. (2016) (Appendix 1d). It distinguishes between three elements of critical appraisal: quality of reporting, study design and bias. In line with recommendations, study-specific questions were incorporated (Sanderson, Tatt, & Higgins, 2007). Two questions covered attrition bias specific to cohort designs, two considered the fidelity of measurement and reporting of illness perceptions and one question considered adjustments for confounding variables. Irrelevant questions were removed (“Was the study design appropriate for the stated aims” and “Were the results internally consistent”). Two researchers independently rated included studies against the items related to quality of reporting, study design and bias. Items were marked yes, no, partially or don’t know. Inter-rater reliability was 81% (Appendix 1e). Disagreements between reviewers were resolved through discussion (for rating discrepancies and examples of discussed resolutions, see Appendix 1f).

Data synthesis

Narrative synthesis was used due to the heterogeneity of result. Recommended guidelines were followed (Popay et al., 2006). Results were synthesised by study design and by physiological or self-reported outcome measurement.

RESULTS

Search results

Figure 1 is a flowchart of the study selection process. Following removal of duplicates screening and the application of the eligibility criteria, 11 of the initial 4553 articles were reviewed. Following data extraction and quality assessment, one further article was excluded due to poor quality (Wierenga, 2017) (see Appendix 1d). The remaining ten studies are reported in this review.

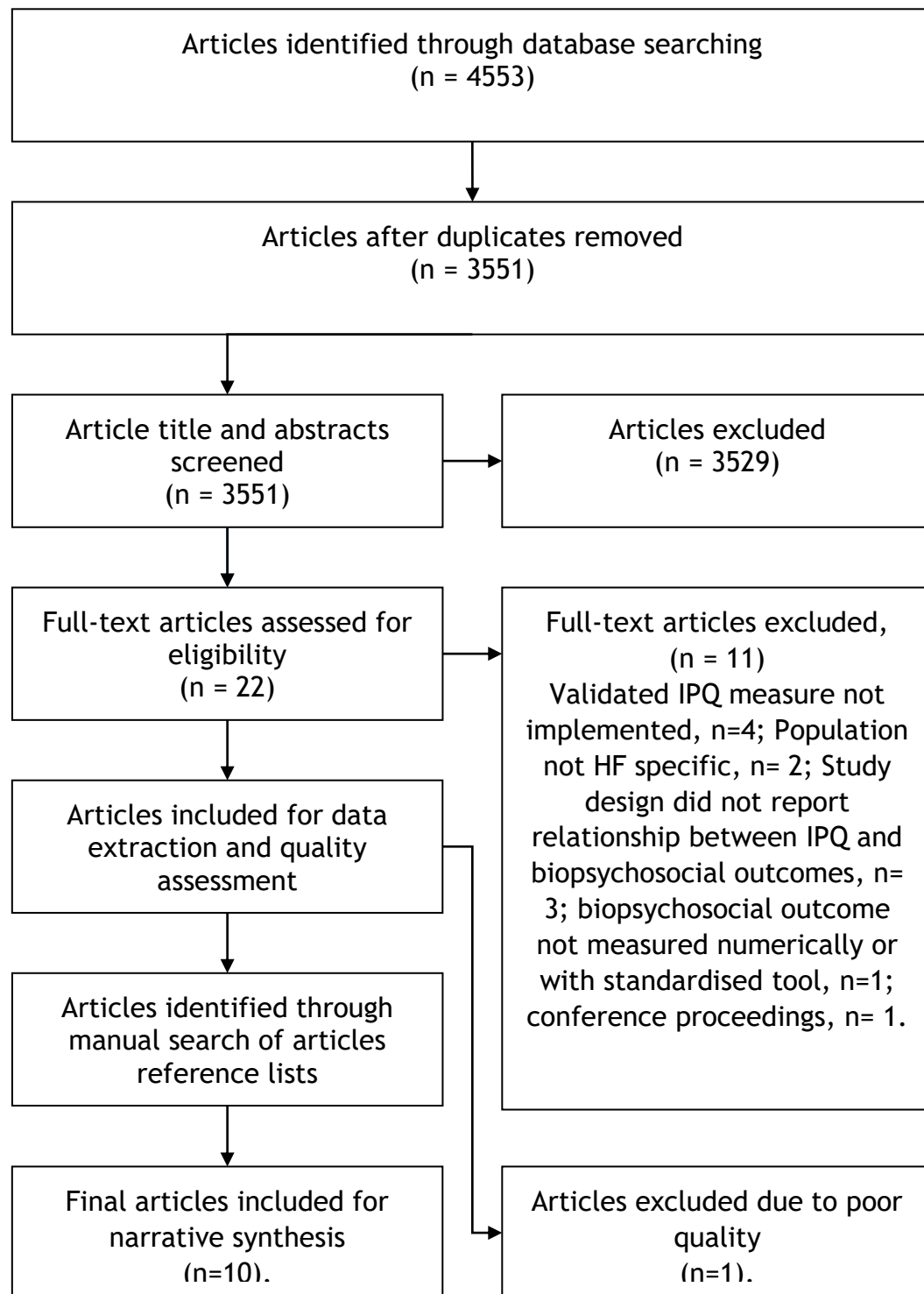


Figure 1 Participant flow diagram

Study characteristics

An overview of the ten included studies can be found in **Error! Reference source not found..** The mean age of participants was 62.4. The average proportion of males was 75%. The sample is therefore younger and predominantly more male compared to the United Kingdom HF population (Conrad et al., 2017). Five studies were conducted in the UK, two in the USA,

one in Italy, one in Ireland and one Europe wide. Studies included participants with different levels of illness severity, as measured by the New York Heart Association classification (NHYA) and only one study reported time with illness. Studies utilised prospective cohort (n=2) and cross-sectional (n=8) designs. The majority of studies used the IPQ-R (n=6), three used the B-IPQ and only one used the IPQ. The most commonly collected outcomes were anxiety and depression symptoms (n=6). Anxiety was measured using the Hospital Anxiety and Depression Scale (HADS) (n=5) and the Generalised Anxiety Disorder (GAD-7) (n=1). Depression was measured using the HADS (n=4), Patient Health Questionnaire (PHQ-9) (n=1) and Beck Depression Inventory (BDI) (n=1). Additional outcomes were self-care (n=3), quality of life (n=2) and medication adherence (n=2).

Quality assessment

Results from the quality assessment are presented in Appendix 1d. Assessment of study design found that two studies had samples with sufficient power (MacInnes, 2013; Turrise, 2016), one acknowledged an underpowered design (Goodman, Firouzi, Banya, Lau-Walker, & Cowie, 2013) and the remainder of studies did not report a sample size justification. Quality of reporting was mixed. Of concern, in half the papers methods were insufficiently described to allow study replication (Appendix 1d, Q10). In four papers inclusion and exclusion criteria were poorly defined (Appendix 1d, Q3). Risk of bias was considered across papers. Of the nine papers conducting statistical regression, only four adjusted for covariates (Appendix 1d, Q15). Eight of the ten studies failed to categorise non-responders (Appendix 1d, Q13). Six of the ten studies reported fewer IPQ dimensions than had been measured (Appendix 1d, Q21).

Table 1: Table of results

Author , Year, Region	Sample N, age, % male,. HF type	Response rate (1) baseline (2) follow up	IPQ version and dimensions reported (n/n)	Outcome measures	Key findings	Quality of reporting items “Yes” (n/n)	Study design items “Yes” (n/n)	Identified bias.
Prospective Cohort Studies								
Goodman et al. 2013. UK	88. Mean age 70.5, 70%. NYHA II = 36 (40%), NYHA III = 25 (28%) , NYHA I or IV = 9% (reported % did not add up to 100%).	(1) 88/170 (52%). (2) T2 6 months: 21 (24%) died; 17 (19%) follow- up questionnaires not returned. No significant differences in baseline characteristics	IPQ-R (3/8)	(1) Anxiety and Depression (HADS), (2) Self -Care (SCHFI), (3) Quality of Life (MLWHF).	CONS: Increased perceptions of HF as having serious consequences were associated with decreased emotional** and physical** quality of life, and “probable” anxiety** and depression** at 6-month follow up. IC: Increased perceptions of understanding HF associated with less “probable” anxiety** and depression** and increased self-care confidence** at 6-month follow up.	4/8	2/3	(1) Sample size not justified (2) No comparison made between responders and non-responders at baseline. (3) Covariates not adjusted for
Mulligan et al. 2012. UK	210. Median age 72, 66%, ethnicity NR. NYHA 1 = 0,	(1) 210/396 (53%). Significantly younger, more	IPQ (5/5 reported but only where	(1) Anxiety and Depression (HADS), (2) Quality of Life	Correlations <i>NR</i> . CONS: greater perceptions of HF as having serious consequences at baseline predicted less improvement in emotional QoL at 6 months**. Over 6 months:	7/8	3/4	(1) 13% lost to follow up unexplained. (2) No comparison with participants at baseline.

NYHA II = 19 (11%), NYHA III = 64 (39%), NYHA IV = 83 (50%).	males, increased LV. (2)T2 6 months: 166/210 (21% lost: 17 (9%) died; 27 (13%) unexplained)	significance (MLHF). found)	greater reduction in ID**, CONS**, C/C** associated with greater reduction in anxiety; greater reduction in ID** and CONS** associated with greater reduction in depression; greater reduction in ID** and CONS** associated with improved QoL.
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Cross Sectional Studies

Cherrington et al, 2006. USA.	22. Mean age 51, gender NR. NYHA III = 3 (13.6%), NYHA IV = 0	(1) 22/34 (64.7%)	IPQ-R (0/8)	Left ventricular dysfunction (LVEF)	No illness perceptions dimensions correlated with Left ventricular dysfunction.	8/8	3/4	(1) Small sample size (2) Non-responders uncategorised
Giardini et al, 2017. Italy.	120. Average age 57.2, 83.3%. NYHA II = 22 (18.3%), NYHA III = 89 (74.2%), NYHA IV = 9 (7.5%).	(1) 120/146 (82.2%)	B IPQ (8/8)	(1) Depression (BDI II), (2) Anxiety (HADS). (3) Dispositional optimism (LOT-R).	CONS: Increased perceptions of serious HF consequences correlated with decreased optimism**, increased depression ** and increased anxiety** symptoms. TC: Greater perceptions of treatment as effective in controlling HF correlated with increased optimism**. ID: Perceptions of HF as having more symptoms correlated with increased depression** and anxiety** symptoms and greater ID perceptions predicted more	7/8	3/4	(1) Non-responders uncategorised (2) Adjusted for age but no other covariates (3) Recruited from existing health programme.

depression symptoms**.

Hallas et al, 2011. UK.	146. Mean age 48.6, 82% NYHA NR.	(1) 146/284 (51.4%)	IPQ-R (8/8)	(1) Anxiety and Depression (HADS), (2) Coping strategies (COPE), (3) QoL measured for additional hypothesis.	Greater perceptions of HF symptoms as cyclical**, HF having serious consequences** and HF being outwith personal control* predicted greater depression scores. Greater perceptions of HF as having more symptoms** and symptoms as cyclical* predicted greater anxiety scores. CONS: Greater perceptions correlated with increased anxiety**, depression** and venting coping*. PC: greater perceptions correlated with decreased anxiety**, depression** and behavioural disengagement coping* TC: greater perceptions correlated with decreased anxiety**, depression**, behavioural disengagement coping**. ID: increased perceptions correlated with increased anxiety** and depression**. TLC: increased perceptions correlated with increased anxiety** and depression** IC decreased perceptions correlated with increased anxiety*, denial coping** and behavioural disengagement coping*.	7/8	3/4	(1) Recruited from one hospital only
MacInnes 2013. UK.	166. Mean age 70.89, 74.1%. NYHA I =	(1) 166/335. 50.4%.	IPQ R (5/8)	(1) Self-Care (LAYHFQ).	Self-care significantly correlated with CONS**, TC**, TLAC*, TLC**, IC**. CONS: greater perceptions that HF will have serious	4/8	3/4	(1) Non-responders uncategorised (2) Self-care measure lacks concurrent

	19.2%, NYHA II = 26%, NYHA III = 35.6%, NYHA IV = 19.2%.				consequences predicted greater total self-care scores**			validity, total score lacks clinical utility and subscales lack reliability (MacInnes, 2011) (3) Socio-demographics and illness severity not adjusted for.
Molloy et al, 2009. UK.	58. Mean age 80.2, 57%. NYHA II = 34 (59%), NYHA III = 24 (41%)	(1) 58/229. (25%) (147 chose not to participate, a further 24 not receiving relevant medication.)	IPQ-R (2/8)	(1) Medical adherence to angiotensin-converting-enzyme inhibitors (ACEI): defined as serum level <5U/L	CONS: greater perceptions that HF will have serious consequences predicted less medical adherence*. TLAC: greater perceptions that HF will last a long time predicted less medical adherence* 19% of the variance explained by model.	7/8	3/4	(1) Covariates not adjusted due to lack of statistical power.
Morgan et al, 2014. IRELAND	95. Mean age 73.1, 81%. NYHA I = 36.2%, NYHA II = 34.7%, NYHA III = 26.3%, NYHA IV = 6.3%.	(1) 95/110. 86%	IPQ-R (8/8)	(1) Anxiety and Depression (HADS)	PC: Decreased perceptions of HF as personally controllable correlated with increased depression** and anxiety**. Illness perceptions explained a significant proportion of the variance in both anxiety (33.7%*) and depression (35.3%*), after sociodemographic and NYHA class accounted for.	6/8	3/4	
Timmermans et al,	585. Average age 65, 79%.	NR	B-IPQ (0/8)	(1) Health Status (KCCQ)	“Threatening illness perceptions” associated with poor health status*, anxiety*, negative	7/8	3/4	(1) Threatening illness perceptions cut off (≥ 46)

2017. EUROPE	NYHA III= 194 (33%). NYHA I, II and IV NR			(2) Self-care (EHFScBS) (3) Anxiety symptoms (GAD-7). (4) Depressive symptoms (PHQ-9), (5) Type D personality (DS14), (6) implantable cardioverter defibrillator (ICD) related concerns (ICDC), (7) ICD acceptance (FPAS).	affectivity*, poor device acceptance* and depression*.			arbitrarily defined.
Turrise, 2016. USA	97. Mean age 68, 60%, NYHA class NR.	NR	B-IPQ (5/8)	(1) Medication Adherence: The Medication Adherence Report Scale (21-25 high adherence, 9- 20 low	PC: Increased perceptions correlated with “low” medical adherence category* but not significantly predictive when medical beliefs adjusted for. TC: Decreased perceptions correlated with a hospital readmission within 30 days of discharge**. Moderation analysis - ID: interacted with number of years living with HF to predict medication adherence -	3/8	1/4	(1) Non-responders uncategorised (2) High and low medication adherence arbitrarily defined. (3) Small sample size in low medication adherence group. (4) Depression measure not stated (5)

adherence). (2) 30 day hospital re- admission.	direction <i>NR</i> . PC : interacted with depression to predict 30-day hospital readmission.	Covariates not adjusted for.
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1Key: N; Number, NR; Not Reported, T1; time passed at first follow up. T2; time passed at second follow up; * = results significant at $p < 0.5$ level; ** results significant at $p < 0.01$;

IPQ dimensions: CONS; IPQ, IPQ-R and B-IPQ consequences subscale. C/C; IPQ control cure subscale, PC; IPQ-R and B-IPQ personal control subscale; TC; IPQ-R and B-IPQ treatment control subscale, ID; IPQ, IPQ-R and B-IPQ identity subscale, TL; IPQ and B-IPQ timeline subscale, TLAC; IPQ-R timeline acute/chronic subscale, TC; IPQ-R timeline cyclical subscale, IC; IPQ-R and B-IPQ illness coherence subscale.

Measures: BDI II; Beck Depression Inventory II, COPE; The Cope Inventory, DS14; Type D Personality Scale; EHFScBS; European Heart Failure Self-care Behaviour Scale, FPAS; Florida Patient Acceptance Scale, GAD-7; Generalized Anxiety Disorder scale, Hospital Anxiety and Depression Scale, ICDC; ICD Patient Concerns questionnaire, KCCQ; Kansas City Cardiomyopathy Questionnaire, LAYHFQ; Looking After Yourself with Heart Failure Questionnaire, LOT-R; Life Orientation Test-Revised; MLHF; Minnesota Living with Heart Failure Questionnaire, PHQ-9; Patient Health Questionnaire, SCHFI; Self-Care Heart Failure Index, WHOQOL; World Health Organisation Quality of Life Brief Assessment.

Narrative Synthesis

Prospective cohort studies (n=2)

Self-report measures:

I. Anxiety and depression:

Two studies measured anxiety and depression (Goodman et al., 2013; Mulligan et al., 2012). Table 1 shows that participants were similarly aged. Their HADS scores were categorised into borderline and probable anxiety or depression (scores of 8-11 and >11 respectively). As seen in table 1, when baseline covariates were adjusted for, perceived consequences and perceived understanding (coherence) were not significantly associated with anxiety and depression at follow up (Mulligan et al., 2012). In contrast, Goodman et al. (2013) did find significant associations with anxiety and depression (Table 1). However, Goodman et al failed to adjust for covariates. Mulligan et al. (2012) explored *changes* in illness perceptions over six months and found that reductions in perceived consequences and perceived symptoms of HF predicted a significant reduction in participants with clinically significant anxiety and depression at follow up (Table 1).

II. Quality of life (QoL):

Goodman et al. (2013) and Mulligan et al. (2012) explored the relationship between illness perceptions and quality of life using the Minnesota Living with Heart Failure Questionnaire. As seen in table 1, both studies produced consistent findings that greater perceived consequences of HF at baseline were significantly associated with poorer quality of life at follow-up. Mulligan et al. (2012) explored changes in illness perceptions over six months and found that reductions in perceived consequences and perceived symptoms of HF predicted significant increases in quality of life scores at follow up.

III. Other:

Goodman et al. (2013) found a significant association between increased perceived understanding (coherence) of HF and increased self-care confidence.

However, these results should be interpreted with caution as covariates were not adjusted for and the construct validity of the self-care measure had not been confirmed by factor analysis (Riegel et al., 2004; Yu, Lee, Thompson, Woo, & Leung, 2010).

Cross sectional studies (n=7)

Physiological measures:

Cherrington, Lawson & Clark (2006) explored whether HF patients' illness perceptions correlated with the percentage of blood pumped out of the heart's left ventricle (LVEF). As seen in table 1, no significant correlations were found. This may in part be due to the small sample size (n=22); equally, the paper lacked a theoretical rationale for the role of illness perceptions in LVEF.

Molloy et al. (2009) measured HF patients' angiotensin-converting-enzyme serum levels as a marker of medical adherence. Greater perceived consequences and greater perceptions of HF duration predicted significantly poorer medical adherence (Table 1). The small sample size (n=58), however meant covariates could not be adjusted for in a multivariate regression. The low response rate (25%) was also concerning as it called into question the generalisability of the findings.

Self-report measures

I. Anxiety and depression:

Four papers measured anxiety and depression symptoms (Table 1). Of these, three papers explored illness perception dimensions (Giardini et al., 2017; Hallas et al., 2011; Morgan, Villiers-Tuthill, Barker, & McGee, 2014) whilst one paper looked at a total illness perception score (Timmermans, Versteeg, Meine, Pedersen, & Denollet, 2017). Relationships with illness perceptions were inconsistent. All studies were conducted in countries in Europe (Table 1).

Two of the three studies investigating illness perception dimensions found significant positive correlations between perceived consequences of HF and number of symptoms (Giardini et al., 2017; Hallas et al., 2011) and lower

perceived personal control (Hallas et al., 2011; Morgan et al., 2014) (Table 1). All three studies conducted statistical regression. Hallas et al. (2011) found perceived consequences, personal control and cyclical symptoms were significantly associated with anxiety and depression whilst Giardini et al. (2017) found significant associations only with illness identity (symptoms). In contrast, Morgan et al. (2014) found no significant associations between illness perception dimensions and anxiety or depression (Table 1). However, Morgan et al. did find that total scores on the IPQ-R accounted for significant variance in anxiety and depression (Table 1). This suggests that overall illness perceptions contributed to anxiety and depression outcomes. All studies measured anxiety and depression as continuous variables. The lack of consistent findings across these studies may be due to the differences in ages and illness severity of the participants. For example, as shown in Table 1, the participants in Morgan et al.'s study were significantly older.

The fourth paper (Timmermans et al., 2017) categorised participants' total B-IPQ score into "threatening" or "non-threatening" illness perceptions. Threatening perceptions were determined by a cut off score of forty-three or above. Table 1 shows that threatening illness perceptions were significantly associated with presence of anxiety or depression, determined by a score of 10 or above on the GAD-7 or PHQ-9. Whilst higher B-IPQ scores may be indicative of more threatening illness perceptions (Broadbent et al., 2006), a cut-off score has not been developed through research evidence, jeopardising ecological validity. Therefore these results should be interpreted cautiously.

II. Self-care:

MacInnes (2013) and Timmermans et al. (2017) examined the relationship between illness perceptions and self-care. MacInnes (2013) found significant correlations between self-care and many IPQ dimensions (Table 1). Whether self-care scores indicated improved or poorer quality of life was not reported, making interpretation of the results difficult. Equally, the development of the self-care tool lacks validity (Table 1; MacInnes, 2011) thus ecological validity is a concern. Timmermans et al. (2017) found no relationships between threatening illness perceptions and self-care (Table 1); however, as already discussed, the ecological validity of this category is questionable.

III. Medication adherence:

Turrisi (2016) found that illness perceptions were not significantly related to self-reported medication adherence (Table 1). However, the definition of high and low medication adherence appeared to be arbitrary and may lack face validity or sensitivity. Therefore, the results should be treated with caution. A more objective measure may have yielded different results (Molloy et al., 2009).

DISCUSSION

A systematic review was conducted to explore the relationship between illness perceptions and outcomes in adult patients with HF. Results were inconsistent and risk of bias noteworthy. Thus only limited conclusions can be drawn. Two preliminary patterns emerged. First, perceptions of greater negative consequences of HF were related to worse outcomes including: increased anxiety and depression symptoms; reduced quality of life; and reduced medical adherence. These findings are in line with a previous meta-analysis which found perceptions of negative consequences were associated with worse psychosocial functioning (Hagger & Orbell, 2003). Second, there was some preliminary evidence for a relationship between illness perceptions and symptoms of anxiety and depression. These relationships were found in both longitudinal and cross-sectional designs. Perceived consequences, symptoms (identity), personal control and total illness perception were associated with anxiety and depression symptoms in several studies (Giardini et al., 2017; Goodman et al., 2013; Hallas et al., 2011; Morgan et al., 2014; Mulligan et al., 2012; Timmermans et al., 2017). Whilst evidence is limited and further research is required, it points to the role of illness perceptions in psychological distress in heart failure. This is in line with findings from patients with other chronic illness such as: cancer (Richardson, Schüz, Sanderson, Scott, & Schüz, 2017); coronary heart disease (Foxwell, Morley, & Frizelle, 2013); irritable bowel syndrome (Rutter & Rutter, 2007); and chronic fatigue syndrome (Edwards, Suresh, Lynch, Clarkson, & Stanley, 2001).

Strengths/limitations of included studies

This review identified a limited number of studies, which varied in the types of illness outcome measured. As the majority of studies were cross-sectional, conclusions regarding causality or predictive relationships are precluded. Response bias across studies is a concern as the majority of studies did not categorise non-responders and some papers did not report numbers eligible for the study. More than half the included studies either did not, or only partially, adjusted for confounding variables including socio-demographic variables, illness severity and duration of illness. Therefore, these results should be interpreted

with caution as validity may have been jeopardised. Moreover some studies adopted arbitrary cut-offs that were not validated for the outcome measures used.

Of particular concern, six studies did not fully report all the IPQ dimensions they measured, reflecting a trend to focus on significant findings (Goodman et al., 2013; MacInnes, 2013; Molloy et al., 2009; Mulligan et al., 2012; Turrise, 2016; Timmermans et al., 2017). Lastly, behaviour and coping are known to be mediators between illness perceptions and outcomes (Leventhal et al., 2016), yet these were not included in any of the study designs. Given the limited number and the variable quality of included studies, it is difficult to draw firm conclusions from the review findings.

Theoretical implications

The common-sense model of illness postulates interactive dynamics between a person's perceptual and behavioural responses to an illness threat (Leventhal et al., 2016). What determines these responses and how they change over time are also relevant when exploring the common-sense model (Leventhal et al., 2016). The studies included in this review predominantly examined a person's perceptual processes captured during a specific moment in time. Therefore, only partial components of the common-sense model were measured making it difficult to draw theoretical conclusions. The results found here may represent an oversimplification of a complex dynamic process (Leventhal et al., 2016).

Recommendations for future research

In general, future studies may benefit from seeking to measure illness perceptions as one element of a complex interactive process leading to health outcomes (Leventhal et al., 2016). Future studies should seek to measure the determinants of illness perceptions, such as communication with care givers and information from medical providers; perceptual changes over time; and how a patient plans for, commits to and adjusts their coping behaviour. It is likely a combination of these elements which determine health outcomes in heart failure and would provide the best evidence for informing clinical practice.

Future studies may benefit from carefully justifying the use of cut-off scores to determine categorical variables. It may be beneficial for future research to statistically adjust for differences in time since diagnosis to help control for psychological distress associated with a new diagnosis of heart failure or with the impact of advancing illness.

Strengths/limitations of review process

This review investigated HF patients' illness-specific representations, as conceptualised and measured in accordance with common sense theory of illness (Leventhal et al., 1980). Incorporation of HF patients' global health representations, as postulated in the health beliefs model (Rosenstock, Strecher, & Becker, 1988) and health locus of control model (Wallston, Strudler Wallston, & DeVellis, 1978), would have broadened the measures included. In doing so, a greater number of studies may have been included. However, this would have precluded theoretical conclusions based on the common-sense theory of illness.

This review sought to explore the role of illness perceptions across any illness outcome in heart failure. The heterogeneity of the outcomes measured in the included studies makes it difficult to draw clear conclusions. It may be more helpful for future systematic reviews to focus on specific outcomes, such as psychological distress. Whilst an effort was made at full review stage to ensure validity and reliability of the self report tool was reported, limitations regarding the validity remained. This included use of cut scores not justified by research literature, the lack of rigorous methodology during tool development and scores lacking clinical utility. A future focus on narrower outcomes would allow an defined list of well developed and clinically utilised self report measures to be used for eligibility screening.

There are several strengths of this review. Search terms were kept broad and references were checked in attempt to capture all available evidence. In doing so, the review has captured and synthesised the growing body of research into the illness perceptions of people with heart failure.

CONCLUSION

In conclusion, this review is the first to synthesise the research evidence into illness perceptions and heart failure outcomes. The ten included studies measured a variety of outcomes. Results were inconsistent. There was preliminary evidence for a relationship between perceived consequences of HF and outcomes. Furthermore, relationships were found between numerous illness perceptions and anxiety and depression symptoms, albeit inconsistently. Illness perceptions may play a role in patients' mental wellbeing and distress. It may therefore be beneficial for health care professionals to understand how patients understand their illness. Additionally, in line with the common-sense model of illness, future studies should seek to measure the interactive dynamics of coping behaviour perceptions and their determinants over time to best inform clinical practice.

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Chapter 2: Major Research Project

Men Waiting for Heart Transplant:

An Interpretative Phenomenological Analysis (IPA)

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Prepared in accordance with guidelines for submission to Journal of Heart and Lung Transplantation (Appendix 2a)

PLAIN LANGUAGE SUMMARY

Background

Heart transplant is an operation to replace a failing heart with a healthy heart and involves waiting for a matching heart from a person who has recently died. This can be a long wait and may be very distressing for people. Very little research has been done looking at how people experience this wait.

Aims

This study aimed to explore people's experiences whilst waiting for heart transplant. This may help to develop support for people in the future who are waiting for a heart transplant.

Method and data analysis

Seven men on the Scottish waiting list for heart transplant agreed to take part in individual interviews with the researcher. Interviews lasted between 50 and 80 minutes. The way we explored people's experiences was through a research method called Interpretative Phenomenological Analysis. It involved conducting and transcribing interviews and then interpreting what the participant said and why they may have said it. The researcher looked for patterns in what people had said and discussed these as 'themes'. Themes were supported by participant quotes.

Results

Three major themes were discussed. The first theme was 'threatened self identity'. Men felt that being ill challenged who they felt they were. The second theme was 'uncertain life or death'. Life in the present and in the future, with or without a transplant, felt very uncertain for the men. Part of this included the knowledge that they could die either waiting, during or after transplant. The third theme was 'complex coping' and captured the nature of trying to cope in a very emotionally and physically challenging wait for heart transplant.

Conclusions

These results provide valuable insights into individuals' personal experience of waiting for transplant. This may help to design supports for transplant patients, including through Psychology. A key finding was that patients need to find meaning in waiting and certain psychological interventions appear likely to help with this. It is important that all health care professionals acknowledge that people make sense of their wait for transplant in a variety of ways.

ABSTRACT

Background

Heart transplant candidates may wait a considerable and usually indeterminable length of time for a donor heart, uncertain if they will live or die. Despite this, there appears to be little research exploring how people experience this wait.

Method

A qualitative design employed Interpretative Phenomenological Analysis. Male patients (n=7) on the routine waiting list for a heart transplant at an advanced heart failure service in Scotland participated in a semi-structured in-depth interview.

Results

Three major themes, each with inter-related sub-themes were produced from the data. 1) 'Threatened self identity': this theme covered the challenge posed to the men's identities as a consequence of illness and their wait for transplant. This included a 'diminished self' and an 'unwanted ill self'. 2) 'Uncertain life or death': this theme concerned the continuing uncertainty men had to live and cope with, and included 'contemplating dying' and 'the unknowns of transplant'. 3) 'Complex coping': this theme covered the challenges of coping during the emotionally and physically challenging wait for transplant.

Conclusions

The importance of finding meaning in waiting is discussed in relation to the revised transactional model of stress and coping, and the implications for health care professionals are discussed. There is a need for health care professionals to appreciate the individual meaning patients ascribe to their experiences.

INTRODUCTION

Waiting for heart transplant

There is a shortage of donor hearts in Scotland, leading to long waiting times for a heart transplant (Scottish Government, 2013). Several months, or possibly years, may pass before a donor heart is identified. In the UK, median wait times are approximately three and a half years (NHS Blood and Transplant, 2017). The journey to transplant is complex; patients may have had an acute episode or a long history of poor cardiac health before receiving a diagnosis of heart failure and it is only when the heart failure is advanced that a transplant is considered (Bunzel, 2012). Illness severity determines individuals' listing status as 'super-urgent', 'urgent', or 'routine' and the likelihood of having to remain within hospital or wait at home. Candidate selection for transplant is not orderly and relies on multifarious considerations including: organ availability, a match of donor, presence of antibodies and recipient body size and blood type. Candidates have no influence over when, or if, they will receive a transplant and escalating health problems may either accelerate their listed position or compromise their candidacy for transplant (Bunzel, 2012).

Research on waiting

There is limited research focussed on patients' wait for heart transplant. Existing research suggests that psychological distress is not uncommon, with patients scoring as mildly depressed or anxious on validated screening instruments (Deshields, McDonough, Mannen, & Miller, 1996). It is generally accepted that the wait for transplant is emotionally challenging with numerous stressors (Bunzel, 2012; Jalowiec, Grady, & White-Williams, 1994). The existing qualitative research is limited. No studies have recruited patients solely during the wait period, nor utilised a phenomenological approach to explore how patients might experience this. One qualitative study, which included participants post transplant, found that participants described a loss of their prior life, their autonomy and considered their own death and the death of the donor (Poole et al., 2016). Another qualitative study, which used a focus group and included patient's relatives, explored opinions on interventions for the

waiting period. Participants referenced a pervasive wondering of “when” transplant would happen (Haugh & Salyer, 2007) however, due to the aims of the study, little other weight was given to detailing participants experiences.

Aim

No studies have focussed on the lived experience of heart transplant candidates from a phenomenological perspective. The aim of the present study was to gain an in-depth insight into heart transplant candidates’ lived experience of waiting for a heart transplant.

METHODS

Design

A qualitative design engaged an interpretative phenomenological approach (IPA). Participants took part in a semi-structured in-depth interviews.

Ethics

Ethical approval was received from the West of Scotland Research Ethics Service (Appendix 2b). Informed consent was taken by the first author (R.J) at the time of interview (Appendix 2c). Participants' names and identifiable information were changed to preserve confidentiality.

Recruitment

Seven participants were recruited from a national advanced heart failure service in Scotland. Participants were included if they were: on the 'routine' list for transplant for at least three months, fluent in English, aged 18 or over and able to give informed consent, and excluded if they had a history of previous heart transplant or learning disability. Transplant co-ordinators identified eligible participants, informed them about the study and provided them with the study information sheet (Appendix 2d). Those interested consented to their contact details being passed on to the researcher, who then contacted them to arrange a suitable interview time. One interested participant cancelled their interview without offering a reason for doing so.

Sample characteristics

All participants were on the 'routine' waiting list and were living at home while waiting for their transplant. The participants were male and aged between 25 - 63. Length of wait at the time of interview varied between nine months to three years. Two of seven participants continued to work. Individual demographics are omitted due to risk of participant identification.

Data collection

Interviews were carried out between September 2017 to April 2018. One interview was conducted with each participant by the primary researcher (R.J). Interviews took place in a non-medical hospital room and lasted between 50 -80 minutes. They began with an open-ended question asking for participants' experience of being told they needed a heart transplant. The interviewer then went onto ask the participants about their experience of waiting for a transplant. The interviewer tried to promote a dialogue and follow the participant's story. Probing questions were used to encourage the participants to develop their accounts, such as "what did you mean by that?" and "what was that like for you?". In line with the exploratory principles of IPA, this approach provided participants the opportunity to tell their story in a way that made sense to them. Areas explored in interviews were adapted as interviews progressed with an increasing focus on issues the participant raised. An interview schedule was constructed via consultation with a clinical psychologist at a heart transplant centre and was drawn from their knowledge of service user experience (Appendix 2e). It was used loosely to guide questions around certain areas when these had not arisen naturally. Interviews were recorded and transcribed verbatim, with exception of identifiable information which was deleted or changed.

Analysis

Data was analysed in accordance with the principles of Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009). Transcripts were read and annotated line-by-line, noting participants' descriptions and use of language and the researcher's ideas regarding the participant's meaning (Appendix 2f). Recurrent patterns in individual transcripts were interpreted as emergent themes. Patterns across transcripts were noted as the analysis of transcripts progressed. These were further interpreted and developed through an iterative process, whereby patterns were clustered together and abstracted into broader interpreted themes such as "death" "uncertainty" or "identity". To ensure an ideographic perspective, these were cross checked against individual transcripts and quotations from each participant for each theme were tabulated (Appendix 2g). Several iterative cycles commenced and continued into the

writing up phase before the major and subthemes presented in this paper were finalised. These were considered the ‘best fit’ to participants’ stories. The selected quotations were those thought to capture the essence of the theme or provided particular insights. An attempt was made to ensure all participants’ voices were represented. Analysis involved supervision with an experienced IPA researcher who read over transcripts, checked initial annotation, suggested alternative interpretations and provided feedback on quote selection. Face validity of the final model was confirmed by one participant (Appendix 2h) and a consultant clinical psychologist working with heart transplant candidates.

Reflexivity

The researcher (R.J.) had previously worked as an assistant psychologist in an advanced heart failure service. R.J. had gained knowledge of the complex processes involved in waiting for heart transplant and had heard first hand accounts of people’s experiences. This influenced the development of the research as R.J. wanted to explore the challenges people faced during their wait for transplant. A developmental journey took place in the course of research. R.J. realised the importance of holding an open mind to participants’ experiences, as opposed to interpreting their narratives as evidence of a *challenging* wait for transplant. R.J. was required to suspend “formulating” the participants’ emotional difficulties during interviews and initial analyses and fully engage with the participants’ narratives, what they meant and how they had made sense of their experiences. R.J. realised that an important narrative was that of resilience and coping, as opposed to purely challenges and distress. R.J. kept a reflexive journal throughout the research to aid awareness of this interpretational process (Appendix 2i).

RESULTS

Three major themes: 1) Threatened self identity; 2) Uncertain life or death; and 3) Complex coping, and four interrelated subthemes were produced from the analyses of the interviews. These themes and subthemes are outlined in Table 2 and described in depth in the following text, illustrated by participant quotes.

The following notation is used when presenting quotes: ".." indicates the person took a short pause, (pause) indicates a longer pause and [...] indicates that a small portion of irrelevant/confidential text has been deleted.

Table 2 Major Themes and Sub Themes

Major theme	Sub theme
1) Threatened self identity	<i>A diminished self</i>
	<i>An unwanted ill self</i>
2) Uncertain life or death	<i>Contemplating dying</i>
	<i>The unknowns of transplant</i>
3) Complex coping	

1. Threatened self identity

The men described the combination of illness and waiting for a heart transplant as a challenge to their self identity. This has been interpreted using two interrelated subthemes: 1) A diminished self and 2) an unwanted ill self.

A diminished self:

All men reported experiencing a reduction in valued aspects and roles from their lives from before illness and their wait for transplant. The use of language suggested that these losses had given rise to a diminished sense of themselves and their worth. Michael was advised by health care professionals to retire due to both ill health and in order to access the transplant waiting list. He explained

that stopping work had impacted on his family role and how he felt about himself:

“it diminishes what you feel you’re worth .. when you’re doing a job and you’re working you know exactly where you are ..you’ve actually got a purpose [...] the main purpose is providing for your family I suppose” (Michael).

In the absence of his role to provide for his family, Michael described diminished self worth and appeared to feel lost. Many men alluded to a diminished self worth following reduced occupation and activity. Christopher, whose successful career in senior management had ended with his illness articulated this as a “loss of status” and appeared to experience a sense of worthlessness:

“I’ve got nothing interesting to say.. cause I didn’t do anything today (cries) .. that’s very tough” (Christopher)

Christopher was clearly distressed, possibly due to the stark contrast of his previous ‘working’ life and his present, reduced, existence. The distress may be a regular occurrence for Christopher when his time contains limited occupation and activity.

For Gregor, general reduced activity alongside the waiting list restrictions on holidays abroad, diminished his role as ‘father’ and his perceived ability to engage with his children:

“you’re only here once, you’re going through a life you’ve got a young family [...] your kids are only young once, you don’t want to go through the majority of their life with you being the one that can’t do activities with them” (Gregor)

And later:

“they’re the ones that suffer through it, through no fault of their own” (Gregor).

Gregor was acutely aware of lost opportunities with his children whilst were still young and there was a painful sense he believed he was letting his family down. When he stated that his children were not to blame there was a sense that he was blaming himself.

An unwanted ill self

Six men spoke of an 'ill self' discordant with who they felt they were. This arose from reduced freedom due to illness and the restrictions placed on their activity and diet as part of their wait for transplant. This 'ill self' seemed related to a fear of becoming lazy or a burden on others and was a source of distress. Peter stated that being inactive did not feel like his real self:

"I don't know why I'd be sitting 'oh I got a heart problem I can't be doing that' sorta thing [...] it's just not me" (Peter)

His sarcastic use of "oh" had connotations of a person making an unworthy excuse, as if his illness was not a valid reason for inactivity, possibly reflecting his broader belief that to be inactive is to be lazy.

The threat of illness was apparent in Alec's narrative. Unlike Peter, the threat of his ill self related to his family:

"because of what I have .. it stops my family from doing what they want to do, so the guilt kicks in [...] if I didn't have this, everybody's else's lives would move on" (Alec)

Alec appeared to have a strong sense that his illness had made him a burden on his family. The "kick" of his "guilt" suggested that this was very painful for him.

Ryan described his frustration at his inability to achieve the things he used to be able to:

"you're trying to do something that you can't do and you get frustrated and you just (sighs) I'm not a bad tempered person (laughs) I'm quite an easy going person" (Ryan)

Here, Ryan expresses ‘frustration’ at his loss of capacity. This lead him to identify with his bad tempered ‘ill’ self that contrasted with his usual “*easy going*” self.

2. Uncertain life or death

All men referred to the paradoxical nature of waiting for heart transplant. There was an acknowledgment that, whilst a transplant might cure them, the wait for the transplant posed numerous threats to their life and could result in death. This theme is discussed as two interrelated subthemes 1) contemplating dying and 2) the unknowns of transplant.

Contemplating dying

All men contemplated their death. Many stated that death was not feared but expressed concern regarding its impact on their families. Christopher was worried his wife would have to “*come round and clean up the mess*” when he referred to the possibility of dying in transplant. Peter wondered how his wife would cope and Gregor felt upset that his children would have to “*live without a Dad*”. Alec’s view that he was a burden on his family extended to his fear of dying in transplant, as he pointedly explained:

“everyone dies I understand that but it goes back to the guilt [...].if I die, their lives .. I can’t even describe how they would cope” (Alec)

Exhaustingly, he appeared to blame himself not only for his illness but for the possibility of dying during transplant. The guilt of being ill coupled with the guilt of being on the transplant list seemed to preoccupy him.

Both Ryan and Andy imagined the benefits that could arise from their death. Andy spoke calmly of an optimal sudden death:

“.. the heart attack will get you first [...] to me that’s actually the best case scenario because its clean .. there’s no waiting about in hospital waiting to die .. I imagine it to be quicker and cleaner to those you’re leaving behind.. that way the wife gets the mortgage paid off, she’s gonna have a bit of money to go do things” (Andy)

He believed a good death to be one that was quick and clean and therefore least burdensome on his wife. Therefore, his conviction he would die from a quick heart attack may have provided comfort and helped him to cope emotionally.

For Michael and Peter, comfort appeared to be gained through placing trust in another. As Michael illustrated:

“I mean people do die but then you're going to die anyway .. it's something people can't escape, nobody escapes it, it's just .. that's it so .. to me ah .. I put my hands in the trust of these Doctors and I do trust them ..” (Michael)

His lack of words to explain what dying would mean might have been due to his wish to avoid this painful topic. He seemed unsettled and his rush to speak about his trust in Doctors suggested this was a method of coping.

Peter did not trust the Doctors but instead placed his trust in God:

“if I do die well I die you know .. obviously you don't want to die, you want to die as late in life as possible and enjoy it .. but if that's what God wants .. then you'll be quite happy with that .. I suppose it comes down to faith and trust in God” (Peter)

Peter revealed contradicting perspectives within his account. He simultaneously conveyed a desire for life yet stated he'd be “quite happy” should he not survive. His use of second person pronoun “you'll” pointed to a personal distance from this conflict. He was perhaps both comforted by the thought of dying with faith in God yet saddened at the thought of his lost life. This dissonance appeared to account for his tension around these opposing emotions.

The unknowns of transplant

All the men talked about the difficulty of waiting for a transplant because of the uncertainty about when it might happen and what life with a transplant could mean. Peter and Ryan described how such thoughts dominated their waking lives:

“you wake up everyday thinking, is this the day? You go to bed ‘oh well that’s another day’ and you wake up tomorrow .. is it gonna be today? And it’s a complete circle it just goes round and round and round and round” (Ryan)

Ryan’s numerous repetitions of “round” gave a sense of exhaustion and conveyed the inescapable nature of his thoughts. For Gregor, the uncertainty of ‘when’ caused him to fear his heart failure would progress and prevent him receiving a transplant:

“you feel that the clock is ticking and my fear is that I end up I start to get ill and I become too ill that I can’t get it” (Gregor)

The passing of time seemed to dominate Gregor’s narrative. There was an apparent pressure of speech which, in itself, evoked the sense of a clock ticking. There was a sense that the passing of time represented reduced opportunity for transplant, for a new lease of life, and to resume his ‘father’ role.

Many of the men were concerned with the uncertain outcome of their prospective transplant. Michael and Peter contemplated whether a transplant would permit a return to their previous, freer lifestyles or whether it would bring a fresh set of health challenges that would restrict their lives. Peter, who spoke of struggling to manage his “medical regimen” explained:

“once heart transplant has been done you know they’re telling you that er .. you’re gonna be on another set of pills and you have to keep a record of when you take them .. and they say you have to be really strict” (Peter)

He appeared anxious about the “strict” medical adherence, perhaps as it represented continuation of the stress associated with his “medical regimen”, beyond transplant. Many of the men recalled the statistics of numbers surviving transplant and considered what this meant for their chance of survival. For some, this caused doubt as to whether the outcome would prove worthwhile. Alec and Christopher rehearsed the reasons to withdraw from the transplant process:

“is this heart transplant such a good idea after all [...] it’s a very, very serious operation and the medication that comes after it is pretty horrible and you’re going to have to have .. the strength and self belief to see it through .. in full knowledge that you’re quite possibly working against percentages because half the people aren’t alive in five years time” (Christopher)

Christopher had a negative view of transplant. He appeared concerned that he’d fail to muster the energy and courage to live with a transplanted heart, knowing that life would be limited.

3. Complex coping

All mens’ narratives provided insight into their nuanced attempts to cope and find meaning in their experience of waiting for heart transplant. Contradictions in participant’s accounts gave a sense of the challenge and evolving dynamic of these coping mechanisms. The contradictions in Ryan’s quote highlighted this:

“I try not to think back to when I was working I just think of .. the present time now and what I’m capable of now [...] (long pause) I suppose that makes it even more difficult because ... things you could do four five weeks ago .. you do the same thing and you think ... I managed this better or I managed this more four or five weeks ago .. so you try and push to get the same thing and you just .. don’t quite make it and that makes you frustrated ... and then the more frustrated you get the more sorta ..ohhh-och! hate this .. why .. why me ... why did I have this heart attack ... what .. what did I do to make me have this heart attack (pause) and you think back (sighs) I didn’t do anything it was just it just ... it just happened (trails off)” (Ryan)

Despite his stated wish to focus on the present, Ryan ultimately ended up ruminating on his past abilities. This made him acutely aware of his declining health and his attempts to “push to get the same thing” further highlighted what could no longer be achieved, causing frustration and sadness. Agonisingly, Ryan’s

attempts to cope with distress seemed to increase his experience of negative emotions.

Similarly, Michael tried to stay aligned to his sense of self, but seemed to have adjusted what he considered acceptable and allowed himself to take longer to complete tasks:

“Personally, I can’t sit by and watch things. I’ve been active all my life I’ve always worked .. when I see things being done in my own place I want to jump in and do things .. probably a job that’ll take me two hours will take me two days but I still try and potter about and do things so I’m in a very fortunate position” (Michael)

Michael acknowledged that to feel like himself he needed activity, and referenced his past active self. Adjusting his expectations of what he could achieve may have allowed him to maintain congruence with this previous “active” self. He framed his experience in a positive light and there was an evident lack of distress both here and across his entire narrative, suggesting this strategy may have been a helpful way of coping.

Alec found benefits to his waiting experience, which also alluded to regaining congruence with his sense of self:

“I take pride in being the guy who needs a transplant [...] it’s given me opportunities to do things I’ve never done before .. all of that is positive things that I’ve taken on board and gained confidence from and I’ve gained that mentality [...] I feel like it’s inner strength” (Alec)

Alec made numerous references to his strengths throughout his narrative and expressed “pride” at the way he was able to cope with waiting for a transplant, which showed his “inner strength”. He seemed to have found meaning in waiting and this helped him to feel strong. However, his mood dropped when he talked about his chances of surviving transplant and it was apparent he had no strategies to reconcile this:

“there’s nothing that will clear the problem there’s nothing that will tackle the things in your head to make them go away nothing will ... and that’s upsetting” (Alec)

Here, Alec seemed overwhelmed by his powerlessness which contrasted with his “inner strength” and it’s possible that in his wait for transplant he fluctuates between feeling strong and his sense of helplessness when faced with overwhelming uncertainty.

Both Christopher and Andy spoke of goals and purpose. Christopher explained:

“Once you go on the heart transplant list you feel there’s now a sense of purpose ... you feel there’s an end game, you’re not sure where the finishing line is”

And later:

*“I’m working towards the finishing line and I’m gonna get this done”
(Christopher)*

Christopher found a renewed sense of purpose in being listed for transplant. His language “end game” and “finishing line” portrayed someone coming to end of a battle or race, suggesting his renewed purpose had given him hope.

Andy also described a new-found purpose - to survive for his granddaughter:

“I don’t want to die .. I don’t want to die you know .. there are so many things I mean I got my first grandchild three months ago .. you know and ok I’ve come to the conclusion I’m not going to see her married sorta thing like but I do want to see her going to school I do want to be involved for a certain amount of her life and it’s a matter of making sure you’re there” (Andy)

His repetition highlighted his determination to survive yet he was pragmatic about his shortened life expectancy, which illustrated the complex balancing act the men faced in their attempts to cope. There was a need to maintain hope and

purpose but this was restricted to the realms of rational reality. His determination *“to make sure you’re there”* seemed to filter into all aspects of his life and shaped his daily behaviour. Andy was convinced he would not receive a transplant and thus took on the responsibility to survive without it:

“it’s about keeping yourself healthy so you don’t actually need the heart transplant so I can stay at the level I am now” (Andy)

And later:

“if I can keep the same sort of health level that I’m at just now .. even though I’m on the list I won’t need it” (Andy)

Andy had set himself the challenge to maintain his current health in the face of a progressing illness. Andy’s past career had involved life threatening challenges, and it’s possible that setting himself this challenge helped him to find meaning and motivated further coping.

Gregor on the other hand explained his struggle to find the benefits to his wait:

“You’ve just got to try and think about the positive things and hopefully at the end you’re going to come through [...] but as I say it isn’t easy because there’s a big bit of negativity there”

And later:

“When you’ve been through so many negatives over the last twenty years of your life .. you don’t see any light at the end of the tunnel [...] you just think do you know what .. it’s just not gonna happen for me [...]”

And later:

“I feel that everything is going to go wrong” (Gregor)

A long history of ill health and history of unsuccessful transplants seemed to have shaped Gregor’s beliefs about the success of transplant and reduced his

ability to remain hopeful.

DISCUSSION

This study examined the lived experience of men on the routine heart transplant waiting list. Mens' accounts of their experiences were analysed using IPA and this process resulted in three major themes: 1) Threatened self identity, 2) Uncertain life or death, 3) Complex coping, and four interrelated subthemes. Deep and rich insights into the complexities of life on the heart transplant waiting list have been garnered and are now discussed with reference to the extant theory and literature.

Threatened self identity

Identity formation is an active process shaped by a person's interaction with their environment (Hammack, 2008). Mens' experience of waiting for heart transplant involved numerous threats to this process. This involved the loss of valued roles and aspects of life alongside the development of an unwanted illness identity. Both seemed partially driven by the life limitations of living with advanced heart failure and the restrictions placed upon the men as part of their wait for heart transplant.

The loss of role whilst waiting for transplant has been documented in a previous qualitative study with pre and post heart transplant candidates (Poole et al., 2016). In patients with a chronic illness the loss of valued attributes and social roles gave rise to a 'loss of self' (Charmaz, 1983). In addition, these findings highlighted the importance of occupation. Occupation is crucial aspect of identity (Laliberte-Rudman, 2002) and the men's narrative described how the loss of this led to a diminished sense of self. The development of an illness identity is supported elsewhere in qualitative research, including in chronic heart failure (Welstand, Carson, & Rutherford, 2009), chronic pain (Smith & Osborn, 2007) and chronic fatigue (Dickson, Knussen, & Flowers, 2008). It has also been described by candidates awaiting liver transplant "That's not who I am, that's not who I have been and who I know" (Brown, Sorrell, McClaren, & Creswell, 2006, Pg. 126). This study found that men perceived illness as a threat of becoming lazy or a burden. This may be partly due to societal expectations

placed on men to be self-sufficient and strong (West & Zimmerman, 1987). This illness threat to masculine identity have been reported in chronic illness and in older adults with advanced heart failure (Aldred, Gott, & Gariballa, 2005; Charmaz, 1994).

Uncertain life or death

The wait for heart transplant involves living and coping with a perpetuating uncertainty around death. Dying, either before or during transplant, predominated many of the men's accounts, and little was heard of their hopes for transplant. These findings suggest that pre-transplant, heart transplant is not necessarily perceived as the 'gift of life' often portrayed (Buldukoglu et al., 2005; Lamanna, 1997). Interviews with young adults post-transplant have found that the 'gift of life' narrative sets unrealistic expectations of life post transplant (Waldron, Malpus, Shearing, Sanchez, & Murray, 2017), suggesting that this societal narrative does not reflect people's experiences either before or after transplant.

Men's accounts of their chances of dying may reflect the shift towards collaborative medical care and promotion of 'shared decision making' (Charles, Gafni, & Whelan, 1997), whereby participants are fully informed of the risks and benefits before agreeing to medical treatment. All men recalled the statistics regarding mortality and life expectancy, suggesting that this information had been a salient and likely frightening experience. Many acknowledged the risks involved and prepared for death. Some feared that their death would cause their family anguish and seemed unable to move past these thoughts whilst some appeared to discuss strategies for coping with the fear of death. This may be evidence of emotion focussed coping, theorised to regulate distress in uncontrollable situations (Lazarus & Folkman, 1987). The strategies appeared to include: relinquishing personal control and placing trust in another - whether spiritually (Albaugh, 2003) or through doctors (Hillen, de Haes, & Smets, 2011); or re-framing death as positive for their family.

When men's accounts alluded to life after transplant, this was discussed with trepidation. This is in contrast to findings from kidney transplant candidates, who described transplant as an opportunity to regain a normal life (Tong et al.,

2015). Uncertainty about the future is common in those living with advanced heart failure (Europe & Tyni-Lenne, 2004) and perhaps represents recognition that the advanced heart failure can be fatal. Some men questioned being on the heart transplant waiting list, consistent with people's experience of awaiting a liver or kidney transplant (Brown et al., 2006; Jonsén, Athlin, & Suhr, 2000; Moran, Scott, & Darbyshire, 2009)

Complex coping

Mens' accounts suggested they were able to draw on a varied number of personal resources in order to cope with their life-threatening wait for transplant. Pertinent in many narratives was the importance of finding meaning. Meaning focussed coping is a component of the revised transactional model of stress and coping (Folkman, 1997) and involves drawing on beliefs, values and one's purpose in life as a coping strategy when a stressor remains irresolvable over time. Aspects of meaning focussed coping such as finding benefits and adapting goals (Folkman & Moskowitz, 2007) appeared relevant in many of the mens' accounts and is consistent with the previous finding that patients can report personal growth from their experience of illness (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Meaning focussed coping is considered important in serious illness as it produces positive emotions, which provides a psychological break from the ongoing threat of illness and restores motivation to cope (Fredrickson, 1998). Negative emotions associated with the threat of transplant may intertwine with the positive emotions from meaning focussed coping, which may account for the contradictions in mens' narratives - such as Alec's conflicting pride and guilt. In a meta-analytic study, benefit finding was related to more positive well-being but also led to more intrusive and avoidant thoughts about the stressor (Helgeson, Reynolds, & Tomich, 2006). These complex processes were mirrored in several of the men's accounts.

Meaning focussed coping requires relinquishing past goals, yet some men appeared focussed on their pre illness abilities and they continued to set their expectations accordingly. This attempt to 'continue life as normal' could equally be seen as an attempt to cope and has been found among those living with other chronic illnesses (Dickson et al., 2008; Smith & Osborn, 2007; Spendelow, Joubert, Lee, & Fairhurst, 2017). This could be considered 'denial' - an emotion

focussed coping strategy aimed at regulating negative affect (Lazarus & Folkman, 1987). Equally, adjustment processes may be complicated by the “suspended animation” of the wait for transplant, whereby at any moment heart transplant may allow the participants a return to ‘normality’, rendering adjustment unnecessary (Spiers & Smith, 2016).

Clinical Implications

These study findings illuminate several important implications for health professionals working with patients awaiting heart transplantation. Firstly, the impact of lost occupation on identity and self-worth is an important finding, as many patients were encouraged to discontinue working once listed for transplant. A recent cross-sectional study found that time off work pre-heart transplant was significantly associated with a longer return to work post-transplant (Thomson, Maddison & Sharp, in press). Supporting patients to continue with work should they wish or access meaningful occupation may be an important element of their health care. Furthermore, work places should consider reasonable adjustments in order to assist heart transplant candidates to remain in work.

Secondly, the findings give weight to the importance of working psychologically with heart transplant candidates. Findings that some men's attempts to cope increased their experience of negative emotions suggests that guided discovery, a technique frequently used by psychologists, could be used to assist patients to break perpetuating cycles of ineffective coping. Additionally, acceptance and commitment therapy (ACT) might be of benefit to some. Acceptance and commitment therapy seeks to foster a person's acceptance of their distressing experiences and help them find ways to live in accordance with their values, despite illness. This approach may help the patient access meaning focussed coping at times when they are overwhelmed by their situation. A recent systematic review of patients with long-term health conditions found that ACT reduced distress, and improved the ability to stay focussed in the present moment and engage in behaviours connected to valued life goals (Graham, Gouick, Krahé, & Gillanders, 2016).

Finally, provision of psychological care for people with physical health conditions is increasingly on the political agenda (Scottish Government, 2016) with governments increasingly aware of the need for parity between physical and mental health. The findings from the present study suggest it is pertinent to consider psychological as well as the physical elements of illness. Provision of emotional support is a recognised role for all health care professionals and guidance for brief 'bedside' care has been documented (Griffith & Gaby, 2005). It notes the importance of witnessing, validating and normalising patients personal experience of illness.

Strengths and limitations

A strength of this study is the recruitment of participants during the actual wait period. In previous studies, participants' retrospective accounts may have been influenced by how they fared after transplant (Poole et al., 2016; Waldron et al., 2017), whereas this study aimed to capture patients' lived experiences in the here and now. This research has focussed solely on men's experience of waiting for transplant. The context of gender has likely shaped the experiences and interpretations reported here. It would be interesting to conduct a similar study with women waiting for transplant. There are several limitations to this study. Firstly, key contextual factors such as age, developmental stage, occupation and length of wait for transplant were removed to preserve participants' confidentiality. Such contextual factors have undoubtedly shaped how the men have experienced their wait for heart transplant and omission of these factors has reduced the depth of the interpretation presented here. Secondly, when participants showed distress or changed topic when discussing an emotive subject, the researcher did not probe for more information in line with ethical agreements. This may have limited a full exploration of their emotional experiences.

CONCLUSION

The men described numerous challenges in their wait for heart transplant. These included threats to their identity and a tormenting uncertainty regarding the transplant and their survival. Many men had found ways to regain meaning, purpose and motivation, yet at times the emotions of the situation were overwhelming. There is a need for health care professionals to appreciate and validate the individual meaning patients ascribe to their experiences. Psychological interventions, such as guided discovery and Acceptance and Commitment Therapy may enhance a person's coping experience.

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APPENDICES

Appendix 1a: Journal of Psychosomatic research guidelines for authors

Submissions

The Journal of Psychosomatic Research utilizes a web-based submission and peer review system. Authors should submit their manuscripts, with figures and tables, electronically at the journal Web site: <https://www.evince.com/profile/api/navigate/JPSYCHORES>. Complete instructions are available on the Web site.

The journal reviews all material that it receives. Approximately 50% of manuscripts are rejected after pre-review by an editor, typically after consultation with another member of the editorial staff or an external peer reviewer. This is done so as to allow authors whose manuscripts would almost certainly be rejected after peer review to submit the work elsewhere with as little delay as possible. Common reasons for rejection at this stage are insufficient originality, low priority of interest to the journal and clear quality deficits. We attempt to reach an initial decision on all articles that go through full peer review within 90 days of submission. Approximately 25% of submitted manuscripts are ultimately accepted for publication.



Preparation

Manuscripts should conform to the uniform requirements known as the 'Vancouver style' (International Committee of Medical Journal Editors. Uniform requirements for manuscripts submitted to biomedical journals. N Engl J Med 1997; 336:309-315). The Editors and Referees attach considerable importance to a succinct and lucid prose style and **well organized tables**. Authors whose native language is not English are advised to seek help before submission. Statistical procedures should be clearly explained.

NEW SUBMISSIONS

Submission to this journal proceeds totally online and you will be guided stepwise through the creation and uploading of your files. The system automatically converts your files to a single PDF file, which is used in the peer-review process.

As part of the Your Paper Your Way service, you may choose to submit your manuscript as a single file to be used in the refereeing process. This can be a PDF file or a Word document, in any format or lay-out that can be used by referees to evaluate your manuscript. It should contain high enough quality figures for refereeing. If you prefer to do so, you may still provide all or some of the source files at the initial submission. Please note that individual figure files larger than 10 MB must be uploaded separately.

References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.

If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

Figures and tables embedded in text

Please ensure the figures and the tables included in the single file are placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file. The corresponding caption should be placed directly below the figure or table.

Peer review

This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. [More information on types of peer review](#).

Appendix 1b: IPQ, IPQ-R and B-IPQ dimensions and example questions

IPQ subscales		Representation	Questionnaire example	Higher scores relate to a stronger perception that...
Cause	Cause	Cognitive		
Consequence	CONS	Cognitive	"my illness has major consequences on my life"	HF will have greater consequences
Control/cure	C/C	Cognitive	"there is little that can be done to improve my illness"	
Identity	ID	Cognitive	"breathlessness/fatigue etc is related to my illness"	HF has more symptoms
Timeline	TL	Cognitive	"my illness will last a long time"	HF will last a long time as opposed to a short time
IPQ-R subscales				
Cause	Cause	Cognitive		
Consequence	CONS	Cognitive	"my illness has major consequences on my life"	HF will have greater consequences
Personal control	PC	Cognitive	"what i do can determine if my illness gets better or worse"	they will have greater control over the HF
Treatment control	TC	Cognitive	"my treatment will be effective in curing my illness"	treatments will be effective in managing the HF
Identity	ID	Cognitive	"breathlessness/fatigue etc is related to my illness"	HF has more symptoms
Timeline acute/chronic	TLAC	Cognitive	"my illness will last a long time"	HF will last a long time as opposed to a short time
Time cyclical	TLC	Cognitive	"the symptoms of my illness change a great deal from day to day"	HF will be cyclical
Illness coherence	IC	Meta-cognition	"My illness doesn't make any sense to me"	HF makes sense
Emotional representations	ER	Emotional	"when i think about my illness i get upset"	HF makes them emotionally distressed.
Brief illness perception questionnaire (0-10 likert scale)				
Cause	Cause	Cognitive		
Consequence	CONS	Cognitive	How much does your illness affect your life?	HF will have greater consequences
Personal Control	PC	Cognitive	How much control do you feel you have over your illness?	they will have greater control over the HF
Treatment Control	TC	Cognitive	How much do you think your treatment can help your illness?	treatments will be effective in managing the HF
Identity	ID	Cognitive	How much do you experience symptoms from your illness?	HF has more symptoms
Timeline	TL	Cognitive	How long do you think your illness will continue?	HF will last a long time as opposed to a short time
Illness coherence	IC	Meta-cognition	How well do you feel you understand your illness?	HF makes sense
		Emotional +		
Illness Concern	Con	cognitive	How concerned are you about your illness?	
Emotional Representation	ER	Emotional	How much does your illness affect you emotionally?	HF makes them emotionally distressed.

Appendix 1c: Search strategy

Searches conducted 12.4.18

Database: Ovid MEDLINE(R) ALL <1946 to April 11, 2018> = 1059

Search Strategy:

- 1 ADAPTATION, PSYCHOLOGICAL/ (86692)
- 2 Health Knowledge, Attitudes, Practice/ (95131)
- 3 Illness Behavior/ (875)
- 4 ((illness* or disease* or condition* or health) adj4 (representation* or perception* or cognition* or belief*)).mp. (27764)
- 5 (common sense or CSM or self regulat* or leventhal).mp. (15825)
- 6 Heart Failure/ (104065)
- 7 ((heart or cardiac) adj failure).mp. (184920)
- 8 ventricular dysfunction.mp. (40224)
- 9 (HF or CHF).mp. (48752)
- 10 1 or 2 or 3 or 4 or 5 (217048)
- 11 6 or 7 or 8 or 9 (232838)
- 12 10 and 11 (1119)
- 13 limit 12 to english language (1064)
- 14 limit 13 to yr="1980 -Current" (1059)

Database: Embase <1974 to 2018 April 11> = 1700

Search Strategy:

- 1 psychological aspect/ (476210)
- 2 health belief/ (8898)
- 3 attitude to illness/ (4652)
- 4 ((illness* or disease* or condition* or health) adj4 (representation* or perception* or cognition* or belief*)).mp. (42431)
- 5 (common sense or CSM or self regulat* or leventhal).mp. (19264)
- 6 heart failure/ (204516)
- 7 ((heart or cardiac) adj failure).mp. (344194)
- 8 ventricular dysfunction.mp. (23831)
- 9 (HF or CHF).mp. (83822)
- 10 1 or 2 or 3 or 4 or 5 (534675)
- 11 6 or 7 or 8 or 9 (387651)
- 12 10 and 11 (1909)
- 13 limit 12 to english language (1706)
- 14 limit 13 to yr="1980 -Current" (1700)

Ebsco host CINAHL plus with full text = 250

Search Options	Actions
S14	S11 AND S12 Limiters: Published Date 1980-2018; English Language
S13	S11 AND S12
S12	S6 OR S7 OR S8 OR S9 OR S10
S11	S1 OR S2 OR S3 OR S4 OR S5
S10	TI ((HF or CHF)) OR AB ((HF or CHF))
S9	TI ventricular dysfunction OR AB ventricular dysfunction
S8	TI cardiac failure OR AB cardiac failure
S7	TI heart failure OR AB heart failure
S6	(MH "Heart Failure")
S5	TI ((common sense or CSM or self regulat* or leventhal)) OR AB ((common sense or CSM or self regulat* or leventhal).)
S4	TI (((illness* or disease* or condition* or health) N4 (representation* or perception* or cognition* or belief*))) OR AB (((illness* or disease* or condition* or health) N4 (representation* or perception* or cognition* or belief*)))
S3	(MH "Attitude to Illness")
S2	(MH "Health Beliefs")
S1	(MH "Psychosocial Aspects of Illness")

Ebsco host psychINFO = 659

S15	S12 AND S13 Limiters - Published Date: 1980-2018; Language: English
S14	S12 AND S13
S13	S6 OR S7 OR S8 OR S9 OR S10 OR S11
S12	S1 OR S2 OR S3 OR S4 OR S5
S11	TI CHF OR AB CHF OR KW CHF
S10	TI HF OR AB HF OR KW HF
S9	TI ventricular dysfunction OR AB ventricular dysfunction OR KW ventricular dysfunction
S8	TI cardiac failure OR AB cardiac failure OR KW cardiac failure
S7	TI heart failure OR AB heart failure OR KW heart failure
S6	DE "Heart Disorders"
S5	TI ((common sense or CSM or self regulat* or leventhal)) OR AB ((common sense or CSM or self regulat* or leventhal)) OR KW ((common sense or CSM or self regulat* or leventhal))
S4	TI (((illness* or disease* or condition* or health) N4 (representation* or perception* or cognition* or belief*))) OR AB (((illness* or disease* or condition* or health) N4 (representation* or perception* or cognition* or belief*))) OR KW (((illness* or disease* or condition* or health) N4 (representation* or perception* or cognition* or belief*)))
S3	DE "Physical Illness (Attitudes Toward)"
S2	DE "Client Attitudes"

S1	DE "Health Care Psychology"
----	-----------------------------

Web of Science Core Collection 885

# 10	885	(#9) AND LANGUAGE: (English) <i>Timespan=1980-2018</i>
# 9	911	#8 AND #7
# 8	381,212	#6 OR #5
# 7	160,231	#4 OR #3 OR #2 OR #1
# 6	112,316	TS=(HF or CHF) OR TI=(HF or CHF)
# 5	294,313	TS= (heart failure OR cardiac failure OR ventricular dysfunction) OR TI=(heart failure OR cardiac failure OR ventricular dysfunction)
# 4	14,731	TI=(common sense or CSM or self regulat* or leventhal)
# 3	123,032	TS=(common sense or CSM or self regulat* or leventhal)
# 2	10,471	TI=((illness* or disease* or condition* or health) NEAR/4 (representation* or perception* or cognition* or belief*))
# 1	38,185	TS=((illness* or disease* or condition* or health) NEAR/4 (representation* or perception* or cognition* or belief*))

Appendix 1d: Adapted AXIS tool for quality assessment

			Yes	No	Partially	Don't know/ comment
Introduction						
QR	1	Were the aims/objectives of the study clear?				
Methods						
SD	2	Was the sample size justified?				
QR	3	Was the target/reference population clearly defined? (Is it clear who the research was about?)				
SD	4	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?				
B	5	Was the selection process likely to select participants that were representative of the target population under investigation?				
B	6	Were measures undertaken to address and categorise non-responders?				
SD	7	Were the outcome measures used appropriate to the aims of the study?				
B	8	Were the outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously? (valid and reliable)				
QR	9	Is it clear what was used to determine statistical significance and/or precision estimates? (eg, p values, CIs)				
QR	10	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?				
Results						
QR	11	Were the basic data adequately described?				
B	12	Does the response rate raise concerns about non-response bias?				
B	13	If appropriate, was information about non-responders described?				
QR	14	Were the results for the analyses described in the methods, presented?				
B	15	<i>Were key potential confounding variables statistically adjusted for (regression only).</i>				
B	16	<i>Does the number of participants lost to follow up raise concern?</i>				
B	17	<i>If appropriate, was comparison made between full participants and those lost to follow up?</i>				
Discussion						
SD	18	Were the authors' discussions and conclusions justified by the results?				
QR	19	Were the limitations of the study discussed?				
IPQ Specific Questions						
	20	<i>Was the selected Illness Perceptions instrument administered as designed and in line with</i>				

		<i>developer's instructions?</i>				
	21	<i>Were IPQ dimensions and their correlations reported on?</i>				

KEY: QR: Items measuring quality reporting; SD: items measuring study design:

B: Items measuring bias; *Italics*: adjusted or added questions from original AXIS tool.

Appendix 1e. Final quality assessment ratings agreed by primary and secondary rater.

	Quality of reporting								Study design				Bias					IPQ bias		Longitudinal bias	
	1	3	8	9	10	11	14	19	2	4	7	18	5	6	12	13	15	20	21	16	17
Cross Sectional																					
Cherrington et al, 2006. USA.	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	P	N	N/A	Y	Y		
Giardini et al, 2017. Italy.	Y	Y	P	Y	Y	Y	Y	Y	N	N	Y	Y	N	N	N	N	P	Y	Y		
Hallas et al, 2011. UK.	Y	P	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	Y	N	Y	Y	Y		
MacInnes 2013. UK.	Y	P	P	Y	P	Y	P	Y	Y	Y	N	Y	Y	N	Y	N	N	P	P		
Molloy et al, 2009. UK.	Y	Y	Y	N	P	Y	Y	Y	N	Y	Y	Y	P	Y	Y	Y	N	Y	N		
Morgan et al, 2014. IRELAND	Y	Y	Y	P	P	Y	P	Y	N	Y	Y	Y	Y	N	N	N	Y	Y	Y		
Timmermans et al, 2017. Europe	Y	Y	Y	Y	Y	Y	Y	P	N	Y	Y	Y	?	N	?	N	Y	N	N		
Turrise, 2014. (USA)	Y	N	P	N	N	Y	P	Y	Y	P	Y	N	P	N	?	N	N	Y	P		
Prospective Cohort																					
Goodman et al. 2013. UK	Y	Y	P	Y	N	P	P	Y	N	P	Y	Y	P	P	Y	Y	N	Y	N	N	Y
Mulligan et al. 2012. UK	Y	Y	Y	Y	Y	Y	P	Y	N	Y	Y	Y	Y	Y	P	Y	Y	Y	P	P	N
Wierenga, 2018. (USA)	P	P	P	N	N	Y	P	P	N	?	N	N	?	P	?	P	Y	N	N	?	?

KEY: Y= YES; N= NO; P= PARTIALLY; N/A not applicable.

IPQ bias; Bias specific to use of IPQ. Longitudinal bias; bias specific to longitudinal designs.

Reverse score: YES is negative; NO is positive.

Resolution of direct Yes/No discrepancies from quality ratings:

MacInnes (2013)	<p><i>Q7) Were the outcome measures used appropriate to the aims of the study?</i></p> <p>Discussed the primary reviewer's findings that self-care tool lacked validity. Both agreed outcome measure was not appropriate because of this. Agreed to keep rating as "no".</p>
Molloy (2009)	<p><i>Q9) Was it clear what was used to determine statistical significance (e.g P values)?</i></p> <p>Discussed that whilst P values given in results, P value was not stated in the methods section. Primary and secondary reviewer had searched for evidence in different sections of the article. As question appears in the methods section of quality assessment tool, agreed that would only score "yes" if this is stated in methods section. Agreed to change rating to "no".</p>
Turris (2014)	<p><i>Q3) Was the target population clearly defined? (Is it clear who the research was about?)</i></p> <p>Discussed that "chronic" heart failure had not been operationalised and illness severity determined by NYHA not provided. Agreed to keep rating as "no".</p>
	<p><i>Q18) Were the authors discussions and conclusions justified by the results?</i></p> <p>Reviewer highlighted areas thought to be overstated conclusions in light of the results. Second reviewer agreed. Rating kept as "no".</p>
Goodman et al. (2013):	<p><i>Q11) Were the basic data adequately described?</i></p> <p>Discussed that basic demographics did not add up to 100% and therefore a "no" rating should be given. Second-rater had not seen this. Agreed to change rating to "partially".</p>
	<p><i>Q16) Does the number of participants lost to follow up raise concern?</i></p> <p>Discussed that whilst numbers lost to follow up, primary reviewer highlighted that no statistical difference was found between those included in analysis and those lost to follow up. Agreed to keep rating as "no".</p>

Appendix 2a: Author submission guidelines to the Journal of Heart and Lung Transplant

Aims and scope

The Journal of Heart and Lung Transplantation, the official publication of the International Society for Heart and Lung Transplantation, brings readers essential scholarly and timely information in the field of cardiopulmonary transplantation, mechanical and biological support of the failing heart, advanced lung disease (including pulmonary vascular disease) and cell replacement therapy; Importantly, the journal also serves as a medium of communication of pre-clinical sciences in all these rapidly expanding areas

Editorial policies

Statements and opinions expressed in the articles and communications herein are those of the author(s) and not necessarily those of the Editor(s) or publisher, and the Editor(s) and publisher disclaim any responsibility or liability for such material. Neither the Editor(s) nor the publisher guarantees, warrants, or endorses any product or service advertised in this publication. Neither do they guarantee any claim made by the manufacturer of such product or service.

Copyright policies

Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form in English or in any other language, without the written consent of the copyright holder.

Upon acceptance of an article, authors will be asked to transfer copyright to the International Society for Heart and Lung Transplantation. A letter will be sent to the corresponding author confirming receipt of the manuscript, and a form facilitating transfer of copyright will be provided.

If excerpts from other copyright works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the articles. Copies of letters granting permission must be submitted with the manuscript.

Authorship

Each person designated as author should qualify for authorship. Each author should have participated sufficiently in the work to take public responsibility for the content. The cover letter should state the participation level of each author.

Conflict of Interest and Funding Sources

All listed authors must complete and submit the ICJME's standardized disclosure form, which can be found at http://www.icmje.org/coi_disclosure.pdf. If uncertain as to what might be considered a potential conflict of interest, authors should err on the side of full disclosure. In addition, each manuscript regardless of its type must include a financial conflict of interest disclosure. This statement should be included AFTER the conclusions and BEFORE the references in a separate section. Such a section must also include any funding sources or acknowledgements of contribution of any material nature. The conflict of interest statement should describe ALL authors' relationships with companies or relevant entities that make products pertinent to the paper. The statement should specify the type of relationships (e.g., consulting, paid speaking, grant support, equity, patents) EACH author has with EACH company. This item is of serious concern to the editorial office and no manuscripts will move forward for processing if this data is not available.

The role(s) of the funding organization, if any, in the collection of data, its analysis and interpretation, and in the right to approve or disapprove publication of the finished manuscript must be described in the section as indicated above.

In general, the Journal follows the COPE (Committee On Publishing Ethics) guidelines and these are available for general review at <http://publicationethics.org/>

Informed consent

Reports describing data obtained from research conducted in human subjects must contain a statement in the Methods section indicating approval by the institutional review board or Ethics board and affirming that informed consent was obtained as required by the study authorizing entity.

All submissions to the journal must attest their strict compliance with the ISHLT ethics statement (<http://www.isHLT.org/ContentDocuments/ISHLT%20Transplant%20ethics%20statement.pdf>). In addition, for specific submissions from countries where it is known that transplants may be performed in violation of these guidelines (e.g. transplants involving executed prisoners), a specific statement to this regard is required within the methods, or the manuscript will be returned during the processing phase by the editorial office.

Author rights

As an author you (or your employer or institution) have certain rights to reuse your work. For more information see <http://www.elsevier.com/copyright>.

Manuscript submission

The Journal of Heart and Lung Transplantation will accept online submissions of original manuscripts through the Elsevier Editorial System (EES) at <http://ees.elsevier.com/jhlt>. Manuscripts submitted through this online system can easily be tracked by the authors, editors, and reviewers through final disposition. The corresponding author involved with a specific manuscript will receive automatic e-mail notification as the manuscript proceeds through the system. To begin using this system, go to <http://ees.elsevier.com/jhlt>. Click the 'Register' link on the toolbar at the top left to input author demographics and set up an account. After registration is complete, a notice will be sent via email indicating a user ID and password. Use this information to log in as an author by choosing the 'Login' link on the toolbar and select 'Submit New Manuscript.' Follow the prompts to complete the submission according to the specifications below. Please be aware that you will need to prepare the manuscript (with abstract included within), each table, and each figure as separate files following the guidelines listed below. Further questions may be directed to our office by e-mail to jhlteditor@ishlt.org or via phone to the editorial office at (617) 732-8534 (Ms. Anne Lau). The user ID and password can be changed at any time by logging into <http://ees.elsevier.com/jhlt> with your username and password and then clicking the 'change details' link at the top of the page.

Please note that we ONLY accept online manuscript submissions.

Abstracts

All manuscripts with the exception of Research Correspondence and Case Anecdotes, Comments and Opinions, MUST contain an abstract of no more than 250 words that briefly summarizes the content. The abstract should be divided into four sections: Background, Methods, Results, and Conclusions. Abstracts must be typewritten, double spaced, single columned with a minimum of 1-inch margins on all four edges using an 11 point font. Manuscripts submitted without an abstract will NOT be considered for publication. Abstracts will not count toward the total manuscript page count.

Manuscript Categories

For **Original Research Communications** we ask authors to adhere to the following policy in order to maximize the number of articles available in each issue. A 3,000 word limit for text plus abstract (excluding tables, figures, and references), on average 10 journal pages per article, will be permitted. A total of 8 figures/tables will be allowed.

Manuscript Review Process and Outcomes

This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. More information on types of peer review can be found at <https://www.elsevier.com/reviewers/what-is-peer-review>.

The Journal initially processes and reviews all papers at the editors' level. A third of half of all papers processed receive a decision without further review. The remaining papers are sent for further peer review to editorial consultants and expert reviews. Typically, the website prompt may indicate "all reviews complete" when 2 reviews are received. Occasionally, the editors will act on 2 reviews but the editorial meeting typically seeks a senior editor's review as well as 3-4 reviews on original science articles. The journal maintains a typical time to first decision of 3-4 weeks but in some cases where discrepant reviews are received, we may take longer. Case reports are generally not accepted as full papers, and the acceptance rates for original science articles are in the 20% range.

Style, abbreviations, and references

References must contain the full title of the citation. Authors are encouraged to refer to the American Medical Association Manual of Style, 10th Edition as a specific style guide. The manuscript must be typewritten, double spaced, single columned with a minimum of 1 inch margins on all four edges. Only standard size type in 11 point font may be used. The first page of the manuscript should begin with the title of the paper in capital letters, followed by the names of the authors. Please be sure to leave sufficient space at the bottom of the first page to provide for the name of the institution, as well as grant support. It is not necessary to create a separate title page. The abstract should

be prepared according to the guidelines listed above. **Double space the manuscript, footnotes, and references.** The editorial office strongly **recommends that authors use tables and/or figures to document the findings described in the manuscript.** Abbreviations should be used sparingly unless they are commonly accepted such as RNA, CsA, etc. When such a word appears for the first time, it should be written out in full, followed by the abbreviation in parentheses. This abbreviation may then be used subsequently when referring to the same term. All hematologic and clinical chemistry measurements should be reported in the metric system in terms of the International System of Units (SI). Abbreviations for titles of medical periodicals should conform to those used in the latest edition of Index Medicus. (A 'List of Journals Indexed in Index Medicus' - with abbreviations is obtainable from the Superintendent of Documents, US Government Printing Office, Washington, DC 20402 at a modest charge.) References should be listed by number in the body of the text, and should be listed in the reference section in the same order in which they appear in the manuscript. Include authors' last names and initials, journal, volume, page, and year. Include the city and the publisher's name for books.

Reference examples

(List all authors when six or fewer; when seven or more, list first three and add et al.)

Tables and figures

Figures

All figures should be submitted in final form ready for publication (this includes all labeling, shading, arrows, and other aspects of the figure). Prepare the figures for reduction in size of at most 50% and ensure that the lettering does not vary in size. **The final font size (after reduction) should be 6-8 point.** The physical dimensions of the figures should match the dimension of the journal. Most figures will be reduced to fit one-column width (3 1/4 inches). Computer-generated illustrations and halftones/line/tones (either color or black & white) are acceptable. **Figures should be submitted in a Graphics Format for PCs (.tif)** on EES along with the manuscript. Please note that there is an additional charge for color printing. Therefore, please ensure that color illustrations are essential to the paper to avoid unnecessary charges. Color figures that are accepted for publication will appear in color online even if the figures print in black & white. EACH figure should be submitted as separate files. Uniform lettering, sizing, type of software used, and logical naming for the artwork files is strongly encouraged when submitting electronically. Line graphs and bar charts should be sent in bitmap TIFF files with a minimum resolution of 1200 dpi, or as EPS files, with a preferred line width of 1 pt (minimum line width of 0.5 pt). Bitmap images should be sent as TIFF files and not placed within EPS files. Pictures, photographs and micrographs should be sent as Grayscale TIFF files with a minimum resolution of 300 dpi without lettering, and 500 dpi with lettering. Color images should be sent as CMYK-encoded TIFF images. RGB-encoded color images will be difficult to match for color. Graphs produced in software such as Excel or Word should be submitted in black and white with different types of dashed lines for total clarity. Please visit the publisher's website (<http://www.elsevier-.com/locate/authorartwork>) for detailed instructions and visual guidelines. **All illustrations should show optimal clarity of detail.** All illustrations should be accompanied by a suitable descriptive text legend.

Tables

Tables must be submitted as separate WORD or EXCEL files and should not be embedded in the WORD document file. Tables should be used to organize key information in the manuscript. Tables should be used to make the presentation more concise and not used to duplicate what is already contained in the text.

Author Agreement

The authors must include a cover letter with the manuscript submission that indicates the manuscript has not been published previously and that it is not under consideration for publication elsewhere. It should be stated that all authors are in agreement with the content of the manuscript. In addition, the authors must also include a statement indicating that all funding sources, financial conflicts and acknowledgements have been written into the main body of the manuscript in a separate section as previously described. We would certainly welcome your explanation of any potential conflict of interest, if you believe that it will help the editorial process.

Appendix 2b: Ethical Approval

WoSRES

West of Scotland Research Ethics Service



Dr Sarah Wilson

Senior Lecturer (Medicine), Associate
Academic (Institute of Health and Wellbeing)
University of Glasgow
University of Glasgow, Institute of Mental
Health and Wellbeing
Hospital
G12 0XH

West of Scotland REC 3

West Ambulatory Care Hospital
Dalnair Street
Yorkhill
Glasgow
Garthnavel Royal

G12 0XH

Date 19 July 2017

Direct line

0141-232-1806

e-mail

Wosrec3@ggc.scot.nhs.uk

Dear Dr Wilson

Study title: Experiences, beliefs and coping whilst waiting for heart transplant: An interpretative phenomenological study.
REC reference: 17/WS/0136
Protocol number: GN17MH284
IRAS project ID: 224868

Thank you for your letter of 13 July 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 26 June 2017

Documents received

The documents received were as follows:

Document	Version	Date
Other [WOSRES conditions met cover letter]		
Participant consent form [Consent Form]	V2.1	27 June 2017
Participant information sheet (PIS) [Participant information sheet]	V2.1	27 June 2017
Research protocol or project proposal [Research protocol]	V2.2	27 June 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
GP/consultant information sheets or letters [GP information sheet]	V1	22 May 2017
Interview schedules or topic guides for participants [Interview schedule]	V1.2	06 June 2017
Letter from sponsor [NHS Sponsorship approved email]		06 June 2017
Other [WOSRES conditions met cover letter]		
Participant consent form [Consent Form]	V2.1	27 June 2017
Document	Version	Date

Participant information sheet (PIS) [Participant information sheet]	V2.1	27 June 2017
REC Application Form [REC_Form_07062017]		07 June 2017
Research protocol or project proposal [Research protocol]	V2.2	27 June 2017
Summary CV for Chief Investigator (CI) [Chief investigator CV Dr Sarah Wilson]		11 May 2017
Summary CV for student [R Jury student CV]		22 May 2017
Summary CV for supervisor (student research) [NHS Field supervisor Dr John Sharp]		23 May 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/WS/0136	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Sophie Bagnall
Assistant Coordinator

Copy to: *Ms Emma Jane Gault*
Dr Catherine Sinclair, NHS National Waiting Times Health Board

Appendix 2c: Participant consent form



Institute of Health
& Wellbeing



Golden Jubilee
National Hospital
Patients at the heart of progress



CONSENT FORM (Version 2.1 27.6.17)

Study: Experiences, beliefs and coping whilst waiting for heart transplant: An interpretative phenomenological study.

Researcher: Rebecca Jury

Please initial the box to indicate you have read and agreed.

I have read the participant information sheet (version 2.1, 27.6.17)	
I have had the chance to consider the information and ask questions.	
My questions have been answered satisfactorily.	
I give permission for my interview to be recorded.	
I understand that my participation is voluntary and that I can stop the interview at any time, without giving a reason and without my medical care being affected.	
I understand that my interview will be transcribed by Rebecca and that my anonymous transcript may be looked at by Rebecca's research supervisors as part of the data analysis	
I consent to Rebecca posting or emailing me a copy of the initial themes she identifies.	
I understand that the study sponsor- NHS Greater Glasgow and Clyde- may request to look at my personal information to make sure the study is being conducted correctly and to ensure that data is not being fabricated.	
I agree that comments from my interview can be used in the final report, presentations and publications. All names, places and any patient identifiable information will be removed. Nothing that identifies me will appear for others to see.	
I consent to Rebecca storing my contact details on a password protected document on a secured NHS computer for the duration of the study.	
I understand that my anonymous interview recording and interview transcript will be privately and securely stored on the University of Glasgow Enlighten research software for 10 years, after which it will be destroyed.	
I agree that my GP can be informed of my involvement in the study.	
I agree to take part in this study.	

Subject Name:	Date:	Signature:
Researcher Name:		

Appendix 2d: Participant information sheet



PARTICIPANT INFORMATION SHEET

Study: Experiences, beliefs and coping whilst waiting for heart transplant: An interpretative phenomenological study.

Researcher: Rebecca Jury

We would like to invite you to take part in a research study. To help you decide if you would like to take part, you need to understand what taking part would involve for you. Please take your time and read the following information carefully.

Who is conducting the research?

The research is being carried out by Ms Rebecca Jury who is a Clinical Psychologist in training at the University of Glasgow. The research is being supervised by Dr Sarah Wilson from the University of Glasgow, and Dr John Sharp from the National Advanced Heart Failure Service. Rebecca does not work at the Golden Jubilee Hospital, but she does have an interest in psychology and cardiac health.

Why are we doing this research?

We know that it can be a long wait from when a person is told they need a heart transplant to when they receive one. Research suggests that this wait can be a distressing time and that people may have to deal with lots of worries and concerns. People may use many different ways to try and cope. We think it would be useful to learn more about how this waiting time is experienced by people and what they do to cope. This may help health care professionals to better understand people's experiences and it may help to develop support for people who are waiting for a heart transplant in the future

Why have I been invited?

We are inviting people who are currently on the routine waiting list for heart transplant with the Scottish National Advanced Heart Failure Service. We believe you fit these criteria and that is why we have invited you to take part.

What does taking part involve?

You will meet with Rebecca Jury to talk about your experiences of waiting for a heart transplant. This will include the challenges you face, your thoughts, concerns or worries about transplant and the ways in which you try to cope with waiting. This interview will take place in a comfortable, non-medical room at the Golden Jubilee Hospital. It will take up to 1 hour, but it may take less. You will be able to take a break at any time during the interview and you don't have to answer any questions you don't want to.

Rebecca will audio record your interview so that she can make sure she captures everything you say and so she can listen back to the discussion and type it up into a transcript. This allows Rebecca to look at the things you said during the interview and compare it to what others have said during their interviews.

The idea is to look for shared themes in people's experiences. With your consent, you will be posted or emailed a copy of the initial themes Rebecca identifies and given the opportunity to think about whether you feel these themes are a good representation of your experience. You will be able to email or telephone Rebecca to share your thoughts, which Rebecca will use to help when analysing the interviews. When Rebecca types up your interview, she will not use your real name, but use a fake name instead. She will also change any family names and significant place names to ensure that your interview transcript is anonymous. Your interview will be kept private and will not be shared with the Scottish National Advanced Heart Failure Service, unless you mention that you or someone else is at risk of harm, in which case we have a duty of care to share this information to ensure your, or another's, safety.

Do I have to take part?

No. The decision to take part is entirely up to you.

What happens if I decide to take part?

If you decide to take part, you can either contact Rebecca by email or agree to your contact details being passed onto Rebecca and she will contact you. She will arrange a time to meet with you. Please let your transplant coordinator or a member of the Scottish National Advanced Heart Failure Service know that you would like to take part, and they will let Rebecca know. If you agree to take

part, you will be asked to sign a consent form to evidence that you are happy to take part and that you understand what this involves. You can change your mind at any point and you won't need to give a reason for this. The care you receive will not be affected. We will let your GP know that you have agreed to take part in the study.

What happens to my information?

The anonymised audio recordings and any written information will be kept on an encrypted University of Glasgow computer and backed up onto the password protected network server for the duration of the research study. This information will be stored in accordance with the Data Protection Act, which means that we keep it securely and cannot reveal it to others without your permission. Rebecca may share your anonymised interview transcript with her research supervisors to ensure accurate data analysis. Sometimes, the study sponsor- NHS Greater Glasgow and Clyde- may want their research representative to look at your personal information, to make sure the study is being conducted correctly and to ensure that data is not being fabricated. When the study is complete, your audio recordings and interview transcripts will be transferred to University of Glasgow research software, for private and secure storage of research data for 10 years. At this time, all your information will be deleted from the encrypted laptop. After 10 years, the research data will also be deleted. The information from your and other people's interviews will be written up into a report. Some direct quotes from your interview may be included in this report, but your name will be changed and nothing which identifies you will be included. The report will be given to the University of Glasgow as part of a doctoral thesis in Clinical Psychology and stored publicly on The University of Glasgow Library website. The report may also be submitted for publication in a research journal, so that other health care professionals around the UK can learn from the study results. If you're interested in seeing the final report, Rebecca can send you this.

What are the possible benefits of taking part?

Your participation will help health care professionals to better understand the challenges experienced by people waiting for heart transplant, which in turn may help to develop new supports for people. It is hoped that you may find some benefit from having the opportunity to talk about your experiences. If you feel

distressed during or after the interview, we will ensure that you have information on how to access appropriate supports, if you need to.

Who has reviewed the study?

To make sure the study is being conducted correctly, it has been reviewed by the West of Scotland Research Ethics Committee and the NHS National Waiting Times Board and Greater Glasgow and Clyde Research & Development Department.

What if you have a complaint about any aspect of the study?

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint procedure is also available to you.

If you have any further questions;

Please contact the researchers at:

Rebecca Jury
Institute of Health & Wellbeing,
University of Glasgow
Administration Building
1st Floor
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Email: r.jury.1@research.gla.ac.uk
Tel: 01412110607

Dr Sarah Wilson
Institute of Mental Health &
Wellbeing,
University of Glasgow
Administration Building,
1st Floor
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Email: Sarah.Wilson@glasgow.ac.uk
Tel: 01412113921

If you would like to speak to someone who is not closely involved in the study, then you can contact Dr Sue Turnbull. Her telephone number is: 0141 211 3900

Thank you for taking the time to read this information sheet.

I would like to take part, what shall I do now?

- You can let Rebecca the researcher know that you would like to take part by email on r.jury.1@research.gla.ac.uk and she will be in touch.
- Alternatively, please let your transplant co-ordinator, or any member of the Scottish National Advanced Heart Failure Service know that you would like to take part.
 - You can do this by telephone on: 0141 951 5472
 - You can do this by letter to:

Scottish National Advanced Heart Failure Service
Golden Jubilee National Hospital
Agamemnon Street
Clydebank G81 4DY

- You can do this at your next appointment.
- The team will let Rebecca know you are interested and she will ring you to arrange a time to conduct your interview.
- Rebecca will be happy to answer any questions or concerns you have.

Appendix 2e: Interview schedule



Institute of Health
& Wellbeing

INTERVIEW SCHEDULE (V1.2 6.6.17)
Study: Experiences, beliefs and coping
whilst waiting for heart transplant: An
interpretative phenomenological study.

Researcher: Rebecca Jury



Introduction

Thank you for meeting with me today. My name is Rebecca. I'm a trainee psychologist and I am researching people's experience of waiting for a heart transplant. I'll be asking you some questions about the challenges of waiting for a heart transplant, what sense you make of heart transplantation and your experience of coping with the wait for a heart transplant. I'm really interested in **you** and **your experience** of waiting for transplant. There are no right or wrong answers - really I just want to hear what you have to say. So I'll be doing a lot of listening, and perhaps not a lot of talking. When I do ask you questions, it will be because I'm really trying to understand how you have experienced something. Sometimes you might say things I want to ask you more about, so I might jot it down on this paper to remind me to come back and ask you about it. I have a digital recorder here to record our interview. This will make sure I have got what you say right.

I know that some things we talk about today **might be upsetting** to talk about. You can **take a break at any point** during the interview, just let me know. Also, **you don't have to answer** any questions you don't want to.

I want you to know that I am not a member of staff here and I do not work with the team. What we talk about today is confidential and will not be shared with the team. However, if you tell me that you or someone else is at risk of harm, then I have a duty of care to report this to a relevant member of staff in order to keep you or someone else safe.

Before we start we'll go through the information sheet to see if you have any questions. After that I will ask you to sign a consent form, which asks whether you understand what is involved in taking part and whether you agree to take part. [Go through participant information sheet and consent form].

Do you have any questions?

Do you have any physical symptoms today that you think might make the interview difficult? [is there anything I can do to make your experience more comfortable/if you feel unwell just let me know and we can take a break or stop the interview].

Any questions? Shall we start?

Administrative question

Once I have written up the interviews from all the participants, I will start to look for shared themes in people's experiences.

- Would you like me to send you a copy of initial themes so that you can consider if they feel like a good representation of your experience?
- Would you like these sent by post or email?
- Would you like copy of final report, once it is all written up?
- Would you like this sent by post or email?

Establishing rapport and general information

1. I'm interested in your experience of being told that you needed a heart transplant, please can you tell me about that?

P: What was that like for you? What did you make of that? How did that feel?

Challenges of waiting for transplant

2. My understanding is that there is a wait involved in getting a heart transplant, how have you experienced that waiting process?

P: To what extent does waiting for a heart transplant affect your life?

P: affect you emotionally? Job? Family? Physically?

3. Please could you tell me about the hardest part of waiting for a heart transplant?

4. Please could you tell me about any worries you have, about your wait for a heart transplant?

Beliefs about waiting for a donor

5. My understanding is that waiting for a heart transplant means you are waiting for a donor heart, I'd be interested to hear what sense you have made of that?

P: What you think about receiving a donor heart? How do you feel?

P: any worries? Affect emotionally?

6. How do any friends or family think about you getting a donor heart?

P: What do you make of that? How have you experienced that? What has that been like for you?

7. Could you tell me what you think will be good about receiving a donor heart?

Coping with waiting for heart transplant

8. Some people talk about how they try to cope with waiting for a heart transplant. Is that something you can relate to?

P: How do you think you are coping?

9. How do others help you to cope with you wait for heart transplant?

P: What is that like for you?

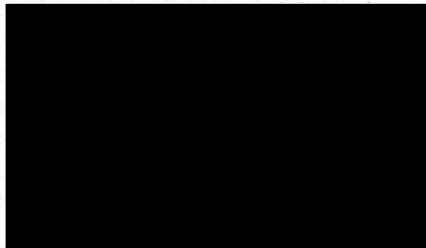
Appendix 2f: Sample analysed transcript

P5: Christopher

15

<p>R: [22:07] so there's something there you're about talking about this loss of role and its impact socially...</p>			
<p>Christopher: yeah erm somebody once what was it .. <u>loss of status</u> of something I think is sort of erm you know if you were an unemployed person and you weren't used to making the day go by in a very sort of laxidascal fashion it would be one thing if your coming from a very high speed environment and <u>just told stop now</u> you've got to sit down sit in the corner and don't get excited by things then you .. its it's a huge adjustment to make</p>	<p>he feels he has lost 'status' <u>Status is an interpersonal state - requires comparison/ relation to others - connotations with position in society</u> old life was fast paced <u>just told "stop now" - VERY sudden</u> <u>told by who? sense this has been forced on him by others? by medical world.</u></p>	<p>diminished in societies eyes! identity constructed at different levels - identity as member of society, member of family as individual etc. - change of role enforced - suddenly, without choice - like a shock or trauma.</p>	<p><u>OLD SELF VS NEW SELF</u> ill self diminished self ill self unvaluable. ill self unworthy status <u>INTERACTIONS MEDICAL WORLD</u> Medical world used labours</p>
<p>R: [22:46] how do you experience that? Whats it feel like for you?</p>			
<p>Christopher: erm I don't let it get me down but ..i can imagine how it would I mean there's been a couple of stages where I've gone no this is this is pretty this is pretty stupid erm I'm just going to go back to work I'm just going to go and start applying for jobs and I'm you you know going to sort this out because erm ... the clocks ticking if I have a heart transplant and it's a roaring success and they give you the percentages of people who don't make it out of the hospital and who are dead within 12 months and all these things and you kind of weigh those up .. and you say to yourself well actually I dont feel too bad I really</p>	<p>Sometimes thinks he should just go back to work. Has been told risks to heart transplant might not survive even after transplant (so whats the point thinking?)</p>	<p>Sometimes incongruence so much he expects though wishful thinking/ longing about return to work. only occupation will help him regain identity - adjusting to 'ill self' is not enough?</p>	<p><u>Attempts to regain identity confidence</u> incongruence unresolvable</p>

on the transplant list its like an acceptance thing some people don't get on the list because they're not mentally strong enough to be on the list they just accept it as a horrible thing and they're so ... pessimistic about it and they don't want to fight and challenge for the future life your possible going to get so .. I appreciate that I am on the list but you do need to speak to people you do need to try and stay positive .. you can't let things get on top of you all the time and for that short period I did its like a manly macho mentality of don't speak about your feelings and don't cry because that makes you look weak .. and all of that is absolute nonsense you need to speak to people about how you're feeling .. physically and mentally .. and I didn't for



felt like .. and I've got the pictures with me ill show you them .. because they don't have the vocabulary to say how they're feeling they draw the pictures and everything that picture in the pictures ill show you was so powerful to

some people not 'mentally strong enough'

future life must be fought for

Didn't talk about feelings or cry in front of others
in case it made him look weak
absolute nonsense - doesn't subscribe to the making anyone
Now talking to family weight off shoulders

Appraises being on the transplant list as being 'mentally strong' - brings congruence to sense of self + new identity as tx candidate not 'ill' but 'strong'.

Appraises situation as 'fight' - in line with himself as 'strong' - helps tolerate ill self/identity - gives drive/motivation. And yet also causes him tension (Pg6) when realises fight is not a fair one - illness too uncontrollable.

Realising that talking about feelings is another way to be strong - not weak - again bringing congruence to old self - ill self?

ATTEMPTS TO COPE/
RESOLVE CONFLICT

regain identity/congruence
Strongness in illness

Self responsible for survival
must fight for survival

Strongness in illness

Appendix 2g: Sample tabulated quotations for Ryan.

THREATENED IDENTITY	UNCERTAIN LIFE OR DEATH	COPING
<p><i>Loss of what defined me?</i></p> <p>"with my heart I can't do what I want to do .. I can't go for along walk up a hill or take the dog for a stroll along the back or climb a mountain or anything like that a flight of stairs is enough for me .. And I want .. I want my life back how it used to be .." pg 5</p> <p>" I think back to when I used to be at work and I love my work .. I used to to a lot of heavy lifting and I think back to when I'd throw a (sofa?) over my shoulder and walk up to the warehouse with a three seater settee , rolls of carpet and anything like that and I think how could I do that when now a couple of bags of shopping and I struggle" pg 23</p> <p><i>Someone I'm not?</i></p> <p>"I gotta set myself goals cause if I didn't set myself goals I'd sit there and I'd watch the tele till I'd watched every programme that was on the planet and I'm sorry but that's just not me ive never been one for sitting down and watching TV or anything like that I've always had to be doing something" pg 17</p> <p>you try and do so much and you just and the frustration kicks in because you can't do it or your trying to do something that you can't do and you get frustrated and you just (sighs) I'm not a bad tempered person (laughs) I'm quite an easy going person" pg 33</p>	<p><i>Daily/ temporal uncertainty?</i></p> <p>"you wake up everyday thinking , is this the day? you go to bed 'oh well that's another day' and you wake up tomorrow .. Is it gonna be today? and its a complete circle it just goes round and round and round and round" pg 15</p> <p>"there's not a day when I haven't had this 'is this gonna be the day' .. And then there's other days you (sighs) there's some days you think like that but other days you think (sighs) I wish it was today I wish it was now I wish it was today" pg 20</p> <p><i>Future uncertainty?</i></p> <p>"your head ends up scrambled because you start thinking oh I could do this and you think oh no I couldn't do this because if I .. Start doing this and I get a phonecall and then that happens and you think ahhh" pg34</p> <p>you think well there's all these statistics that they have .. a percentage live this long there's a percentage live that long .. even though I'm looking forward to the transplant (pause) I know there's still this (pause) still a percentage game of how long I'm gonna get out of it" pg 26</p>	<p><i>Family</i></p> <p>"everything's sorted so she not got to worry about anything like that .. Everything's sorted so she's .. she knows everything my poor wife knows that if (laughs) I'd be quite happy that if I was climbing up the side of a building and I dropped down .. Shes knows I'd die happy" pg26</p> <p>"Everything's in order everything's sorted out .. my wife knows every insurance policy our finances are sorted out .. it has to be as stupid as it sounds it has to be because if you get this phone call and its literally as case of your gone .. everything has to be you know to keep running ..[...] everything's sorted so she's not go to worry about anything like that pg 25 26</p> <p><i>Accepting death? Minimising death?</i></p> <p>"I didn't think about the dying thing the dying thing the dying thing doesn't actually bother us because everybody at some points going to die that's settled " pg 26</p> <p>If I'm cutting the grass and I drop down dead .. That's it .. Fair enough if I happen to be playing bowls on the bowling green and I've fallen that'll be it its no something I think about its no something I worry about errr everything ..</p>

Appendix 2h: Feedback from participants regarding themes.

Participants were sent descriptions of the themes and then asked the following

Which of the below statements do you agree with:

- A) I think the themes do a good job of capturing my experience of waiting for transplant
- B) I think the themes partially capture my experience of waiting for transplant
- C) I think the themes do not really capture my experience of waiting for transplant.

I would also welcome any other comments you may have below:

Hi Rebecca

Sorry for taking so long to reply.

The answer to the question at the bottom is A

I think you have done a great job of putting down on paper the majority of my thoughts and fears.

I hope the project turns out to be a success and some good comes of it.

Appendix 2i: Excerpt from reflexive journal

After [XX] interview

Struck by idea of identity shaped by meaningful purposeful life and activity. This then influenced how I reflected back to P2 and P4 – could see how this was relevant for their narratives. Thought back to P4 and realised I may have missed what was salient for his experience – wondered if I tried too hard to stick to schedule. Felt like I could start to see the bigger picture knitting narratives together – recognising that I will probably now be looking for this in transcripts and how supervision and coding by others will be important to check analysis not biased by this. Also struck by trust in others and how this interacts with wait.

After [XX] interview

Struck by halting of developmental trajectory.

After coding [XX]

With new reflections on the need for meaningful activity – as I was coding I could see there were moments where I could have probed about this but didn't as it wasn't on my mind during the interview – at the time of interview I was biased in my thinking by my experience of P1+2. So whilst now I can see that need for work is present - I didn't explore this as much as might have been useful.

Reflecting on process of analysis to date + supervision

From coding the first two interviews it helped me recognise that peoples core experience will come up throughout the narrative – helped me to see that people to repeat key points - this influenced how i conducted later interview. I've focussed more on active listening – I've noticed how participants will often guide you to what feels salient for their core experience regardless of questions – used schedule loosely. Importance of real active listening and curiosity – similar to my clinical work. For some people questions did not feel core to their experience – for example questions about donor hearts – not really relevant for some people. This experience helped me to reflect that actually were some of my questions biased by what I expected to find? Expected 'anxst' about donor heart and expected themes of constant distress around the uncertainty of waiting ... whilst P1 and 2 maybe adhered more to my expectations – the following participants did not which help me think more broadly. Reflected on how life experiences and the shaping of personality and coping can lead to huge variations on how wait experienced. This also influence how my interviews went – again trying to really tune in to what felt salient rather than hunt for what I expected to find. IN supervision today we reflected how, from my reflections about the need for occupation and meaning might point towards how waiting is actually experienced as loss of meaning – rather than being this experience of constant dread of waiting. I can see how the coding and interpretation of P3-7 will be influenced by this. With each transcripts I spot more elements which then mean I pay attention for these when doing the next transcript. Recognise I will need to go back and do P1+2 as well to try and counteract this bias towards more insightful interpretations for later transcripts only.

Appendix 2j: Major Research Project Proposal



Institute of Health & Wellbeing

DOCTORATE IN CLINICAL PSYCHOLOGY

MRP Proposal:

Experiences, beliefs and coping whilst waiting for heart transplant: An interpretative phenomenological study.

Version Number: V2.2 27.6.17
Word Count: 2997

ABSTRACT

Background

Heart transplant is considered for people with end stage heart failure whose lives are at risk. It involves waiting for an unknown amount of time for a donor heart from a person who has recently died, during which the person may not survive. This wait can be a long and distressing, yet little research has explored how people experience this process. Such research may be important for informing intervention.

Aims

To explore people's experiences of waiting for heart transplant in order to gain a better understanding of the challenges they encounter, their beliefs around transplant and their experience of coping.

Methods

Interpretative phenomenological analysis will be used with people 18 or over on the waiting list for heart transplant at the Scottish National Advanced Heart Failure Service (SNAHFS) who have consented to an interview regarding their experiences of waiting for transplant.

Applications

This research may allow teams to develop interventions for people waiting for heart transplant to decrease distress and improve quality of life during the wait period. Research will be circulated to SNAHFS staff and will be submitted for publication.

INTRODUCTION

1.1 Waiting for heart transplant in Scotland

Heart transplantation is an established treatment for end-stage heart failure (HF) yet donor heart availability is below that needed, leading to a wait for transplant (Scottish Government, 2013). The journey to transplant is complex; initially, patients with HF are monitored within their local health board and only referred to the Scottish National Advanced Heart Failure Service (SNAHFS) when advanced therapies, such as heart transplantation, are indicated. Following referral, patients undergo extensive assessment from a multi-disciplinary team to ensure their suitability for transplant. If transplantation is agreed, prospective candidates are listed as super-urgent, urgent or routine depending on illness severity. Typically, those on the super urgent or urgent list are required to remain in hospital, whilst those routinely listed are required to wait at home. The length of, determined by a range of factors including; organ availability, the need to match donor and recipient size and blood type, presence of antibodies, and the candidates position on the UK-wide transplant list. In 2003 the average adult wait was 164 days (Scottish Government, 2003). The person must tolerate numerous stressors during this wait, including; worry about family, illness symptoms, waiting for a donor, uncertainty about the future, fatigue, less control over their lives and an increased dependency on others as well as the concept of losing one's heart and accepting another from someone who has died (Bunzel, 2012; Jalowiec, Grady, & White-Williams, 1994). Anecdotally, candidates can experience hopelessness and go through periods of existential crisis, at times leading to increase in apprehension and anxiety. Psychological distress during this time is not uncommon, with the majority of patients scoring from the subclinical to mild range for depression and anxiety (Burker, Evon, Losielle, Finkel, & Mill, 2005; Deshields, McDonough, Mannen, & Miller, 1996). As the wait period extends, patient's depression, physical symptoms and impairment in functioning can increase (Zipfel et al., 1998).

1.2 Coping with the wait for heart transplantation.

Throughout the wait period, heart transplant candidates may engage in numerous coping strategies, conceptualised as either problem solving strategies, which are attempts to alter the situation, or emotion focussed strategies, which are attempts to alter the emotional distress (Lazarus & Folkman, 1987). Candidates reportedly use both, including planning, seeking social support and trying to keep life normal as well as positive reinterpretation, humour use and gaining comfort from religion (Burker et al., 2005; Porter et al., 1994). According to the self regulation model, selected coping strategies can be influenced by a person's perception of their illness

(Leventhal, Diefenbach, & Leventhal, 1992). When candidates perceive HF as linked to negative consequences or a lack of control, people tend to select denial and disengagement (Hallas, Wray, Andreou, & Banner, 2011). This could affect their candidacy if they are seen as not engaging with treatment process, as well as increasing their risk of mortality and depression (Burker et al., 2005; Murberg & Bru, 2001). Exploring candidate's perceptions of their illness and coping whilst waiting for heart transplant may uncover a greater understanding of their needs at this time.

1.3 Existing qualitative literature

Qualitative research conducted post-transplant has largely focussed on information and support, finding that support during the wait period from post-transplant individual is perceived as positive and beneficial (Ivarsson, Ekmeahag, & Sjöberg, 2013; Sadala & Stolf, 2008). However, the retrospective designs may be vulnerable to recall bias (Singer & Salovey, 1988), thus jeopardising the studies validity. Research conducted during the actual wait period have utilised thematic analysis and focus groups to explore perceived care needs (Haugh & Salyer, 2007; Yorke & Cameron-Traub, 2008) or an existential phenomenological approach to explore candidates experience of loss (Poole et al., 2016). These studies have all implemented a mixed participant group; including either lung transplant candidates; post-transplant recipients or family members. Therefore, the emerging themes may not best represent heart transplant candidates true experiences, nor uncovered the depth of issues discussed above. An in depth exploration solely with heart transplant candidates may allow transplant teams to better understand patient experience and tailor interventions accordingly.

2 AIMS

This research aims to better understand the lived experience of, and the meanings associated with, the process of waiting for heart transplantation. This may inform interventions to optimise the patient experience throughout the wait period.

The following will be explored;

1. The challenges patients experience
2. Patients beliefs around heart transplantation
3. Patients experiences of coping

3 PLAN OF INVESTIGATION

3.1 Participants

Individuals will be recruited from the SNAHFS heart transplant waiting list at the Golden Jubilee National Hospital (GJNH). The routine list comprises individuals awaiting transplant as outpatients, for an unknown amount of time. This differs to individuals

listed as super urgent or urgent, who are required to wait in hospital for a potentially imminent transplant. Only those routinely listed will be included in order to preserve sample homogeneity required by IPA (Smith, Flowers, & Larkin, 2009). Additionally, over a four-month period only two people were identified on the super urgent and urgent list compared to nine-fourteen on the routine list, highlighting the routine list as a more suitable recruitment option. Individuals will only be recruited 3 months post referral for transplant, to allow for a potential 3 month adjustment period following a psychosocial stressor, termed an adjustment disorder (American Psychiatric Association, 2013).

Inclusion criteria

- Written informed consent
- Fluent in English
- Aged 18 or over
- 3 months or more since referral for heart transplant.
- Listed on routine transplant list

Exclusion criteria

- Patient's with a history of previous heart transplant.
- Listed on super urgent or urgent transplant list
- Learning disability

3.2 Recruitment Procedures

Recruitment will last throughout the study until the target sample is met. The transplant coordinators working at SNAHFS will identify individuals who meet the inclusion criteria. Transplant coordinators will inform individuals of the study during routine appointments or telephone calls, and provide them with the participant information sheet. Individuals interested in participating will have the option to contact the team or the researcher directly. The researcher will arrange a suitable time to conduct the interview. Where feasible, the person will be offered the opportunity to attend directly before or after a routine hospital appointment. Confirmation of the interview date and the participant information sheet will be sent by post. On the day of interview, individuals will be given the opportunity to ask further questions, confidentiality will be discussed and signed written consent gained. Participants will be recruited on a first come basis until the required number is met.

3.3 Design

To allow participants to share their unique experiences, a qualitative design will be used. Interpretative phenomenological analysis (IPA) was considered most appropriate as it was developed for use in health psychology (Smith, 2011), is suited to helping clinicians understand the meaning of patients lived experience (Harper,

2011; Starks & Trinidad, 2007) and has been frequently applied to understanding experiences of physical illness (Smith et al., 2009).

3.4 Research Procedures

Face-to-face, semi structured interviews will be conducted, utilising an interview guide developed from three sources. Firstly, the researcher will attend a pre transplant clinic to glean a better understanding of patient experience, secondly, through consultation with clinical psychologists working within heart transplant centres and thirdly, from the research literature. The interview guide will include questions on individual's experiences, beliefs and coping with waiting for heart transplant. Further ideas will be incorporated as appropriate. Interviews will be conducted by the principal researcher in a GJNH room, using a digital voice recorder and will last up to one hour. This is not dissimilar to the time required for routine SNAHFS appointments and is less time than in previous IPA studies with an end stage HF population (Murray, Kendall, Boyd, Worth, & Benton, 2004; Murray et al., 2002; Rogers et al., 2002). Participants will be reminded of the purpose of the interview and to inform the principal researcher if they begin to feel unwell or wish to discontinue.

3.5 Data storage

Consent forms will be stored in a locked filing cabinet within NHS GJNH, and transferred to a locked filing cabinet at the University of Glasgow on study completion. Recordings will be immediately transferred to a University of Glasgow encrypted laptop and deleted from the digital voice recorder. Once transcribed, transcriptions will be stored on the laptop, with all identifiable patient information removed and pseudonyms provided. Back-up copies of recordings and transcripts will be stored within a password protected part of the Glasgow University network, only accessible to the principal researcher. On study completion, transcripts and recordings will be deleted from the laptop and network and transferred to enlighten for 10 years, as per the Code of Good Practice in Research (University of Glasgow, 2016) and thereafter deleted in accordance with the Data Protection Act (London: Stationery Office, 1998).

3.6 Data Analysis

Recordings will be anonymously transcribed. Transcripts will be analysed using IPA, following the six steps outlined in (Smith et al., 2009) (p.79-103);

1. *Reading and re-reading.*
2. *Initial noting.*
3. *Developing emergent themes.*
4. *Searching for connections across emergent themes.*
5. *Move to the next case.*

6. Looking for themes across cases.

Emerging themes will have validity confirmed through blind transcript review by two research supervisors and through feedback on themes from interested participants.

3.8 Justification of sample size

IPA research uses samples of between one and ten participants (Starks & Trinidad, 2007) and four to ten is considered suitable for professional doctorate research (Smith et al., 2009). A four month waiting list review approximates 9-14 eligible patients. Past research evidences that over half of people with chronic HF uptake the offer to take part in qualitative research (Klindtworth et al., 2015; Mair et al., 2011; Rogers et al., 2002), therefore the target sample is 6-10 participants.

3.9 Settings and Equipment

Interviews will be conducted within GJNH private rooms. A digital voice recorder, headphones and an encrypted laptop will be provided by the University of Glasgow.

4 HEALTH AND SAFETY ISSUES

4.1 Researcher Safety Issues

See appendix.

4.2 Participant Safety Issues

See appendix.

5 ETHICAL ISSUES

Ethical approval will be sought from the West of Scotland Research Ethics committee and from NHS Research and Development at the NHS National Waiting Times Board. In line with the BPS code of human research ethics (British Psychological Society, 2014) the potential risk to participants will be managed (see appendix A), an information sheet will clearly communicate the research aims, written consent will be gained, data will be anonymised so that participants cannot be personally identified and a research dissemination plan agreed which will seek to maximise the benefits of the research. A summary of the results will be made available to interested participants. All data collected will remain confidential and stored in line with the Data Protection Act (1998), Freedom of Information Act (2000), and the NHS Confidentiality Code of Practice on Protecting Patient (NHS Scotland, 2012).

6 FINANCIAL ISSUES

Telephone calls cost will be met by SNAHFS. Administration costs will be covered by Glasgow University, see appendix.

7 TIMETABLE

01/17	Submit final MRP proposal to University for peer review
05/2017	Gain NHS sponsorship
06/2017	Apply for REC application (4-8 weeks).
08/2017	REC approval, apply NHS R&D approval
08/2017	Begin recruitment/ data collection
12/17-01/18	Data transcription and analysis.
02/18	Blind review of emerging themes.
05/18	First MRP draft submitted
07/18	Final MRP draft submitted

8 PRATICAL APPLICATIONS

The results will be written up as part of a Clinical Psychology professional doctoral thesis and the report published on Glasgow University thesis website. The research will be shared with interested participants, the SNAHFS team and submitted for publication. It may inform interventions for patients during the wait period and has the opportunity to directly impact on the clinical psychology services offered at the GJNH.

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