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Evaluation of measurement properties of posttraumatic growth questionnaires in physical health and predictors of posttraumatic growth post lung transplant

By

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ABSTRACT

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

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EVALUATION OF MEASUREMENT PROPERTIES OF POSTTRAUMATIC GROWTH QUESTIONNAIRES IN PHYSCIAL HEALTH AND PREDICTORS OF POSTTRAUMATIC GROWTH POST LUNG TRANSPLANT

By Sarah Elizabeth Airdrie

A systematic review evaluated the psychometric properties of 23 studies examining posttraumatic growth (PTG) instruments in physical health. The methodological quality of peer-reviewed studies was assessed using the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) checklist. The findings suggest that the Benefit Finding Scale, Posttraumatic Growth Inventory and Impact of Self-Concept Scale are the most psychometrically sound measures of PTG in physical health. However, further research is needed to ensure that good quality, theoretically-driven PTG instruments are developed within physical health and informed by established criteria, such as the COSMIN.

There has been growing evidence examining the existence of, and benefits from, PTG. However, limited research has been conducted with transplant patients. A mixed methods cross-sectional design explored the relationships between cognitive processing, distress, social support, resilience and PTG following lung transplant. Overall, 147 participants completed the quantitative and 12 competed the qualitative components of the study. The results showed that higher levels of deliberate rumination and social support, particularly friends, significantly predicted greater PTG. Higher levels of resilience also significantly predicted higher levels of PTG but, contrary to prediction, resilience did not mediate the relationship between deliberate rumination and social support with PTG.

Qualitative analysis provided additional support for the mechanisms underlying PTG. Deliberate rumination and social support were reflected in the themes ‘steps towards rebuilding life’, ‘looking beyond transplant’ and ‘importance of peer support’. Individuals also identified experiences related to PTG, illustrated by the subordinate themes ‘discovering a new potential’, ‘change in outlook’ and ‘appreciation for life’. This research provides a platform for further research in this area and encourages professionals to consider these constructs and ensure positive outcomes of the transplant journey. Limitations, further research and implications for clinical practice are discussed.

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Declaration of Authorship

I, Sarah Airdrie declare that this thesis entitled **‘Evaluation of measurement properties of posttraumatic growth questionnaires in physical health and predictors of posttraumatic growth post lung transplant’** and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: ....

Date: ....

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Chapter 1: Evaluation of Measurement Properties of Posttraumatic Growth Questionnaires in Physical Health: A Systematic Review

1.1 Introduction

"Cancer is tough, and it still claims too many lives, but I think that hope is the greatest weapon a person has. Ask the tough questions, get a second opinion, take care of yourself, surround yourself with family and friends, and do whatever you have to do to keep hope alive…. I am grateful for the tremendous and unforgettable experiences my cycling career has brought me, but I am most proud to be a cancer survivor and a parent. It is these two roles that will guide my future" (Lance Armstrong; "Winning the race", 2006).

History has highlighted excellent examples of people experiencing personal growth after suffering. The quote from Lance Armstrong demonstrates how cancer created personal growth and a different outlook on life. There is a growing body of literature exploring the positive effects of trauma, following events including military combat, experiencing a heart attack or cancer, having a severe accident, and in parents of children with disabilities (Tedeschi & McNally, 2011; Helgeson, Reynolds & Tomich, 2006; Rabe et al., 2006; Park & Helgeson, 2006). However, this literature depends on good measurement tools. There is currently significant variation in measures used to capture growth. The aim of this systematic review was to examine whether these measures of growth are valid and reliable within a physical health population.

1.1.1 Posttraumatic Growth

Experiencing positive life changes following a trauma or challenging life experiences has been conceptualised in different ways including benefit finding (Tennen & Affleck, 2002), adversarial growth (Linley & Joseph, 2004), positive adjustment (Lyons, 1991), stress related growth (Park, Cohen, & Murch, 1996), perceived benefit (McMillen, Smith & Fisher, 1997), and positive adaptation (Linley, 2003). The most widely used term and the most well-documented (Joseph & Butler, 2010) is posttraumatic growth (PTG; Calhoun & Tedeschi, 1999). Therefore, for the purpose of this review the term PTG will be used.

PTG is defined by a change in psychological functioning encapsulated by three broad dimensions. These are captured by a change in the perception of self, which helps to create a sense of strength and possibility for new opportunities in life, as well as accepting personal vulnerabilities. Secondly, the important role of relationships with others in creating greater intimacy and connection with others, whilst experiencing greater compassion towards other people. Finally, a change in life philosophy is characterised by a change in priorities, new appreciation for life, and increase in religious or spiritual beliefs (Tedeschi & Calhoun, 1995). In contrast, individuals with posttraumatic stress disorder (PTSD) experience no benefit from their trauma, instead they experience distress through re-experiencing symptoms, avoidance, hyperarousal and anxiety (Haidt, 2006).

The growing body of evidence demonstrating the existence of PTG and its benefits has led to the development of several models of PTG. The most comprehensive description of PTG is captured by the functional-descriptive (FD) model (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004). This model was based on the posttraumatic stress literature, which emphasised the importance of appraisal processes (Janoff-Bulman, 1992).

The FD model highlights that PTG commences after a crisis, where an individual's beliefs about themselves and the world are shattered. PTG occurs due to an individual's struggle with the new reality following a trauma. After the initial emotional distress of such an experience, cognitive processing and restructuring is essential to the development of PTG. Initially automatic, negative, intrusive thoughts and images, known as intrusive rumination (consistent with re-experiencing and avoidance symptoms of PTSD; American Psychiatric Association [APA], 1994) creates a platform for disengagement with previously held goals and assumptions about life. Figures suggest changes in PTSD symptoms following a trauma dropped from 94% to 47% at three months (Rothbaum et al., 1992). This reduction in distress occurs due to engagement with deliberate rumination, which is vital to the development of PTG. This enables cognitive processing of the traumatic experiences and creation of alternative beliefs and goals that incorporate beliefs about the trauma and possible events in the future, that are more resistant to being shattered. This process is influenced by personality type and social support. Social support is defined as self-disclosure of emotions to others in a supportive environment. These elements facilitate deliberate and reflective rumination, create a reduction in distress/PTSD symptoms and facilitate new coping behaviours. Deliberate rumination enables the development of wisdom and an individual narrative of the experience (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004).

The FD model conceptualises PTG as an outcome of coping with a crisis; however, there is an alternative view in which PTG is conceptualised as a process that occurs following stressful events. There is a paucity of evidence exploring these differences and measurement instruments do not make distinctions between these concepts of PTG. There is some debate about whether it is possible to link PTG to other outcomes, particularly if PTG is perceived as an outcome. Literature has highlighted the strongest indicator of adjustment to health was found between growth and positive affect (Helgeson et al., 2006), and positive and negative affect are two independent constructs of well-being (Watson, Clark, & Tellegen, 1988). Therefore, growth and psychological distress may also be independent constructs of well-being. This suggests PTG should be viewed as an outcome alone, rather than a predictor of other outcomes (Park & Helgeson, 2006). Therefore, it is important to utilise a psychometrically robust instrument. This review aimed to identify these measures for this purpose.

1.1.2 Role of PTG in Physical Health Conditions

This review focused on PTG in physical health and specifically on research that examines the most appropriate way to measure PTG. Diagnosis of severe disease or life-threatening illness can be a stressful and traumatic experience. This may lead to psychological distress including symptoms of depression, anxiety and PTSD (Cordova & Andrykowski, 2003; Gries et al., 2013; Schelling et al., 2004). However, many individuals are able to adjust psychologically to their health condition and some also experience positive changes in the form of PTG, which can lead to improved coping overall (Helgeson et al., 2006).

The growing body of evidence for PTG in physical health conditions including cancer (Scrignaro, Barni & Magrin, 2011), heart attack (Leung et al., 2012), HIV and AIDS (Siegel & Schrimshaw, 2000) illustrates that PTG is an important aspect of recovery from physical health conditions and can be associated with improved outcomes. This demonstrates it is imperative to identify good quality measures of PTG. If measures have good test-rest reliability and are internally consistent, it is possible to be confident that changes are real rather than due to measurement error. This would benefit both the clinical and research field. This would help support researchers to have greater clarity of the mechanisms involved in PTG and support clinicians with the development of more effective interventions.

Evidence highlights that PTG plays a key role in recovery from physical health conditions. PTG is associated with better mental health outcomes and some improvements in health indicators (Barskova & Oesterreich, 2009). Some reviews have highlighted that PTG is related to less depression, greater positive well-being and more adaptive coping strategies (Barskova & Oesterreich, 2009; Helgeson et al., 2006). However, there are numerous factors that may moderate this effect including gender, health-related indicators, time since diagnosis and type of disease. This evidence demonstrates the complex processes that occur in PTG. These are multi-faceted processes and the effects on physical and mental well-being change over time.

This evidence supports the theoretical underpinning of PTG. However, the methodological quality of the instruments used in these studies remains unclear. As a result, these findings may not accurately reflect the relationships between these variables and PTG.

1.1.3 Measurement of PTG and Psychometrics

As noted above, PTG has been captured in different ways using self-report measures and these measures need to be valid and reliable in order to have confidence in the results of research examining PTG. Psychometrics is the field that explores psychological measurement and utilises a framework for evaluating measurement instruments, including reliability and validity (Barker, Pistrang, & Elliott, 2002). The literature highlights the development and validation of psychometrically robust measures of PTG in psychological health. Moreover, some studies present information on the measurement properties of standardised measures used in experimental studies. However, to the best of the researcher's knowledge, there has been no systematic review examining the measurement properties of PTG measures in physical health. The aim of this review is to fill that gap and, in so doing, benefit both the clinical and research fields.

This review used the COSMIN (COnsensus-based Standards for the selection of health Measurement Instruments) research group guidelines to systematically evaluate the available psychometric data. This was based on the taxonomy identified in Terwee et al.'s (2007) quality criteria for evaluating psychometric properties in instruments. The review employed both tools which provided key criteria to assess the evaluation and an assessment of the strength of the measurement properties in the studies under review. This assessment process is vital in systematic reviews given that low quality studies are at risk of having biased results.

There is a growing evidence-base for the utility of the COSMIN guidelines in the evaluation of psychometric properties in instruments to help inform further research and clinical practice (Schellingerhout et al., 2012; Windle, Bennett, & Noyes, 2011). This robust evaluation framework highlights useful strengths and weaknesses. These criteria are paramount in ensuring identification and evaluation of high quality instruments.

1.1.4 Objectives

In summary, this systematic review aimed to identify and critically evaluate the measurement properties of self-report PTG questionnaires in physical health using the COSMIN criteria to assess health-related measures. Identification of appropriate instruments will support researchers and clinicians by highlighting psychometric properties of questionnaires and help guide further research.

1.2 Method

1.2.1 Search Strategy

Systematic searches of the following databases were made from their commencement to 25 October 2016: PsycINFO, Web of Science, MEDLINE, EMBASE and CINAHL. Table 1 lists the search terms included to identify relevant studies examining measurement properties in self-report PTG questionnaires in physical health conditions. Two reviewers independently screened all titles and abstracts to ensure reliability, which suggested excellent inter-rater reliability (Cohen’s kappa = .84; 95% agreement). One reviewer was the main researcher and the other reviewer was a healthcare professional. The reviewers jointly discussed any unresolved conflicts and articles appropriate for full text review were based on the criteria below. Reference lists of selected studies were scanned for relevant studies and added accordingly.

Table 1
Search Terms Entered in Databases

	Posttraumatic growth	Questionnaires	Physical health	Psychometrics
Search terms	"posttraumatic growth" OR "post traumatic growth" OR “benefit finding” OR “stress related growth” OR "positive adjustment" OR "positive change" OR “perceived benefit*” OR “change* in outlook” OR "positive adaptation" NOT "health belief model*"	inventory OR instrument* OR scale* OR questionnaire* OR interview OR measur* OR index OR test OR checklist OR tool* OR outcome OR assess*	chronic N2 (disease* OR illness*) OR physical N2 (disease* OR illness*) OR disease* OR illness*	psychometr* OR reliab* OR valid*

1.2.2 Eligibility Criteria

Inclusion criteria included:

- Studies examining the psychometric properties of questionnaires (uni-dimensional or multi-dimensional) measuring self-report PTG in patients with physical health conditions
- Studies considered at least two aspects of reliability or validity
- Published in a peer reviewed journal
- Available in English

Exclusion criteria included:

- Studies examining caregivers or significant others’ experience of PTG
- Samples involving participants below 18 years old
- Case studies
- Unpublished dissertations or reviews

1.2.3 Data Extraction

Data extraction included: study characteristics (country, participant sample size, age, gender, physical health condition, sampling method) and questionnaire characteristics (measures used, duration of administration, construct measured, item number and subscales and scoring method).

Measurement properties were extracted based on guidance from the COSMIN checklist research group (Mokkink et al., 2010b) which includes: internal consistency, reliability (test-retest and inter-rater), measurement error, content validity, structural validity, hypotheses testing, cross cultural validity, criterion validity and responsiveness.

1.2.4 Quality Assessment

Quality was assessed based on three components: strength of measurement properties, methodological quality, and rating of measurement property. This ensures a thorough assessment of the extracted psychometric data. Methodological quality enables evaluation of study design and methodology across different properties. The property ratings provide a summary for the measurement properties for selected studies.

Strength of measurement property.

The strength of reliability and validity statistics were based on standard criteria which helped to guide the assessment process. Table 2 presents the criteria used to assess the internal consistency, inter-rater reliability/test-retest reliability and correlations.

Table 2

Strength of Measurement Property Criteria

Cronbach's alpha criteria[a]	Inter-rater reliability and test-retest reliability[b]	Correlations[c]
<.5 unacceptable	<.0 poor	>.1 small
≥.5 poor	.0-.20 slight	>.3 moderate
≥.6 questionable	.21-.40 fair	>.5 large
≥.7 acceptable	.41- .60 moderate	
≥.8 good	.61 -.80 substantial	
≥.9 excellent	.81 – 1 almost perfect	

Note. [a]Criteria developed by Kline (2000). [b]Based on Cohen's kappa guidelines (Landis & Koch, 1977). [c]Criteria developed by Cohen (1988).

Methodological quality.

The methodological quality of studies was evaluated using the COSMIN checklist (Mokkini et al., 2010b; see Appendix D). Another reviewer (research assistant in medical research) also independently assessed 25% of papers to check reliability which suggested substantial inter-rater reliability (Cohen's kappa = .63; 83% agreement).

Definitions and domains of the measurement properties within the taxonomy are represented in Appendix B. These domains are divided into reliability, validity and responsiveness which consist of different measurement properties. Reliability is defined as the degree to which repeated measurement using different conditions produce similar scores. Aspects of reliability are assessed by internal consistency (degree of interrelatedness of items), inter-rater reliability (consistency in scoring between different raters), test-retest reliability (consistency of scores measured at different time points), and measurement error (degree of error in scores not related to true changes in the construct to be measured).

Validity is defined as the degree to which an instrument measures the construct(s) it is aiming to measure. This is assessed by content validity which includes face validity (a measure accurately reflects the construct to be measured), structural validity (degree scores on an instrument reflect the dimensionality of construct to be measured), hypothesis testing (degree to which scores of an instrument are consistent with hypothesised relationships based on the instrument validly measuring the construct to be measured), cross-cultural validity (degree to which instrument items that are translated or culturally adapted accurately reflect performance of original instrument), criterion validity (degree instrument scores reflect a 'gold standard'). Responsiveness is the last component in the taxonomy and is defined by a measure's ability to detect change over time in the construct measured.

The checklist consists of twelve sets of items or 'boxes', which include 114 items. Nine boxes relate to standards for measurement properties: internal consistency, reliability, measurement error, content validity, structural validity, hypotheses testing, cross-cultural validity, criterion validity, and responsiveness. Another two boxes assess standards for interpretability and generalisability. The final box examines whether item response theory (IRT) methods were utilised. IRT methods were not used in any of the included studies and therefore are not reported in this review. The box is only completed if the measurement property has been considered in the study under review. Each item was scored using a 4-point scale (poor, fair, good or excellent). Overall scores for each box used the 'worst score counts' approach (Terwee et al., 2012) which is based on the lowest rating of any item in a box. Calculations were also conducted of the percentage excellent ratings across all items for each measure.

Quality of measurement property.

Each paper was assessed using the criteria stated by Terwee et al. (2007; Appendix C). Each property on the checklist was rated as positive (= +), indeterminate (= ?), negative (= -), or no information available (= 0). This rating is based on the amount of evidence for each property and strength of measurement property.

1.3 Results

1.3.1 Search

The study search process is represented in Figure 1. The initial search of the database produced 957 records. Duplicates were removed and titles and abstracts were screened. Full text articles were identified for 126 articles and assessed for eligibility. 106 articles were excluded; the reasons for exclusion were as follows: studies did not measure PTG, psychometrics were not considered or only included basic psychometrics. Three additional papers were identified from reference lists. Overall 23 studies were eligible for inclusion in the review, which are summarised in Table 3.

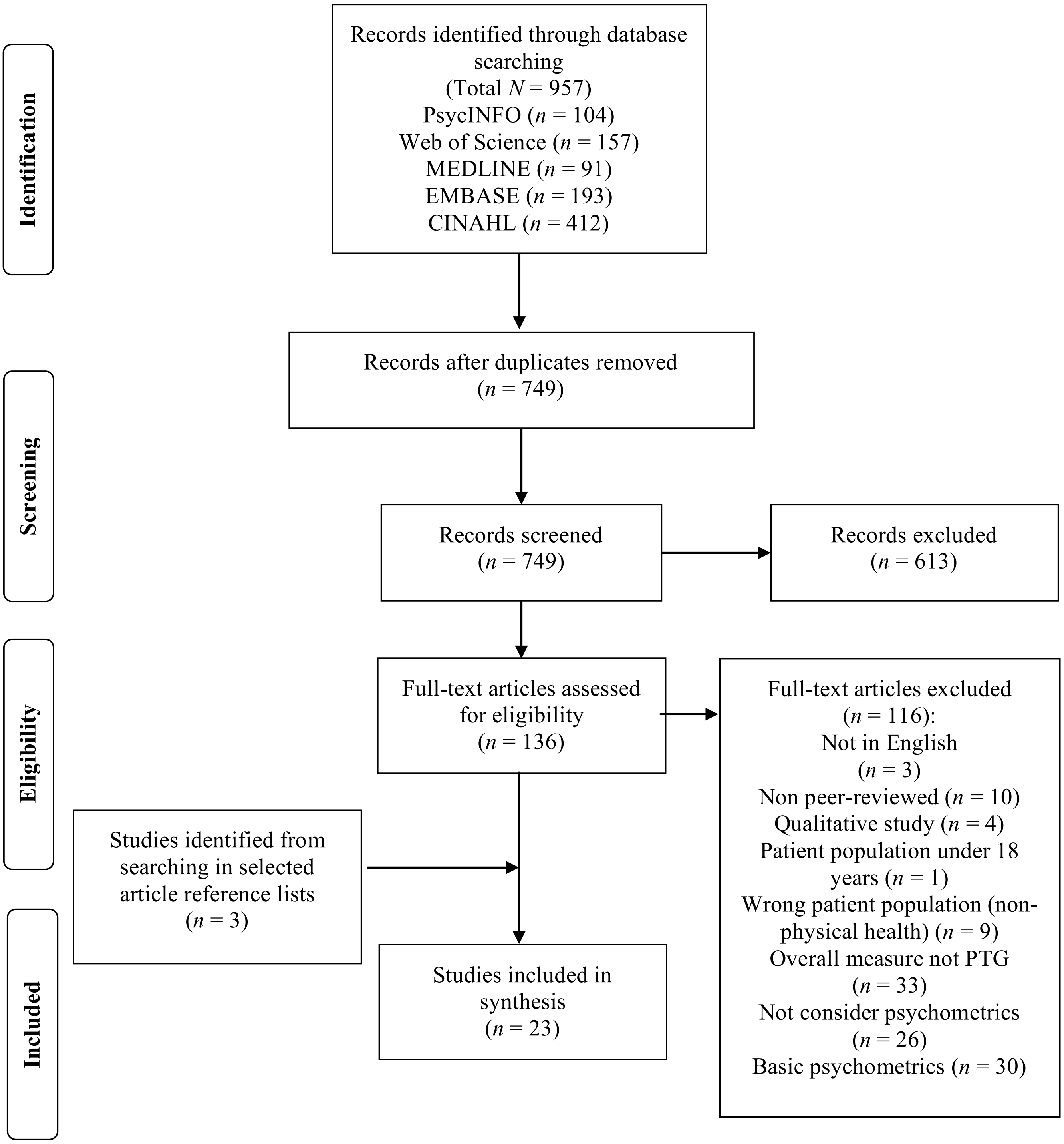

Figure 1. Flow diagram of study selection based on PRISMA group guidance (Moher et al., 2009).

1.3.2 Description of Included Studies

Tables 3 and 4 present the characteristics of the studies included in this review and the self-report instruments that they used. The majority of studies were conducted with female participants diagnosed with cancer. Overall, there were eight different instruments in the evaluation. All were easy to administer, and to calculate total and subscale scores. None of the included studies reported on the time needed to complete the questionnaires.

1.3.3 Measurement Properties and Methodological Quality

The measurement properties reported in the selected studies were internal consistency, reliability, content validity, structural validity, hypothesis testing, and cross-cultural validity. None of the studies considered measurement error, criterion validity or responsiveness. The different properties considered in each of the included studies are highlighted in Table 3. Reliability and validity statistics for the included studies are presented in Table 5. Table 6 also presents a summary of the quality ratings for the measurement properties based on Terwee’s criteria and methodological quality ratings for the psychometric properties based on the COSMIN checklist for each measure.

Table 3

Characteristics of Included Studies

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
Ando et al. (2011)	Japan (Japanese)	Cross-sectional	98	Cancer: Breast (22), uterus (12), lung (16), stomach (2), pancreas (2), uterine (1), kidney (3), leukemia (1), rectal (2), colon (1), others (36)	63 (12.5)	47 male 51 female	NR	Opportunity sampling	JBFS	NR	IC, CV, SV
Abraido-Lanza et al. (1998)	USA (Spanish or English)	Longitudinal	109	Rheumatoid arthritis (54), lupus (16), osteoarthritis (16), scleroderma (2), arteritis (2), osteoporosis (1), fibromyalgia (1), more than 1 type	51 (14.1) *19-86*	100% female	13.9 years	Opportunity sampling	TS	3.01 (.72)	IC, CV, SV, HT, CCV

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
				of arthritis (9)							
Boot et al. (2010)	UK (English)	Cross-sectional	156	Breast cancer: presented with symptomatic breast cancer (58); palpable breast lump (65), palpable lymph node (15); Tumour grade: Grade 1 tumour (12), Grade 2 (26), Grade 3 (30), non-invasive tumour (20)	56 *30-88*	100% female	3 groups: 2-4 weeks, 6 months-2 years, 2-5 years	Opportunity sampling	PAQ	NR	IC, CV, SV, HT

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
Cheng et al. (2006)	China (Chinese)	Cross-sectional	57	Severe Acute Respiratory Syndrome (100)	38 (10.4) *22-72*	19 male (33.3) 38 female (66.7)	2-6 months post discharge	Opportunity sampling	TS	54.57 (6.62)	IC, SV, HT, CCV
Costa & Pakenham (2012)	Australia (English)	Cross-sectional	154	Thyroid cancer (100)	50.96 (14.4) *19-87*	46 male (29.9) 108 female (70.1)	4.83 years	Opportunity sampling	SRGS-R	NR	IC, CV, SV, HT
Gall et al. (2011)	Canada (English)	Longitudinal	93	Breast cancer (100)	60.95 (11.25)	Female (100)	Newly diagnosed	Purposive sampling	PTGI	NR	IC, TR HT
Golub et al. (2013)	USA (English)	Cross-sectional	129	HIV-positive	42.46 (10.12) *18-54*	Men (100)	50% diagnosed with HIV more than 10 years ago	Purposive sampling (secondary data analysis)	ISCS	Growth scale: 4.06 Loss scale: 2.92	IC, CV, SV, HT
Ho et al. (2004)	China (Chinese)	Cross-sectional	188	Cancer: breast (54), nasopharynx (17), gynaecological (9), lymphoma	49.29 (.62) *26-69*	32 male 156 female	At least 5 years disease free	Convenience sampling	CPTGI	NR	IC, SV, HT, CCV

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
				(7), colorectal (5), liver (3), stomach (2), bladder (2), brain (1), lung (1)							
Jaarsma et al. (2006)	Netherlands (Dutch)	Cross-sectional	294	Cancer	55.56 *21-84*	82 male 212 female	3.90 years	Purposive sampling	DPTGI	47.87	IC, SV, HT, CCV
Liu et al. (2014)	China (Chinese)	Longitudinal	120	Early stage breast cancer (Stage I or II) (100)	51.27 (8.72) *30-72*	Female (100)	3, 6 and 9 months post diagnosis	Purposive sampling	PTGI-SC	62.72	IC, TR, CV, HT, CCV
Liu et al. (2016)	China (Chinese)	Cross-sectional	Part 2: 200 Part 3: 351	Early stage cancer (Stage I to IIa) (100): Part 2: breast (27), gastric (20), colorectal (21), liver (16), oesophageal	Part 2: 57.06 (9.02) Part 3: 57.34 (9.05)	Part 2: 108 male (54) 92 female (46) Part 3: 184 male (52) 167 female (48)	Part 2: 18.46 Part 3: 18.94	Convenience sampling	CBFS	NR	IC, TR, CV, SV HT, CCV

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
				(12), head and neck (3). Part 3: breast (32), gastric (21), colorectal (23), liver (9), oesophageal (11), head and neck (2).							
McBride et al. (2008)	Northern Ireland (English)	Cross-sectional	560	Chronic illness: Multiple sclerosis (47), cancer (18), cardiac (18) and renal disease (18)	NR	72 male 188 female	NR	Purposive sampling	SLQ-38	NR	IC, SV, HT
McBride et al. (2009)	Netherlands (Dutch)	Longitudinal (part of larger study; Schroevers et al., 2006)	206	Cancer: breast (53), colorectal (22), gynae-cological (19), lung (4), other (2)	54 (13.6) *23-82*	43 male (21) 163 female (79)	8 years	Purposive sampling	SLQ-38	NR	IC, SV

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
Mohr et al. (1999)	USA (English)		94	Relapsing-remitting multiple sclerosis (100)	43 (9.18) *18-66*	24 male (26) 70 female (75)	8.1 years	Purposive sampling	BFiMSS	NR	IC, CV, SV
Mystakidou et al. (2008)	Greece (Greek)	Longitudinal	131	Incurable cancer: breast (24), lung (20), gastro-intestinal (21), urogenital (33), other (3)	59.8 (12.4) *31-84*	58 male (44) 73 female (56)	4.29 years	Purposive sampling	PTGI	42.47	IC, TR, SV, HT, CCV
Pakenham (2005)	Australia (English)	Longitudinal	502	Multiple sclerosis (100)	47.7 (11.48) *18-78*	109 male (23) 365 female (77)	117.24 months	Purposive sampling	BFiMSS (19 BFS items)	35.05	IC, SV, HT
Pakenham & Cox (2009)	Australia (English)	Longitudinal	388	Multiple sclerosis	49.33 *21-80*	68 male 313 female	NR	Purposive sampling	BFiMSS	2.06	IC, TR, SV, HT
Purc-Stephenson (2014)	Canada (English)	Cross-sectional	845	Relapse-remittent chronic disease: arthritis (36),	Arthritis: 45.55 (13.59)	137 male (16) 708 female (84)	Arthritis: 12.25 years, IBD:	Opportunity sampling	PTGI	53.26	SV, HT

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
				inflammatory bowel disease (64)	Bowel disease: 33.56 (12.45)		10.07 years				
Sheikh & Morotta (2005)	UK and USA (English)	Cross-sectional	124	Cardio-vascular disease	64 (10) *36-87*	97 male (78) 27 female (22)	5 years	Opportunity sampling	PTGI	56.84	IC, SV
Sodergren et al. (2002)	UK (English)	Longitudinal	94	Chronic Obstructive Pulmonary Disease (COPD) and cardiac patients in cardiac rehabilitation	COPD on rehab wait list: *N* = 20, 69.35. Completed rehab: *N* = 35, 67.03, Cardiac rehab: N = 29, 60.52.	76 male 28 female	NR	Opportunity sample	SLQ-38	10.31	IC, TR, HT
Steel et al. (2008)	USA (English)	Longitudinal	120	Hepato-biliary cancer	63 *30-86*	89 male 31 female	0, 3, 6 months	Opportunity sampling	PTGI	51 (base-line)	IC, TR
Urcuyo et al. (2005)	USA (English)	Cross-sectional	230	Post-surgery after breast cancer (100)	53.45 (12.34) *27-87*	Female (100)	3, 6 or 12 months	Purposive sampling	BFS	36.58	IC, SV

Reference	Country (language)	Design	Participant characteristics					Sampling method	Measure of growth	Mean growth score (SD)	Psycho-metric data
			N	Health event (%)	Mean age/ years (SD) *range*	Gender composition	Mean time since event				
Zhai et al. (2014)	China (Chinese)	Cross-sectional	297	Chronic skin disease (100)	40.29 (0.50) *16-89*	NR	NR	Convenience sampling	PTGI-MC	NR	IC, SV, CCV

Note. NR = not recorded. BFS = Benefit Finding Scale; CBFS = Benefit Finding Scale (Chinese version); JBFS = Benefit Finding Scale (Japanese version); BFiMSS = Benefit Finding in Multiple Sclerosis Scale; ISCS = Impact on Self Concept Scale; PAQ = Positive Adjustment Questionnaire; CPTGI = Posttraumatic Growth Inventory (Chinese version); DPTGI = Posttraumatic Growth Inventory (Dutch version); PTGI-MC = Posttraumatic Growth Inventory (Mainland Chinese version); PTGI-SC = Posttraumatic Growth Inventory (simplified Chinese version); SLQ-38 = Silver Lining Questionnaire; SRGS-R = Stress Related Growth Scale (revised); IC = internal consistency; TR = test-retest reliability; HT = hypothesis testing; CV = construct validity; SV = structural validity, CCV = cross-cultural validity

Table 4

Characteristics of PTG Measures

Measure	Construct measured	Number of items	Scale structure	Response options (range)	Scoring method
BFS	Benefit Finding	17	NR	4-point scale (0 = I disagree a lot to 3 = I agree a lot)	Sum all items
CBFS	Benefit finding	22	6 (acceptance, family relations, personal growth, world view, social relations, health behaviours)	5-point scale (1 = not at all to 5 = extremely)	Sum all items, subscale totals
JBFS	Benefit finding	26	4 (growth, personal priorities, daily activities, and family)	7-point scale	Mean score for each question
BFiMSS	Benefit finding	67	3 (demoralisation, benefit finding, deterioration in relationships)	5-point scale (1 = strongly disagree to 5 = strongly agree)	Sum all items, subscale totals
BFS from BFiMSS	Benefit Finding	19	2 (family relations growth, personal growth)	5-point scale (1 = strongly disagree to 5 = strongly agree)	Sum all items
BFiMSS	Benefit Finding	67	7 (compassion/empathy, spiritual growth, mindfulness, changes to lifestyle, family relations growth, personal growth)	3-point scale (1 = not at all to 3 = a great deal)	Sum all items
ISCS	PTG capturing self-growth and self-loss	10	2 (self-growth and self-loss)	5-point scale (1 = never to 6 = always)	Subscale totals
PAQ	Positive adjustment	39	4 (fulfilment, re-evaluation, new ways of living, valuing life)	6-point scale (1-7)	Sum all items, subscale totals
PTGI/ DPTGI/ PTGI-MC	PTG	21	5 (relating to others, new possibilities, personal strength, spiritual change, appreciation for life)	6-point scale (0 = I did not experience this change as a result of my crisis to 5= I experienced this change to a very great degree as a result of my crisis)	Sum all items, and subscale totals

Measure	Construct measured	Number of items	Scale structure	Response options (range)	Scoring method
CPTGI	PTG	15	4 (self, interpersonal, spiritual, life orientation)	NR	Sum all items, subscale totals
PTGI-SC	PTG	21	5 (appreciation of life, new possibilities, relating to others, personal strength, spiritual change.	6-point scale (0 = I did not experience this change at all to 5 = I experienced this changed to a very great degree)	Sum all items and subscale totals
PTGI-Gr	PTG	21	5 (confrontation, relating to others, new possibilities, appreciation of life, spiritual change)	6-point scale (0 = I experienced this change to a very small degree as a result of my crisis to 5 = I experienced this change to a very great degree as a result of my crisis)	Sum all items and subscale totals
SLQ-38	Adversarial growth	38	5 (Personal relationships, appreciation for life, influence on others, inner strength, life philosophy)	5-point scale (1 = strongly disagree to 5 = strongly agree)	Sum all items and subscale totals
SRGS-R	Benefit finding (positive and negative change)	43	Unidimensional	7-point scale (1 = greatly decreased to 7 = greatly increased)	Sum all items
TS	Thriving	20	Unidimensional	5-point scale (0 = this didn’t happen to me to 4 = I experienced a great deal of this)	Sum all items
TS (Chinese version)	Thriving	20	3 (personal growth, spiritual growth, relationship growth)	4-point scale (1 = strongly disagree to 4 = strongly agree)	Sum all items, subscale totals

Note. NR = not recorded. BFS = Benefit Finding Scale; CBFS = Benefit Finding Scale (Chinese version); JBFS = Benefit Finding Scale (Japanese version); BFiMSS = Benefit Finding in Multiple Sclerosis Scale; ISCS = Impact on Self Concept Scale; PAQ = Positive Adjustment Questionnaire; CPTGI = Posttraumatic Growth Inventory (Chinese version); DPTGI = Posttraumatic Growth Inventory (Dutch version); PTGI-MC = Posttraumatic Growth Inventory (Mainland Chinese version); PTGI-SC = Posttraumatic Growth Inventory (simplified Chinese version); SLQ-38 = Silver Lining Questionnaire; SRGS-R = Stress Related Growth Scale (revised); TS = Thriving Scale.

Table 5

Reliability and Validity Statistics for PTG Measures in Physical Health Samples

PTG measure	Article references	Internal consistency	Test-retest reliability	Structural validity	Convergent validity
BFS	Ando et al. (2011) (Japanese version)	SS: .80, .74, .70*	-	22 items with 3 factors	-
	Liu et al. (2016) (Chinese version)	.95*	.93*	22 items with 6 factors	CPTGI: .79*
	Urcuyo et al. (2005)	.91*	-	-	-
BFiMSS	Mohr et al. (1999)	.87* (BFSS = .84*)	-	48 items with 3 factors	-
	Pakenham (2005)	.89*	-	19 items with 2 factors	-
	Pakenham & Cox (2009)	.94*	.74*	43 items with 7 factors	-
ISCS	Golub et al. (2013)	SS: .88, .82	-	10 items with 2 factors	-
PAQ	Boot et al. (2010)	>.70	-	35 items with 4 factors	SLQ: for subscales range .24*-.45*
PTGI	Gall et al. (2011)	.95*	.71*	-	-
	Ho et al. (2004) (Chinese version)	.83*	-	15 items with 4 factors	
	Jaarsma et al. (2006) (Dutch version)	.95*	-	21 items with 5 factors	
	Liu et al. (2014) (simplified Chinese	.92*	-	-	
	version)	.92*	.92*	17 items with 5 factors	
	Mystakidou et al. (2008) (Greek version)	-	-	21 items with 5 factors	
	Purc-Stephenson (2014)	.96	-	21 items with 2 factors	
	Sheikh & Marotta (2005)	.96	.87*	-	
	Steel et al. (2008)	.91*	-	18 items with 3 factors	
	Zhai et al. (2014) (Chinese version)				
SLQ-38	McBride et al. (2008)	SS: .65-.89	-	24 items with 5 factors	-
	McBride et al. (2009) (Dutch version)	SS: .83, .90, .85*	-	16 items with 3 factors	-
	Sodergren et al. (2002)	.93*	.90*	-	
SRGS-R	Costa & Pakenham (2012)	.97	-	-	PTGI: .69*
TS	Abraido-Lanza et al. (1998) (Spanish	.92*	-	20 items with 4 factors	-
	version)	.93*	-	19 items with 3 factors	-
	Cheng et al. (2006) (Chinese version)				

Note. * = acceptable internal consistency and reliability based on Terwee et al. (2007); - = not reported; SS = subscales given when overall internal consistency not provided. BFS = Benefit Finding Scale; BFiMSS = Benefit Finding in Multiple Sclerosis Scale; ISCS = Impact on Self Concept Scale; PAQ = Positive Adjustment Questionnaire; PTGI = Posttraumatic Growth Inventory; SLQ-38 = Silver Lining Questionnaire; SRGS-R = Stress Related Growth Scale (revised); TS = Thriving Scale.

1.3.4 Characteristics of Questionnaires

Benefit Finding Scale (BFS; Tomich & Helgeson, 2004)

The BFS measures benefit finding and considers the domains of growth, personal priorities, daily activities and family. The BFS was constructed based on theories of meaning-focused coping (Folkman, 2008) and cognitive adaptation theory (Taylor, 1983). These theories suggest that when individuals cope with adversity and engage in selective cognitive evaluations, this supports individuals to restore self-esteem and utilise behavioural control strategies. However, none of the described studies considered the theoretical background of the BFS.

Overall, the BFS had variable methodological quality and measurement ratings. In cancer patients, the internal consistency of the BFS ranged from acceptable (Ando et al., 2011) to excellent (Liu, Gudenkauf, Zhang & Wang, 2016; Urcuyo et al., 2005) and had excellent test-retest reliability (Liu et al., 2016). One study had excellent methodological quality for internal consistency and structural validity. However, based on Terwee's criteria, negative ratings were given for internal consistency as the Cronbach's alpha was too high (.96). In contrast, two studies had poor methodological quality (Ando et al., 2011; Urcuyo et al, 2005) on these measurement properties. Higher ratings were not given due to an inadequate sample size in the unidimensionality analysis and an absence of description for the rotation method.

The content validity had poor and excellent methodological quality in Ando et al. (2011) and Liu et al. (2016). There was no assessment of whether all items were relevant for the study population. By comparison, the Terwee criteria justified a positive rating for Liu et al. (2016) due to a clear description of the target population and concepts measured. Hypothesis testing had good methodological quality but higher ratings were not given because the authors did not report the expected relative magnitude of the mean differences in the hypotheses (Liu et al., 2016). The BFS also demonstrated a large correlation and satisfactory convergent validity with the PTGI, $r = .65$, $p < .05$.

Benefit Finding in Multiple Sclerosis Scale (BFiMSS; Mohr et al., 1999)

The BFiMSS was developed from interviews with multiple sclerosis patients to produce a 63-item questionnaire (Mohr et al., 1999). Subsequently a 19-item benefit finding subscale emerged and has been used as a standalone instrument. The BFiMSS was developed independently of the BFS. However, similarly to the BFS, the BFiMSS is theoretically based on the assertion that a reappraisal coping strategy underlines aspects of growth in the face of adversity (Park & Folkman, 1997).

Overall, the BFiMSS had good methodological quality and positive quality ratings (Pakenham & Cox, 2009; Pakenham, 2005). Higher rates were not given because of the limited sample sizes, the absence of a description for handling missing data, and failure to show the expected magnitude of the correlations of differences. Test-retest reliability was methodologically poor due to the inappropriate time interval between the two assessments and uncertainty about whether the participants were stable.

Issues were identified with the internal consistency and structural validity in Mohr et al. (1999). This study received poor methodological quality and indeterminate quality ratings. Failings were noted due to an insufficient sample size and no clarity about missing data handling.

Impact of Self Concept Scale (ISCS; Golub, Rendina & Gamarel, 2013)

The ISCS was designed to measure positive and negative HIV-related identity change, captured in the subscales: self-growth and self-loss (Golub et al., 2013). Theoretically, the ISCS is based on literature suggesting growth and loss are independent constructs useful for considering adaptation processes in people experiencing HIV. Growth following trauma has positive effects, providing there is consideration of costs (Taylor et al. 1991).

Overall the ISCS is methodologically good and had positive quality ratings for internal consistency, structural validity and hypothesis testing (Golub et al., 2013). The study had an adequate sample size and directional hypotheses were consistent with the results. However, concerns were raised about the content validity. This received fair methodological quality and indeterminate quality rating due to no assessment of items relevance to the construct.

Positive Adjustment Questionnaire (PAQ; Boot, Holcombe & Salmon, 2010)

The PAQ was developed to assess positive adjustment in women with breast cancer and is divided into four domains: fulfilment, re-evaluation, new ways of living and valuing life (Boot et al., 2010). This instrument is based on developmental theory which proposes that positive adjustment occurs as part of a change in view of self which enables more effective management of trauma in the future (Salmon, Manzi, & Valori, 1996; Linley & Joseph, 2004).

The PAQ had mixed quality ratings in women diagnosed with breast cancer (Boot et al., 2010). The content validity had excellent methodological quality and a positive quality rating because there was a thorough assessment of the items used to measure the instrument construct. However, the internal consistency was methodologically poor and only had acceptable internal consistency. The overall quality rating was indeterminate due to an insufficient sample size for unidimensionality analysis. The methodological quality for hypothesis testing was rated as fair due to a failure to describe the handling of missing data. Nevertheless, a small to moderate correlation with the Silver Lining Questionnaire (SLQ) indicated good convergent validity, $r = .24\text{-}.45$, $p < .01$.

Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996)

The most widely used measure in this review was the PTGI. The PTGI was developed to measure positive change after a trauma or negative life event (Tedeschi & Calhoun, 1996). Originally it was standardised on a student population, but it has subsequently been used with a variety of samples who have experienced bereavement, abuse and cancer. This measure can be divided into five subscales: relating to others, new possibilities, personal strength, spiritual change and appreciation for life. The PTGI is based on the FD model suggesting growth occurs after an individual's beliefs are shattered following a trauma. Subsequently, individuals discover new meaning and adjust previously held beliefs (Tedeshi & Calhoun, 2004).

Overall, the PTGI had varied methodological quality across the studies being reviewed. Seven studies using the PTGI with samples who had cancer or chronic diseases, reported excellent internal consistency (Gall, Charbonneau & Florack, 2011; Purc-Stephenson, 2014; Sheikh & Marotta, 2005; Steel, Gamblin & Carr, 2008; Jaarsma, Pool, Sanderman, & Ranchor, 2006; Zhai et al., 2014; Liu et al., 2014; Mystakidou et al., 2008) and the remaining study (Ho et al., 2004) was good.

One study considered content validity (Liu et al., 2014). It received excellent methodological quality and a positive quality rating. These ratings were given in light of the assessment conducted to ensure the items were appropriate and calculation of a content validity index. Structural validity and hypothesis testing had fair and good methodological quality and positive ratings overall. No studies considered convergent validity with other instruments. Higher ratings were not given for these measures of validity due to a lack of information about missing items, inadequate sample size, and non-directional hypotheses. Factor analysis revealed varying numbers of factors, ranging from two to five across different studies and patient populations. However, most studies suggested the presence of the five factors stated above.

Three studies had substantial or almost perfect inter-rater reliability (Liu et al, 2014; Steel et al., 2008; Sodergren et al., 2002). However, there were problems with the methodological quality and overall ratings. Negative and poor ratings were given as the time interval between assessments were inadequate for measuring inter-rater reliability (varying between 3 to 24 months). Liu et al. (2014) also failed to calculate intraclass correlation coefficient or Pearson's correlations.

Five studies assessed cross-cultural validity and translated the PTGI into a variety of languages including Chinese, Dutch and Greek. According to the COSMIN checklist, these studies had poor methodological quality. Reasons for this rating included failure to conduct a confirmatory factor analysis and the translated instrument was not pre-tested to ensure interpretative and cultural relevance.

Silver Lining Questionnaire (SLQ-38; Sodergren & Hyland, 2000)

The SLQ-38 assessed positive consequences of chronic disease (Sodergren & Hyland, 2000). The SLQ-38 is theoretically-based on ideas around positivity occurring following reappraisal of trauma (Taylor, 1983) and existential growth (LeShan, 1994).

Three studies used the SLQ-38 in samples with multiple sclerosis, cancer, cardiac and renal disease (McBride et al., 2008; McBride, Schroevers, & Ranchor, 2009; Sodergren, Hyland, Singh, & Sewell, 2002). Overall methodological quality ratings varied from poor to good. Two studies performed structural validity assessments (McBride et al., 2008, 2009) and both had good methodological validity. Higher ratings were not given due to the absence of percentage of missing items. Interestingly, factor analysis revealed differences in the factor structure between these two studies, which may have been influenced by insufficient sample sizes, heterogeneous samples and cultural differences.

Two studies had good and excellent internal consistency for the 16 and 38 item versions (McBride et al., 2009; Sodergren et al., 2002). However, Sordegren et al. (2002) had poor methodological quality and an indeterminate quality rating because of a failure to check unidimensionality. McBride et al. (2009) also used a Dutch version of the SLQ-38, however, they did not reference the translation process and it was not possible to assess cross-cultural validity.

Stress Related Growth Scale (SRGS-R; Armeli, Gunthert, & Cohen, 2001)

The SRGS-R measured positive and negative change following a significant trauma, and it was originally standardised with college students (Armeli et al., 2001). This measure is based on theories suggesting that benefit finding re-establishes meaning and promotes adjustment following trauma (Tedeschi & Calhoun, 2004).

The SRGS-R had poor overall methodological quality identified from a sample with thyroid cancer (Costa & Pakenham, 2012). However, one measurement property that received fair methodological quality and positive quality ratings was hypothesis testing. Convergent validity revealed a large correlation with the PTGI, $r = .69, p < .01$. However, there was an inadequate description of the comparator instrument and failure to describe management of missing data.

Other issues pertained to the internal consistency, content validity and structural validity and were methodologically poor. Higher ratings were not given due to an insufficient sample size and no assessment of item appropriateness.

Thriving Scale (TS; Abraido-Lanza, Guier, & Colon, 1998)

The TS assessed perceived growth following adversity of physical illness (Abraido-Lanza et al., 1998). This instrument is based on the value-added model of thriving whereby individuals find strength, insight and meaning in life following illness (Abraido-Lanza et al., 1998).

Two studies used the TS in samples with chronic illness and mainly received poor or fair methodological ratings (Abraido et al., 1998; Cheng et al., 2006). However, Abraido et al. (1998) had excellent methodological quality and based on Terwee's criteria received a positive rating. This was given due to the detailed assessment process used to ensure items were relevant to the identified study population.

Concerns were raised about the cross-cultural validity and internal consistency of these studies. The translated versions had poor methodological quality. These ratings were given due to a failure to show confirmatory factor analysis of the translated instrument and no pre-test was conducted to check interpretations and cultural relevance. Although the TS had excellent internal consistency and there was an adequate sample size, the authors failed to calculate internal consistency statistics for each subscale.

1.3.5 Overall Strength of Measurement Properties

Table 5 illustrates that across all studies the majority of internal consistencies reported were good or excellent. However, some only provided Cronbach's alphas for the subscales. Fewer studies considered test-retest reliability and most of these were either substantial or almost perfect. Convergent validity with other instruments also suggested that correlations were large.

1.3.6 Summary of COSMIN Methodological Quality Checklist

The COSMIN checklist enabled a detailed evaluation of the quality of the design and methods used by studies using PTG instruments. Based on guidance in the checklist and following the worst score counts method, the majority of ratings were of either poor or good quality. The most common limitations were failure to ensure sufficient sample size for the unidimensionality analysis, inadequate information and handling on percentage missing data, inappropriate time intervals used between time points, and translated instruments not pre-tested appropriately.

In light of the COSMIN criteria employing the worst score counts method this may have created a bias towards low ratings and the excellent ratings within a category may have been missed. Therefore, it was important to include percentage of excellent ratings and these are presented in Table 6. The highest percentage was achieved by Liu et al. (2016) for the BFS, followed by Mystakidou et al. (2008) for the PTGI, and Golub et al. (2013) for the ISCS with values of 86.79%, 49.06% and 45.28% respectively. Percentage excellent ratings ranged from 7.55 to 86.79% with a mean of 25.68% (*SD* = 17.67).

1.3.7 Summary of Terwee's Quality Criteria

Terwee's quality criteria provided overall quality ratings for the measurement properties. Table 6 highlights some aspects of the studies received positive ratings but the vast majority were rated as indeterminate. There were seven negative ratings across all studies, six were related to internal consistency for Cronbach's alpha falling below .70 or above .95 (Liu et al, 2016; Ho et al., 2004; McBride et al. 2008; Sheikh & Marotta, 2005; Steel et al., 2008; Costa & Pakenham, 2012), and the remaining one was related to reliability (subscale Kappa values less than .70; Steel et al., 2008).

The reasons for the indeterminate ratings were related to inadequate descriptions of the target population for content validity, studies not formulating clear hypotheses, and inappropriate time intervals between testing for reliability.

Table 6

Summary of Levels of Evidence for Measurement Properties of Included Questionnaires

	Terwee criteria									COSMIN criteria						
					Reproducibility											
Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Agreement	Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Internal consistency	Reliability	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	% excellent ratings
BFS																
Ando et al. (2011)	0	?	0	0	0	0	0	0	0	Poor	-	Poor	Poor	-	-	7.55
Liu et al. (2016)	+	-	0	+	?	+	0	0	0	Excellent	Fair	Excellent	Excellent	Good	Fair	86.79
Urcuyo et al. (2005)	0	?	0	?	0	0	0	0	0	Poor	-	-	Poor	-	-	7.55
BFiMSS																
Mohr et al. (1999)	+	?	0	?	0	0	0	0	0	Poor	-	Fair	Poor	-	-	18.87
Pakenham (2005)	0	+	0	0	0	0	0	0	0	Good	-	-	Good	Good	-	18.87
Pakenham & Cox (2009)	0	+	0	+	0	0	0	0	0	Good	Poor	-	Good	Good	-	41.51
ISCS																
Golub et al. (2013)	?	+	0	+	0	0	0	0	0	Good	-	Fair	Good	Good	-	45.28
PAQ																
Boot et al. (2010)	+	?	0	+	0	0	0	0	0	Poor	-	Excellent	Fair	Fair	-	32.08
PTGI																
Gall et al. (2011)	0	?	0	0	?	+	0	0	0	Poor	Poor	-	-	Good	-	26.42
Ho et al. (2004)	0	-	0	+	0	0	0	0	0	Fair	-	-	Fair	Fair	Poor	24.53
Jaarsma et al. (2006)	?	?	0	+	0	0	0	0	0	Good	-	-	Fair	Good	Poor	22.64
Liu et al. (2014)	+	?	0	+	0	0	0	0	0	Poor	Poor	Excellent	-	Fair	Poor	39.62
Mystakidou et al. (2008)	?	?	0	+	+	+	0	0	0	Good	Good	-	Good	Good	Poor	49.06

	Terwee criteria									COSMIN criteria						
					Reproducibility											
Questionnaire	Content validity	Internal consistency	Criterion validity	Construct validity	Agreement	Reliability	Responsiveness	Floor or ceiling effect	Interpretability	Internal consistency	Reliability	Content validity	Structural validity	Hypothesis testing	Cross-cultural validity	% excellent ratings
Purc-Stephenson (2014)	0	0	0	+	0	0	0	0	0	-	-	-	Good	Good	-	18.87
Sheikh & Marotta (2005)	0	-	0	?	0	0	0	0	0	Good	-	-	Good	-	-	18.87
Steel et al. (2008)	0	-	0	0	?	-	0	0	0	Poor	Fair	-	Good	-	-	15.09
Zhai et al. (2014)	0	+	0	?	0	0	0	0	0	Poor	-	-	Fair	-	Poor	18.87
SLQ-38																
McBride et al. (2008)	0	-	0	?	0	0	0	0	0	Fair	-	-	Good	Good	-	24.53
McBride et al. (2009)	0	+	0	?	0	0	0	0	0	Fair	-	-	Good	-	-	16.98
Sodergren et al. (2002)	0	?	0	+	0	0	0	0	0	Poor	Fair	-	-	Fair	-	11.32
SRGS-R																
Costa & Pakenham (2012)	?	+	0	+	0	0	0	0	0	Poor	-	Poor	Poor	Fair	-	18.87
TS																
Abraido-Lanza et al. (1998)	+	?	0	+	0	0	0	0	0	Poor	-	Excellent	Poor	Fair	Poor	18.87
Cheng et al. (2006)	0	?	0	0	0	0	0	0	0	Poor	-	-	Fair	Fair	Poor	7.55

Note. Rating: + = positive; 0 = indeterminate; - = poor; ? = no information available.; COSMIN checklist: - = no data available. BFS = Benefit Finding Scale; BFiMSS = Benefit Finding in Multiple Sclerosis Scale; ISCS = Impact on Self Concept Scale; PAQ = Positive Adjustment Questionnaire; PTGI = Posttraumatic Growth Inventory; SLQ-38 = Silver Lining Questionnaire; SRGS-R = Stress Related Growth Scale (revised); TS = Thriving Scale. There was no evidence to evaluate measurement error, criterion validity, responsiveness, floor or ceiling effect, interpretability for these instruments.

1.4 Discussion

1.4.1 Summary of Findings

This systematic review of PTG measures in physical health identified 23 eligible studies, which evaluated the measurement properties of eight different instruments and the reliability and validity statistics ranged from substantial to almost perfect, and questionable to excellent respectively. For each of the psychometric properties, most studies received either poor or good methodological quality ratings. The overall strength of the psychometric properties were primarily rated as indeterminate. Only six studies received excellent methodological quality ratings on different measurement properties. Excellent overall ratings were predominantly given for studies that evaluated content validity of the PAQ (Boot et al., 2010), PTGI (Liu et al., 2014), BFS (Liu et al., 2016) and TS (Abraido-Lanza et al., 1998), as well as internal consistency and structural validity of the BFS (Liu et al., 2016).

One criticism of the COSMIN criteria used to evaluate the methodological quality created bias in the findings due to their stringency. This was related to utilisation of the ‘worst score counts’ approach. The quality score is obtained by taking the lowest rating on any item in each psychometric property, which resulted in large numbers of poor and fair ratings, and few properties achieved excellent in a given category. Therefore, to distinguish between instruments it felt appropriate to highlight the percentage excellent ratings given across all measurement properties. This showed studies evaluating the BFS (Liu et al., 2016), PTGI (Mystakidou et al., 2008) and ISCS (Golub et al., 2013) had the highest excellent ratings for methodological quality. These studies received at least two positive overall ratings and had relatively good methodological design and methodology. These findings suggest there is more evidence to recommend the use of the BFS, PTGI and ISCS compared to other measures of PTG. Both the BFS and PTGI measured personal growth and the ISCS considered growth and loss following a significant event. However, these results should be interpreted with caution as all instruments failed to consider the full range of measurement properties, and there were instances where no information was available, or information was indeterminate.

1.4.2 Utility of PTG Measures in Physical Health

Some studies developed PTG measures specifically for physical health populations. Three studies used the BFiMSS designed for people with multiple sclerosis (Mohr et al., 1999; Pakenham, 2005; Pakenham & Cox, 2009), another used the ISCS designed to reflect HIV-related identity changes (Golub et al., 2013), the PAQ was developed for breast cancer patients (Boot et al., 2010), SLQ was developed for physical illness (McBride et al., 2008), and TS was developed for chronic illness (Abraido-Lanza et al., 1998). Other studies used pre-existing instruments (for example, BFS and PTGI) that were originally validated in a general population sample and subsequently used in physical health. This approach has some limitations because psychometric properties should be evaluated based on a representative population and these properties may differ across populations and settings (Terwee et al., 2007). Previous research has also shown that the nature of PTG is strongly related to the type of significant, traumatic event experienced (Sumalla, Ochoa, & Blanco, 2009; Weaver et al., 2008).

Previous literature has raised concerns that existing PTG instruments may have limited reliability and validity. Firstly, PTG measures are predominantly positively biased (Smith & Cook, 2004) and do not consider negatively evaluated processes of change (Wittmann & Büchi, 2010). Most PTG instruments included in the review focused on the positive aspects of change after a significant event and only one study used the ISCS, which reflected on both positive and negative aspects. The literature also highlighted that it is theoretically important to consider both the positive and negative changes experienced by people after a trauma as these processes are often occurring simultaneously (Joseph et al., 2012). Secondly, the literature illustrates the range of different terms that are used for PTG, which is reflected in the included instruments. No clear standard definition characterising PTG suggests that these terms may represent different epistemological positions and lack clear theoretical conceptualisation (Joseph & Linley, 2008). Thirdly, evidence indicates there is variation in the number of dimensions of PTG. For example, the SRGS is unidimensional revealing a single score of growth, whereas the PTGI and TS are both multidimensional, with different conceptualised domains of PTG. Finally, PTG measures are dependent on retrospective self-report and on an individual's ability to reflect on perceived change following a significant life event (Joseph, 2015). This raises concern about possible reporting bias due to limits in accuracy (Ford, Tennen & Albert, 2008). Therefore, the existing measures may fail to accurately reflect actual change (Frazier et al., 2009). Taking these issues into account for the current findings, these PTG instruments may have limited validity and reliability.

1.4.3 Summary of Theoretical Grounding of PTG Measures

The PTG measures were theoretically based on various frameworks. However, most instruments (BFS, BFiMSS, PAQ, PTGI, SLQ-38, SRGS, and TS) were conceptually grounded in the idea that the process of cognitive reappraisal of a trauma can lead to new meaning and the adjustment of previously held beliefs (Abraido-Lanza et al., 1998; Park & Folkman, 1997; Taylor, 1983; Tedeschi & Calhoun, 2004). Linley and Joseph (2004) suggested the adjustment process enabled more effective management of trauma in the future. The ISCS was also grounded in literature emphasising growth following trauma has positive effects, providing there is consideration of costs (Taylor et al., 1991).

Models of PTG reflected in these measures include the value-added model of thriving (Abraido-Lanza et al., 1998), cognitive adaption theory (Taylor, 1983) and developmental theory (Salmon et al., 1996). However, the most comprehensive framework is the FD model (Tedeschi &

Calhoun, 2004). This highlights the different ways of conceptualising PTG, which makes it difficult to draw parallels between the PTG measures as they may be measuring slightly different constructs. Nevertheless, the language used to describe PTG was similar across the different measures.

1.4.4 Implications of Findings and Further Research

This review suggests that the current evidence is insufficient to comprehensively assess the reliability and validity of PTG instruments in physical health. Further research is needed and it is important for researchers to design methodologically sound studies and utilise guidance provided by the COSMIN group to ensure that the psychometric properties of PTG measures are high quality. Important aspects to address include ensuring that studies report both the percentage of missing data and how missing data is handled; having sufficiently large samples for factor analysis and unidimensionality analysis; ensuring that the time interval between ratings is appropriate for assessments of test-retest reliability; making sure that translated instruments are pre-tested for cross-cultural validity; using specific hypotheses for hypothesis testing; and finally ensuring that items are relevant and appropriate for the target population when assessing content validity.

Researchers should also encompass a greater range of measurement properties to ensure that studies use high quality and robust PTG measures in physical health. This work may include the PTG measures with relatively good design and methodology such as the BFS, PTGI, or ISCS. This would address gaps identified in the included studies within this review, such as criterion validity, measurement error, and responsiveness. This could help to establish whether scores on PTG measures adequately reflect a gold standard measure, the extent that changes in PTG scores are not related to measurement error, and the ability for PTG measures to detect change over time.

This current evidence obtained through a systematic search for this review predominantly identified studies involving participants with cancer. Further research should consider the psychometric properties of existing measures using participants with a broader range of health conditions. This would add to the current PTG evidence-base and may provide clearer evidence for the theoretical processes involved in PTG. One neglected population is people who have experienced transplant. Evidence suggests post-transplant experiences of PTG may differ to other trauma experiences due to a unique set of stresses and emotions, and ongoing health needs (Muehrer & Becker, 2005). Given that psychometric properties may differ across populations and settings (Terwee et al., 2007) it would be valuable to examine the psychometric properties of PTG measures in this sample.

Additionally, one instrument yet to be validated in physical health, which may have utility is the Psychological Well-Being–Post Traumatic Changes Questionnaire (PWB-PTCQ; Joseph et al., 2012). This instrument has good reliability and validity using a non-health population and assesses the perceived positive and negative changes after a significant event.

1.4.5 Limitations

This review has some important limitations that need to be considered. Firstly, only one investigator conducted the full text study identification. However, all study titles and abstracts were reviewed by two researchers and reference lists were searched to identify further articles to ensure completeness. Moreover, the inclusion criteria excluded non-English articles, which may have limited the breadth of evidence in the review. Nevertheless, it was possible to evaluate several translated PTG measures and consider cross-cultural validity.

Another criticism of this review is that the inclusion criteria stated articles that should be included if they reported at least two psychometric properties of PTG instruments in physical health within the context of an empirical paper. Therefore, these studies had not been specifically designed to evaluate the psychometric properties of measures. Previous reviews have only included studies that specifically intended to evaluate psychometric properties (Elbers et al., 2012) and other reviews considered at least one measurement property (Dobson et al., 2012). The slightly broader inclusion criteria used in this review may have contributed to studies receiving lower ratings because their primary focus was not to develop new instruments or evaluate psychometric properties. Examples of these studies include Costa and Pakenham (2012), Steel et al. (2008) and Zhai et al. (2014).

The COSMIN criteria have been a useful tool introduced into the field to support evaluation of psychometric properties; however, it has somewhat restrictive criteria, as already discussed, by using a ‘worst score counts’ approach. Moreover, missing data reporting and handling is highly regarded, which led to some studies receiving no ratings higher than fair. Studies that did not report the expected magnitude of hypotheses also received lower ratings. Therefore, this may have reduced the overall quality rating of some studies and it is unclear whether these criteria would affect the overall quality of the instrument. Nevertheless, adequate reporting of missing data and handling, and clear study hypotheses are important for ensuring robust studies that are replicable, and for preventing erroneous fishing for results. It is also important to acknowledge there may have been discrepancies between what authors actually did and what they reported due to limited word count. Authors may have checked missing data but it was not reported. Other examples include authors ensuring that items are relevant and appropriate for content validity, and pre-testing of translated instruments but again this may not have been reported. Given the relatively recent publication of the COSMIN and Terwee criteria, many studies will not have utilised these tools to help guide the design and analysis of instruments. Despite these limitations, this review has provided useful insights into the quality of psychometric properties in PTG measures in physical health.

1.4.6 Conclusions

This systematic review of PTG measures in physical health provides useful guidance for researchers and clinicians, as well as directions for further research. Evidence highlights it is difficult to draw conclusions from the current literature due to the paucity of high quality evidence of the psychometric properties of PTG instruments. However, as well as their advantages, there are some possible limitations to the COSMIN assessment tools, in particular the restrictive criteria which led to PTG measures receiving poor quality ratings. Therefore, the findings need to be interpreted with caution. Based on the percentage excellent methodological quality ratings and positive overall ratings there is more evidence to recommend the use of the BFS, PTGI and ISCS. It remains vital for further research to be conducted to ensure good quality assessments are developed to assess the measurement properties within physical health. With this in mind, PTG measures may have utility in supporting clinicians to evaluate therapeutic interventions in physical health.

Chapter 2: Empirical paper: Predictors of Posttraumatic Growth and the Role of Resilience Post Lung Transplant

2.1 Introduction

Over the last decade there has been a growing evidence-base examining the existence of, and benefits from, posttraumatic growth (PTG) in patients with serious physical health conditions (Helgeson, Reynolds, & Tomich, 2006). However, one population that is notably absent from this literature is transplant patients. The aim of this paper is to address this gap with specific reference to patients who have undergone a lung transplant. First, this paper will consider the existing literature on PTG, with specific reference to, and critique of, the functional-descriptive (FD) model of PTG (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004). Second, a cross-sectional study will examine the theoretical underpinning of the FD model in a lung transplant population and explore the role played by resilience. Finally, the implications of these findings for theory, clinical practice and further research are considered.

2.1.1 Lung transplant

Lung transplant is an effective treatment for patients experiencing chronic illnesses such as cystic fibrosis (CF) and chronic obstructive pulmonary disease (COPD). With medical and surgical advances, lung transplantation aims to extend patients' life expectancy and significantly improve their physical and psychological quality of life (Dierich et al., 2013). The annual report on cardiothoracic transplantation states that more than 1,550 adults (aged >16 years) have received lung transplants over the last 10 years in the United Kingdom. Survival rates are also increasing and are at 89% after 90 days' post-transplant (NHS England, 2016). The current evidence suggests that experiences of PTG post-transplant may differ from other traumatic experiences due to a unique set of stresses, emotions, and ongoing health needs associated with transplant (Muehrer & Becker, 2005). Typically, transplant is perceived as life-giving rather than life-threatening (Dew & DiMartini, 2011). Nevertheless, the experience includes many potentially traumatic components. Therefore, it is important to explore whether the transplant population experience higher or lower levels of PTG and to explore the possible psychological mechanisms involved.

At the moment, there is a limited evidence-base for PTG post lung transplant. Previous literature highlighted that transplant recipients experience both increased physical and emotional well-being (Smeritschnig et al., 2005), as well as a reduction in symptoms of depression and anxiety (Limbos, Joye, Chan, & Kesten, 2000). However, recipients also experience psychological distress and posttraumatic stress disorder (PTSD; Cupples et al., 2006; Dew et al., 2012). Dew et al. (2012) highlighted that this was more common in the first two years' post-transplant. However, this relationship is not maintained in longer term survivors of transplant (ranging between 6 to 11 years). In a sample of 210 participants, rates of PTSD post-transplant were 12.6%, which are similar to other chronic health conditions (Gries et al., 2013). Factors associated with post-transplant PTSD were pre-transplant mental health difficulties and poor social support post-transplant (Davydow, Lease, & Reyes, 2015). In one study, the only predictor of PTG was panic disorder early post-transplant (first two years), whereas PTSD and depression during this period did not predict PTG (Fox et al., 2014). Moreover, greater social support from friends was related to more PTG at long-term follow up. The aim of this paper is to build on the current limited evidence-base and explore the relationships between distress, social support and PTG.

2.1.2 Posttraumatic Growth

PTG (also known as benefit finding) is conceptualised as experiencing a positive life change following a trauma or challenging life experiences (Calhoun & Tedeschi, 1999; Linley & Joseph, 2004). PTG reflects a change in psychological functioning that encompasses perception of self, and relationships with others, and can lead to changes in life philosophy (Tedeschi & Calhoun, 1995). The existence of PTG has been documented in a number of studies including cancer (Scrignaro, Barni, & Magrin, 2011), heart attack (Leung et al., 2010), HIV and AIDS (Siegel & Schrimshaw, 2000).

A recent review found that PTG was related to less depression and more positive well-being, but not related to anxiety and global distress (Helgeson et al., 2006). However, these relationships were moderated by the time since the trauma and PTG was associated with more global distress after a relatively recent event. Moreover, PTG was related to the subjective appraisal of an event; specifically greater levels of perceived threat and harm were associated with PTG (Linley & Joseph, 2004). To understand and facilitate PTG it is important to base research on a theoretical model that seeks to identify underlying mechanisms. The functional-descriptive (FD) model (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004) has provided the most comprehensive description of PTG and has been examined extensively in the literature. Therefore, it was appropriate to explore the predictions within this model in the context of a lung transplant population to identify possible supporting or conflicting evidence.

2.1.3 Functional-Descriptive Model of PTG

The FD model proposes that PTG is a process that commences following a crisis where an individuals' beliefs about themselves and the world are shattered. The model proposes that engagement in cognitive processing alleviates this distress. Initially this processing involves automatic, intrusive thoughts, known as intrusive rumination, (consistent with re-experiencing and avoidance symptoms of PTSD; American Psychiatric Association [APA], 1994) and individuals attempt to understand and manage the aftermath of the trauma through disengagement with previously held goals and assumptions about life. If effective, this creates a reduction in distress and commencement of reflective and deliberate rumination occurs through individual's search for meaning and development of a coherent narrative of the event, which is vital to the development of PTG. This process is facilitated by social support through the mechanisms of self-disclosure of emotions to others in a supportive environment. This leads to a further reduction in distress/PTSD symptoms and development of coping strategies (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004). This process is contrary to the experience of PTSD, whereby individuals do not have a coherent narrative of the trauma experience and hold beliefs that the trauma has permanently changed their sense of self and feel unable to achieve life goals thus, maintaining a sense of threat (Brewin & Holmes, 2003).

Figure 2 highlights the FD model. The first stage in the model represents the person prior to the trauma, which is followed by the seismic event representing the trauma. This challenges an individual's management of emotional distress, beliefs and goals and the narratives held about themselves and the world. Individuals experience automatic, intrusive rumination, which leads to a reduction in distress, disengagement of goals and engagement with more deliberate rumination. These processes are further facilitated by self-disclosure and social support, further enhancing schema change and narrative development; all these components enhance the development of PTG.

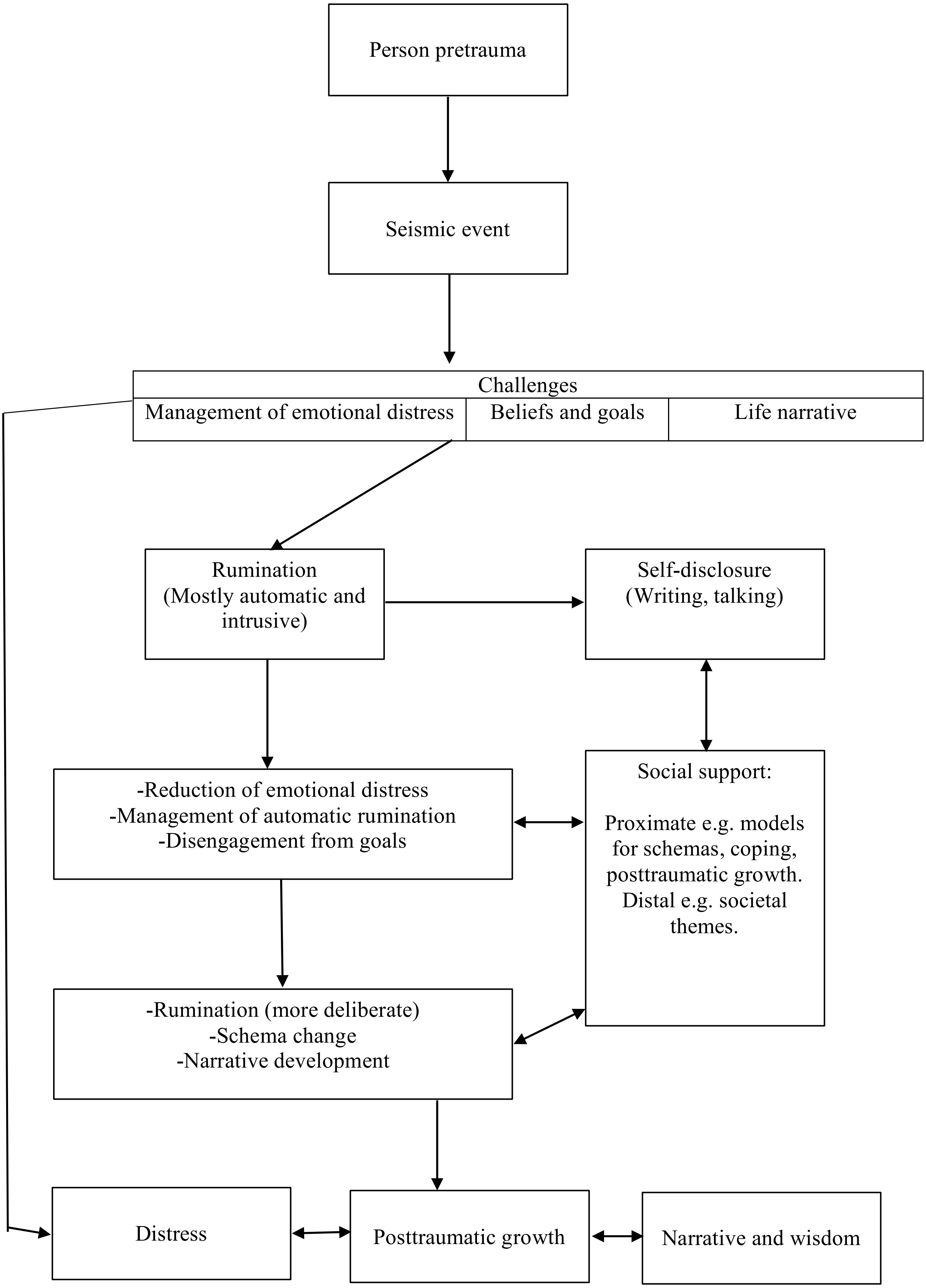

Figure 2. *Functional-descriptive model of PTG (Calhoun & Tedeschi, 1998; Tedeschi & Calhoun, 2004)*

The current evidence for the model in physical health focuses predominantly on the cancer population and is quite mixed. On the one hand, women and younger people are more likely to experience PTG (Linley & Joseph, 2004; Helgeson et al., 2006), which may be related to greater engagement in positive reappraisal and self-talk (Tamres, Janicki, & Helegson, 2002). The importance of reappraisal processes are highlighted by Morris and Shakespeare-Finch (2011), who found deliberate rumination on benefits was associated with PTG, and intrusive rumination on the purpose of life was associated with distress. On the other hand, Wilson, Morris and Chambers (2014) did not find any direct relationships between deliberate rumination and PTG and intrusive rumination was associated with PTG. However, the findings by Wilson et al. (2014) need to be interpreted with caution due to the time elapsed post diagnosis (more than seven years) and deliberate rumination may have played a key role in the preceding years.

With regards to distress, some studies have found positive associations between distress and PTG (Tomich & Helgeson, 2004). In contrast, others found higher levels of PTG were associated with less distress (Ruini, Vescovelli, & Albieri, 2013), whereas some studies have found no relationship (Costa & Pakenham, 2012). These inconsistencies may be related to differences in conceptualising measures of distress and in the timings of assessments (Helgeson et al., 2006). Overall, research suggests the strongest relationships are evident within the first two years after the trauma (Helgeson et al., 2006).

Evidence consistent with the model and a key component within Figure 2 emphasises social support is important for reducing distress (Taylor, 2007). Research highlighted positive associations between PTG and social support (Morris & Shakespeare-Finch, 2011; Schroevers, Helgeson, Sandeman, & Ranchor, 2010); however, inconsistent findings have been reported in breast cancer (Cordova et al., 2001) and bone marrow transplant recipients (Widows, Jacobsen, Booth-Jones, & Fields, 2005). Support from family has been identified as particularly beneficial in long-term breast cancer survivors (Lelorain, Tessier, Florin & Bonnaud-Antignac, 2012). Instrumental social support is encapsulated by tangible assistance from others and emotional support allows disclosure and processing of experiences (Taylor, 2007). However, Fox et al. (2014) found more instrumental and emotional support from friends was related to more PTG at long-term follow up. Limitations of these studies are that small sample sizes limit the potential to identity a true effect and Fox et al. (2014) only considered this relationship at long-term follow up (6 to 11 years post-transplant).

2.1.4 Critique of Model

The FD model comprehensively outlines the processes underpinning PTG; however, it is largely descriptive and does not specify the time frame required for these processes to occur. As such it fails to explain why PTG increases over time (Fox et al., 2014; Helgeson et al., 2006; Leung et al. 2010). This absence of any consideration of the role of time may provide an explanation for variations in the relationships between distress, cognitive processing, social support and PTG, as described above. In the literature, there are ambiguous findings for the association between time since the event and PTG and the relationship with individual demographic characteristics. Furthermore, the model does not suggest what type of social support is most advantageous for the development of PTG, such as instrumental or emotional (Schroevers et al., 2010) and there is no clarity as to whether friends, family or significant others are key to PTG. Finally, the model does not account for specific individual characteristics that are most likely to promote PTG, despite evidence suggesting a relationship with personality characteristics. One study using a transplant population has demonstrated the presence of PTG, and factors associated with PTG included female gender, lower education and greater friend support (Fox et al., 2014). In contrast, poorer perceived health was associated with a reduction in PTG. However, this study was not theoretically driven and only included transplant recipients who were at least five years post-transplant.

Despite the importance of the FD model in providing a theoretical framework there is currently no clear picture of the relationships between the hypothesised predictors in the model and the development of PTG. Furthermore, the transplant population is barely represented in the literature. Therefore, the primary aims are to explore the extent to which lung transplant recipients experience PTG and whether time post-transplant predicts PTG, and, second, to gain a greater understanding of the role played by intrusive and deliberate rumination, distress and social support on the development of PTG.

2.1.5 Resilience and PTG

Before proceeding to the study, we need to consider the relationships between PTG and a similar concept, resilience. Resilience was omitted from the FD model but the literature suggests that resilience may play an important role in the development of PTG, reflecting a dynamic process occurring over time (Lepore & Revenson, 2006). Therefore, this study attempts to address this gap in the literature.

There is some debate about whether PTG is a form of resilience or whether PTG encompasses resilience but refers to a wider group of processes that confer benefits and is therefore superior to resilience (Lepore & Revenson, 2006; Westphal & Bonanno, 2007). Resilience can be defined as the person's ability to thrive when faced with adversity (Connor & Davidson, 2003). Resilience has three components: recovery, resistance and reconfiguration which captures positive and negative adaptations when dealing with stressful life events, whereas PTG is a reconfiguration process reflecting positive transformation following trauma (Lepore & Revenson, 2006). The characteristics of resilience include viewing the stressor as a value or opportunity, having secure and close attachment relationships to others, an ability to problem-solve in an action-focussed manner, and being able to tolerate negative emotions (Connor & Davidson, 2003). These characteristics reflect many components of the FD model and incorporating resilience might improve the model's explanatory power.

Inconclusive findings are evident between resilience, PTG and PTSD. Previous studies showed that higher levels of resilience are associated with a reduction in psychological distress, particularly depression and PTSD symptoms in lung transplant recipients (Cohen et al., 2014). Levine et al. (2009) examined these relationships in survivors of war and terror and found that resilience was inversely related to PTG. This suggests that resilience may protect people from experiencing the trauma as threatening to their view of self and the world and consequently they may experience fewer cognitive and psychological difficulties. However, in this study resilience was measured by the absence of PTSD symptoms. This has been strongly criticised in the literature (Almedom & Glandon, 2007) as the concept of resilience is more than just the absence of PTSD; this reductionist approach prevents consideration of resilience being a multidimensional construct. Therefore, this current study measured resilience in a more meaningful way to ascertain the possible role resilience plays in the process of PTG and whether resilience explains the relationships in the model. To the author's knowledge studies have not previously investigated the role played by resilience on PTG in physical health conditions.

2.1.6 Research objectives

The current study consisted of quantitative and qualitative components in order to explore the relationships between predictors of PTG devised from the FD model and PTG. The quantitative component explored the role played by intrusive and deliberate rumination, distress, social support and resilience on the development of PTG. However, this did not reveal how individuals engage with these processes post-transplant. Therefore, qualitative methodology complemented the quantitative component by providing transplant recipients an opportunity to express their experiences using their own language and encourage exploration and interpretation of their experiences. These in-depth accounts also enabled triangulation with the quantitative components.

2.1.7 Hypotheses

1. Time since transplant will be associated positively with PTG.
2. Deliberate rumination, distress and social support will significantly predict PTG.
3. Higher levels of resilience will predict PTG and may mediate the relationship between the psychological variables and PTG.

2.2 Method

The University of Southampton (Appendix E) Research Ethics Committee and the Health Research Authority reviewed the study (Appendix F) and granted ethical approval. The corresponding NHS trusts granted permission for the study to commence. Ethical consideration was given to potentially recruiting vulnerable adults with a degree of complexity and possible physical limitations. Therefore, it was important that the information sheets (see Appendices H and M) and consent forms (Appendices J and N) clearly outlined the project aims and allowed participants to withdraw at any time. It was explained that all information would be kept confidential unless there were any concerns about possible risk to themselves or others. It was considered unlikely that the questionnaires or interview would cause distress to participants. However, if participants appeared visibly distressed or if they scored in the clinical range on the Impact of Events Scale-Revised (IES-R; Weiss, 2007) and/or Depression, Anxiety and Stress Scale-21 Items (DASS-21; Lovibond & Lovibond, 1995) the researcher discussed with the participant if they were happy to be referred to the psychology team. If participants did not want to be referred to the psychology team, they were given details of additional support and resources highlighted in the debrief. However, all participants were happy to be referred. The debrief provided a range of resources of support including different services and charities (see Appendices K and P). Participants were told that all data collected would be anonymised and kept confidential in compliance with the Data Protection Act 1998. This process involved ensuring the audio-recorded interviews were transferred as soon as possible from the recording device to password-protected storage and deleted from the recording device. Personal identifiable information was removed from the transcribed interviews and the audio-recording was deleted.

2.2.1 Participants

Participants were recruited from two transplant centres in the United Kingdom between October 2016 and January 2017. Eligible participants were identified and approached by clinical staff and invited to participate. Participants were a self-selected sample who had consented to take part. Inclusion criteria for recruitment included:

1. Experienced a unilateral or bilateral lung transplant at least one month post-surgery and no more than 10 years ago;
2. Were aged over 18 years old; and
3. Were able to speak English and understand the consent process, questionnaires and interview questions.

Participants were excluded if they had received multi-organ transplants, second graft transplants, or partial lung transplants, or if they were too physically unwell, cognitively impaired, or were experiencing current major mental health difficulties in the opinion of the supervising medical consultant.

Overall, 147 participants completed the study. The sample comprised 136 outpatients and 11 inpatients across the two transplant centres (131 and 16 respectively). Figure 3 illustrates the participant recruitment flow chart. A total of 16 participants did not return completed questionnaires and 31 participants declined to take part. It was not possible to identify the reasons for this due to confidentiality. Overall, the response rate from participants who had been invited to take part was 76%. The study was also advertised online on the following forums: Cystic Fibrosis Trust Forum, NIHR People in Research website and lung transplant Facebook pages. However, no participants completed the questionnaires online.

Overall, 91 participants agreed to be contacted for the qualitative component. Due to time constraints, a pragmatic approach was used to approach participants, either to coincide with their return to clinic or availability. A sub-group of 12 participants took part in a semi-structured interview that was developed from reviewing current literature.

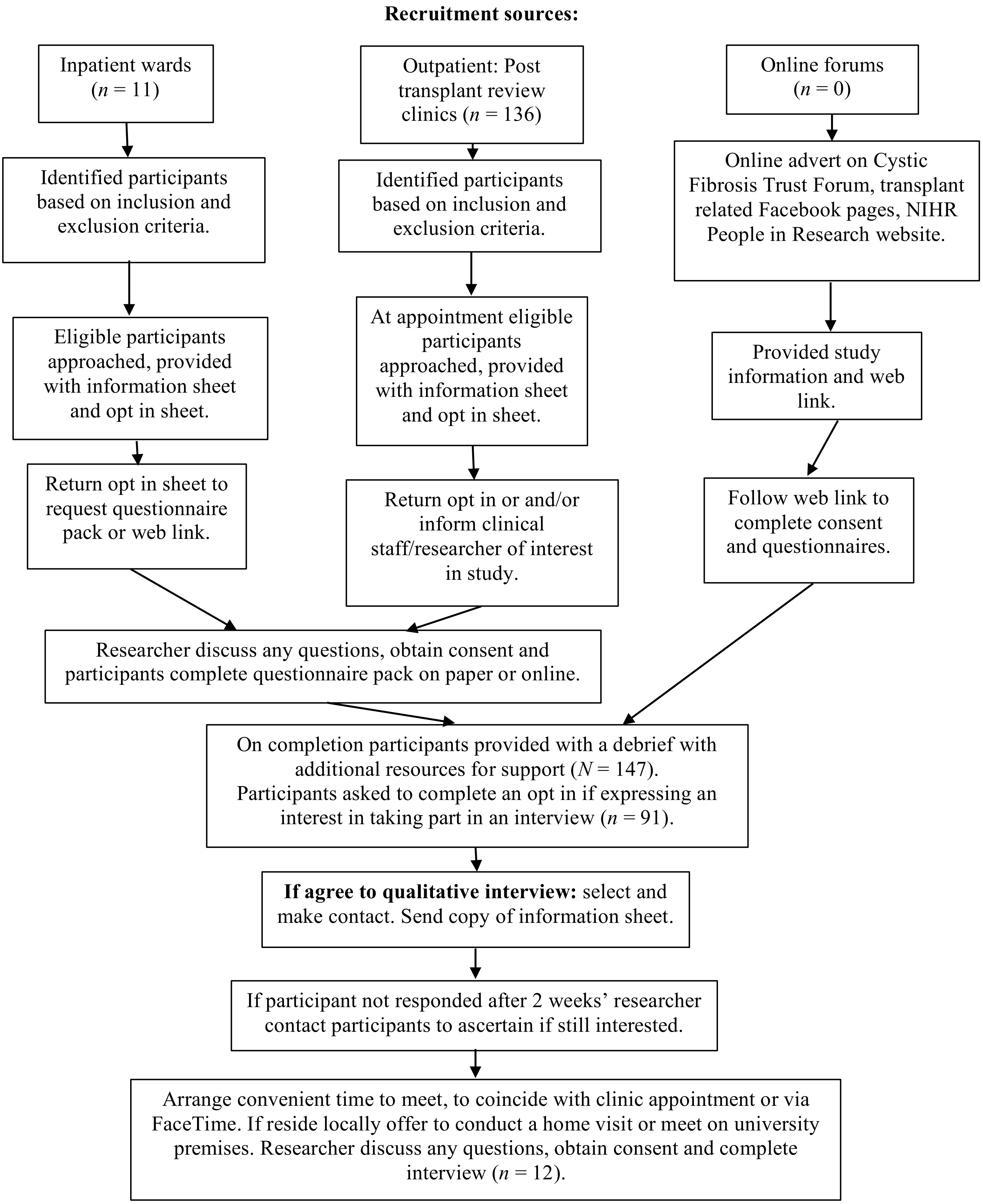

Figure 3. Recruitment process flow diagram

2.2.2 Design

The quantitative part of the study used a cross-sectional correlational design to establish the relationships between demographic, clinical and psychological variables, and their association with PTG. This part used a within-subjects design to examine the contribution of continuous predictor variables (time post-transplant, intrusive rumination, deliberate rumination, PTSD symptoms, distress, social support, and resilience) on a continuous outcome variable (PTG). Further analysis examined the mediating relationship of resilience between these predictors and PTG. The qualitative part of the study explored recipients' experiences of the transplant process in more detail. The aim was to enhance the quantitative findings by exploring recipients' experiences of transplant and to explore whether in-depth data obtained with this method could further explicate the observed relationships in the quantitative study, or the opposite and challenge the findings.

2.2.3 Measures

Measures of growth and resilience.

The **Post Traumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996)** assesses positive change following major life crises or traumatic events. This 21-item multi-dimensional scale is divided into five subscales: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life. Each item is rated on a 6-point scale ranging from 0 to 5, 'I did not experience this change as a result of my crisis' and 'I experienced this change to a very great degree' respectively. Total scores could range from 0 to 105. In the current study, participants reported on the degree of change experienced following their lung transplant. Internal consistency of the total score was excellent ($\alpha = .94$) and the subscales ranged from acceptable to excellent ($\alpha = .72$ to $.90$) in this sample.

The **Connor-Davidson Resilience Scale (CD-RISC-25; Connor & Davidson, 2003)** was used to measure resilience. The CDRISC consists of 25 items, rated on a 5-point scale ranging from 0 to 4 ('Not true at all' to 'True nearly all of the time' respectively) based on how an individual has felt over the last month. Higher scores illustrate more resilience and could range from 0 to 100. In the current study, internal consistency was excellent ($\alpha = .92$).

Measure of cognitive processing.

The **Event Related Rumination Inventory (ERRI; Cann et al., 2011)** consists of two subscales each containing ten statements relating to intrusive or deliberate rumination. Participants reported on whether they had particular thoughts without wanting them or deliberately spent time thinking about their transplant experience. Items are rated on a 4-point Likert scale ranging from 0 to 3 ('Not at all' to 'Often' respectively). Higher scores suggest more rumination and then averaged, so could range from 0 to 3. Both intrusive and deliberate rumination subscales have excellent internal consistency in the current study, with Cronbach's alphas of .94 to .91 respectively.

Measures of distress.

The **Impact of Events Scale-Revised (IES-R; Weiss, 2007)** is a 22-item scale where participants rate the frequency and distress of intrusive, avoidant and hyperarousal symptoms characteristic of PTSD symptoms over the last seven days.[1] Participants completed the IES-R in relation to their lung transplant. Items are rated on a 5-point scale ranging from 0 to 4 ('Not at all' to 'Extremely' respectively). The IES produces a total score and three subscales: intrusions, avoidance and hyperarousal. Higher scores are associated with more PTSD symptoms and higher levels of distress. Clinical cut off for a probable PTSD diagnosis is scores of 33 and above (Creamer, Bell & Falilla, 2002). In the current study this measure had good to excellent internal consistency for total scores (α = .94), and the intrusions (α = .87), avoidance (α = .88) and hyperarousal (α = .83) subscales.

The **Depression, Anxiety and Stress Scale-21 Items (DASS-21; Lovibond & Lovibond, 1995)** is a 21-item self-report scale measuring depression, anxiety and stress (DAS) during the previous week. Items are rated on a 4-point scale ranging from 0 to 3 ('Did not apply to me at all' to 'Applied to me very much or most of the time' respectively). Higher scores are suggestive of higher levels of distress and subscale scores were calculated for depression, anxiety and stress. Internal consistencies for the total scores (α = .94) and DASS-21 subscales for the current study were good to excellent (α =.89 to .92).

Measure of social support.

The **Multi-Dimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)** is a 12-item measure that examines perceived emotional and instrumental social support from family, friends and significant others. Participants rated items on a 7-point Likert scale, ranging from 1 (very strongly disagree) to 7 (very strongly agree). Higher scores suggest higher levels of perceived support. The MSPSS is divided into subscales for family, friends and significant others. In this sample, internal consistencies were excellent with Cronbach's alpha for total scores and subscales ranging from .91 to .96.

Demographic Information (Appendix G) included gender, age, education, relationship status, employment status, ethnicity, time on transplant waiting list, time since transplant, type of transplant, primary medical condition for which transplant was required, height, weight, and current percentage FEV1 lung function.

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[1] Note. This is based on Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for PTSD rather than DSM-5.

2.2.4 Procedure

Participants were recruited from inpatient and post-transplant review clinics. Clinical staff identified potential participants through a computerised search of patient medical records. They then approached participants and provided them with an information (Appendix H) and opt in sheet (Appendix I). Willing participants informed clinic staff or the researcher of their interest in the study. The researcher then met with participants to verbally explain the study, complete the consent process (Appendix J) and provided them with a paper copy of the questionnaire pack to complete in a quiet area. Completion of the questionnaire pack took approximately 35 minutes and if required participants could return the questionnaire pack to the researcher in a pre-paid envelope. If participants required additional support due to visual or motor impairments the researcher read items (n = 2). Alternatively, participants were provided with the online link which directed them to the demographic questions and measures.

Participants completed an opt in sheet providing their contact details (Appendix L) if they were happy to be contacted about taking part in the qualitative interview. Participants were provided with a debrief sheet (Appendix K) and could raise any questions or concerns with the researcher.

If participants were distressed after completing the questionnaires or if they scored above the clinical cut off on the IES-R (scores of 33 or above) or in the moderate range on the DASS-21, they were offered the opportunity to discuss their concerns with a member of the clinical psychology team at the research site.

Semi-structured interview.

A sub-group of 12 participants took part in the interview and were contacted via their preferred mode of contact. Participants were sent the interview information sheet (Appendix M). If participants had not made contact after two weeks, they were contacted to ascertain whether they were still interested in taking part. Appointments were made at a mutually convenient time to either coincide with outpatient appointments or conducted via FaceTime. Once consent was obtained (Appendix N), participants took part in an audio-recorded, semi-structured interview (Appendix O for topic guide). Interviews focused on participants' transplant experiences, possible cognitive ruminations, self-perception and support from others. Participants were encouraged to reflect on the positives and challenges of having a transplant and further probing questions were asked to obtain additional information. Interviews ranged from 20 to 65 minutes in length and participants were debriefed accordingly (Appendix P). Participants were given a £20 Amazon voucher for their time and effort.

2.3 Results

2.3.1 Part 1: Quantitative Analysis

Quantitative data analysis used the Statistics Package for Social Scientists (SPSS; version 24.0) based on a probability value of $p < .05$ as the level of statistical significance. The PROCESS macro (Hayes, 2013) was used to conduct bootstrapped mediation analysis. Power analyses indicated that with nine predictors for multiple regression analyses a sample size of 122 would be adequate for a medium effect size (Green, 1991)[2]. A random selection of 10% of the data was double entered to check data entry. Initial data cleaning suggested that missing data was random and overall there was 0.21% missing data across measures. There were a total of 38 missing values, one participant did not complete 11 of the 12 items on the MSPSS and were removed from the bivariate and multivariate analysis. The remaining missing items were substituted with mean subscale scores. Four participants were excluded from bivariate and multivariate data analysis as the IES-R had not been completed in relation to their lung transplant.

The demographic information was collated and presented to provide percentages, means and standard deviations. Descriptive statistical analyses were conducted to examine distributions, and to highlight possible outliers and data entry errors. Most total scores and subscales were non-normally distributed and skewed. Transformations were computed, which slightly improved the distributions for some variables. However, based on recommended criteria bootstrapping was used (see Appendix Q for further details of data analysis).

Bivariate correlations of demographics (age, gender, BMI), clinical (time on transplant waiting list, time since transplant, lung function), and psychological variables (cognitive processing, distress, PTSD symptoms, social support, resilience) with PTG were analysed using Pearson's product-moment correlations. Hierarchical multiple regression was used to determine the predictive value of the variables with PTG. Test assumptions were met (Appendix Q). Mediational analysis was conducted to ascertain whether resilience mediates the relationships between the significant psychological predictors and PTG.

Demographics.

Overall, 147 participants were included in the data analyses. The sample consisted of 51.1% male and 44.9% female and the age range was from 18 to 72 (M = 47.84, SD = 15.18). Majority of participants were married (53.7%), White British (99.3%) and had obtained O levels,

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[2] This is based on Green's (1991) formula (N = 50 + 8k) for calculating multiple regression sample size as a minimum recommended sample size. This is assuming there is a medium effect size relationship between the variables and there are 9 predictors (time post-transplant, intrusive rumination, deliberate rumination, PTSD symptoms, anxiety, depression, stress, social support, resilience) which would require at least 122 participants.

GCSEs or equivalent level of educational attainment. Most participants had a bilateral lung transplant (90.5%) and the mean time since transplant was 46.56 months, ranging from 1.16 to 119.99 (*SD* = 30.80). See Table 7 for details.

Table 7

Demographic and Clinical Characteristics of Study Participants (N = 147)

Variable	*N*	%	*M (SD)*	Range
Gender				
Male	81	55.1		
Female	66	44.9		
Age			47.84 (15.18)	18-72
Education				
Less than high school degree	17	11.6		
O Levels, GCSEs (or equivalents)	38	25.9		
A Levels (or equivalents)	17	11.6		
Vocational training certificate(s)	27	18.4		
Bachelor's degree	16	10.9		
Master's degree	7	4.8		
Doctoral degree	1	0.7		
Higher professional qualifications	16	10.9		
Other	6	4.1		
Relationship status				
Married	79	53.7		
Widowed	0	0		
Single	34	23.1		
Divorced	15	10.2		
Civil partnership	3	2.0		
Co-habiting	15	10.2		
Employment status				
Employed	56	38.1		
Not employed	25	17.0		
Unable to work	31	21.1		
Retired	35	23.8		
Ethnicity				
White	146	99.3		
Other	1	0.7		
Time on lung transplant waiting list (days)			121.27 (91.67)	1.00-334.62
Time post lung transplant (months)			46.56 (30.80)	1.16-119.99
Type of lung transplant				
Unilateral (single) lung transplant	14	9.5		
Bilateral (double) lung transplant	133	90.5		
Primary medical condition				
Cystic Fibrosis (CF) and bronchiectasis	64	43.5		
Chronic Obstructive Pulmonary Disease (COPD) and emphysema	56	38.1		
Fibrosing lung disease	18	12.2		
Primary pulmonary hypertension	3	2.0		
Other	5	3.4		
BMI			24.58 (4.95)	15.94-38.42
Current FEV1 lung function			78.77 (19.86)	21.60-138

Note. BMI = body mass index. Given small sizes in Ethnicity variable other than White, this variable was excluded from further analyses. Missing data: Education = 1.4% (*N*=2), Relationship status = 0.7% (*N*=1), Primary medical conditions = 0.7% (*N*=1), BMI = 4.1% (*N*=6), Current FEV1 lung function 6.8% (*N*=10).

Descriptive statistics.

Table 8 presents the means, standard deviations and ranges for all questionnaire variables. The results support the hypothesis that transplant recipients experience similar levels of PTG to other health conditions, with an average PTG of 64.15 (*SD* = 24.31) post lung transplant. The new possibilities and appreciation of life subscales had the highest mean scores. Participants reported greater levels of deliberate rumination than intrusive rumination (*M* = 1.46, *SD* = .79 and *M* = 1.16, *SD* = .82 respectively). Overall, the measures of distress showed non-clinical levels of depression, anxiety, stress and PTSD. However, clinical cut-off criteria were examined based on individual scores of the DASS-21 and IES-R. For depression, anxiety and stress, 8 (5.44%), 10 (6.80%), and 4 (2.72%) participants respectively scored in the moderate range, and 2 (1.36%), 9 (6.12%), and 1 (0.68%) participants respectively scored in the severe to extremely severe range. Findings also showed that 16 (10.49%) participants scored in the clinical range for PTSD.

Table 8
Means, Standard Deviations and Range of Scores for Questionnaire Measures

Variable	*N*	*M*	*SD*	Actual range	Potential range
PTGI					
Total	147	64.15	24.31	1-105	0-105
Relating to others	147	3.04	1.37	0-5	0-5
New possibilities	147	3.24	1.29	0-5	0-5
Personal strength	147	2.49	1.18	0-4	0-5
Spiritual change	147	1.56	1.57	0-5	0-5
Appreciation of life	147	3.71	1.31	0-5	0-5
ERRI					
Intrusive	147	1.16	0.82	0-3	0-3
Deliberate	147	1.46	0.79	0-3	0-3
DASS-21					
Total	147	15.05	13.86	0-57	0-63
Depression	147	0.56	0.75	0-3	0-3
Anxiety	147	0.74	0.69	0-3	0-3
Stress	147	0.85	0.77	0-3	0-3
IES-R					
Total	143	14.08	15.55	0-75	0-88
Intrusion	143	0.73	0.75	0-3.5	0-4
Avoidance	143	0.58	0.76	0-4	0-4
Hyperarousal	143	0.59	0.79	0-3.3	0-4
MSPSS					
Total	146	70.21	13.86	23-84	1-84
Family	146	5.89	1.42	1-7	1-7
Friends	146	5.60	1.51	1-7	1-7
Significant other	146	6.07	1.54	1-7	1-7
CDRISC	147	74.85	14.51	26-100	0-100

Relation of demographic and clinical variables to PTG.

Bivariate Pearson's correlations were used to assess the association between demographic and clinical variables with PTG. Table 9 shows that there were no significant correlations between age, gender, time on waiting list, time post-transplant, lung function and BMI with PTG. Unsurprisingly, age and BMI are significantly correlated with each other.

Table 9

Bivariate Correlations (Pearson's r) between Demographic and Clinical Variables to PTG

Variable	*1*	*2*	*3*	*4*	*5*	*6*	*7*
1. PTG	-						
2. Gender	-.19	-					
3. Age	.03	.04	-				
4. Time on waiting list	.04	-.10	.04	-			
5. Time post-transplant	.05	.02	.02	-.10	-		
6. Lung function	.14	-.11	.03	-.04	-.05	-	
7. BMI	.16	-.01	.49*	.02	.07	.03	-

Note. PTG = posttraumatic growth, BMI = body mass index, * $p < .05$.

Relation of psychological variables to PTG.

Bivariate Pearson's correlations assessed the association between the psychological variables (cognitive processing, distress, PTSD symptoms, social support and resilience) with PTG. Table 10 shows the correlations between the two cognitive processes hypothesised to influence PTG in the FD model. Intrusive and deliberate rumination were significantly correlated with each other. Intrusive rumination was significantly correlated with PTG and social support, and unsurprisingly, correlated with intrusive PTSD symptoms. Consistent with the model, deliberate rumination was more highly correlated with PTG than intrusive rumination. These correlations with PTG are significantly different, $Z = -2.04$, $p < .05$. Deliberate rumination was also positively correlated with all of the symptomatic measures but was not associated with social support. Furthermore, PTSD intrusions were significantly correlated with PTG. Social support, specifically friends and significant others were also significantly associated with PTG. However, there are no significant correlations with any of the symptomatic measures/family social support and PTG. Resilience was significantly correlated with all measures, except for deliberate rumination. In summary, from the relationships of interest, higher levels of deliberate rumination, PTSD intrusions, social support (specifically friends and significant others), and resilience were significantly associated with higher levels of PTG.

Table 10

Bivariate Correlations between Psychological Variables and PTG

Variables	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*14*	*15*	*16*
1. PTG	-															
2. Intrusive rumination	.28***	-														
3. Deliberate rumination	.41***	.67***	-													
4. Distress	.04	.42***	.34***	-												
5. Depression	.00	.33***	.20**	.91***	-											
6. Anxiety	.04	.41***	.34***	.89***	.74***	-										
7. Stress	.08	.38***	.36***	.89***	.70***	.69***	-									
8. PTSD symptoms	.15	.49***	.43***	.62***	.46***	.61***	.60***	-								
9. Intrusions	.17*	.53***	.48***	.54***	.38***	.55***	.52***	.93***	-							
10. Avoidance	.13	.39***	.33***	.50***	.36***	.49***	.51***	.93***	.80***	-						
11. Hyper-arousal	.12	.43***	.36***	.70***	.57***	.66***	.67***	.90***	.76***	.76***	-					
12. Social support	.32***	.02	.14	-.28***	-.31***	-.20*	-.25**	-.26**	-.17*	-.21**	-.35***	-				
13. Family	.16	.00	.07	-.25**	-.26**	-.18*	-.23**	-.26**	-.17*	-.22**	-.34***	.81***	-			
14. Friends	.33***	-.11	.09	-.32***	-.35***	-.26**	-.24**	-.22**	-.16	-.16	-.31***	.75***	.44***	-		
15. Significant others	.25**	.15	.16	-.10	-.13	-.02	-.11	-.12	-.05	-.12	-.18*	.77***	.46***	.32***	-	
16. Resilience	.23**	-.27*	-.13	-.44***	-.48***	-.33***	-.36***	-.32***	-.30***	-.24**	-.35***	.45***	.34***	.43***	.27***	-

Note. * $p < .05$, ** $p < .01$, *** $p < .001$.

Regression analysis of PTG.

The observed correlations were consistent with the FD model, and to explore the relationships further multiple regression was used to ascertain which predictors explain the most variance using the enter method. Variables were included in the model if they were related to PTG at $p = .05$ level. Table 11 shows that the overall model was significant, Total $R^2 = .24$, F (3, 138) = 14.66, $p < .001$***: higher levels of deliberate rumination and social support were associated with more PTG. The overall model accounted for 24% of the variance in PTG with a large effect size.

Table 11

Multiple Regression for Predictive Variables with PTG (N = 142)

Variable	*B*	*SE B*	*ß*	95%BCa CI
Constant	14.22	12.71		[-9.62, 37.14]
Intrusive rumination	1.40	3.56	.05	[-6.31, 7.98]
Deliberate rumination	10.57	4.01	.34***	[2.32, 18.85]
Social support	0.47	0.17	.27***	[0.13, 0.85]

Note. Confidence intervals and standard errors based on 1000 bootstrap samples. Total $R^2 = .24$, F (3, 138) = 14.66, $p < .001$***. BCa CI = Bootstrapped confidence interval, * $p < .05$, ** $p < .01$ ***, $p < .001$.

The FD model (Tedeschi & Calhoun, 1996) suggests that PTG occurs in stages. To explore this prediction the variables were entered in the hierarchical multiple regression in blocks. Table 12 shows that each model was significant. Intrusive and deliberate rumination accounted for 17% of the variance in PTG and higher levels of deliberate rumination were associated with higher levels of PTG. Social support also accounted for 24% of the variance in PTG, with higher levels of social support associated with higher levels of PTG. Resilience was entered to ascertain the predictive value to PTG. The overall model was significant, F (4,137) = 13.15, $p < .01$**, and accounted for 28% of the variance in PTG with a large effect size. Higher levels of resilience were associated with higher levels of PTG, whilst controlling for the other variables and higher levels of social support and deliberate rumination also significantly predicted a higher level of PTG.

Table 12

Hierarchical Multiple Regression for Predictive Psychological Variables with PTG (N = 142)

Predictor	*B*	*SE B*	*ß*	95%BCa CI
Step 1				
Constant	45.84	4.56		[36.84, 56.61]
Intrusive rumination	0.33	3.54	.01	[-6.80, 7.07]
Deliberate rumination	12.43	3.81	.41***	[5.66, 21.14]
R^2	.17			
F	14.25***			
Step 2				
Constant	14.22	12.43		[-8.99, 36.69]
Intrusive rumination	1.40	3.51	.05	[-5.77, 8.54]
Deliberate rumination	10.57	3.86	.34**	[3.09, 18.73]
Social support	0.47	0.17	.27***	[0.13, 0.84]
Total R^2	.24			
F	14.66***			
ΔR^2	.07***			
ΔF	13.01			
Step 3				
Constant	-3.86	12.49		[-28.39, 19.42]
Intrusive deliberation	3.06	3.38	.10	[-3.82, 9.69]
Deliberate rumination	10.74	3.81	.35	[3.53, 18.58]
Social support	0.30	0.19	.17	[-0.06, 0.69]
Resilience	0.38	0.14	.22	[0.11, 0.64]
Total R^2	.28			
F	13.15			
ΔR^2	.04***			
ΔF	6.78			

Note. Confidence intervals and standard errors based on 1000 bootstrap samples. Total R^2 = .28; Step 1: R^2 = .17, F (2,139) = 14.25, $p < .001$***, Step 2: R^2 = .24, F (3,138) = 14.66, $p < .001$***, R^2 change = .07, p = <.001***, Step 3: R^2 = .28, F (4,137) = 13.15, $p < .01$**, R^2 change = .04, $p < .001$***. BCa CI = Bootstrapped confidence interval, ** $p < .01$ *** $p < .001$.

Finally, hierarchical multiple regression examined whether the significant psychological subscale variables (intrusions, friends and significant others) predicted PTG. Table 13 shows that each model was significant. Similar to previous analyses, intrusive and deliberate rumination accounted for 17% of the variance in PTG and higher levels of deliberate rumination were associated with higher levels of PTG. Intrusions also accounted for 17% of the variance in PTG when added in a second block and these variables did not significantly predict PTG (p = .59). Social support from friends, and significant others accounted for 27% of the variance in PTG. Higher levels of friend support were associated with higher levels of PTG. The overall model was significant, F (6,135) = 9.61, $p < .001$***, accounting for 30% of the variance in PTG with a large effect size. Higher levels of resilience were associated with higher levels of PTG, whilst controlling for the other variables, and higher levels of friends support and deliberate rumination continued to significantly predict higher levels of PTG.

Table 13

Hierarchical Multiple Regression for Predictive Subscale Variables with PTG (N = 142)

Predictor	*B*	*SE B*	*ß*	95%BCa CI	R^2	*F*	ΔR^2	ΔF
Step 1					.17	14.25***		
Constant	45.84	4.73		[37.33, 55.21]				
Intrusive rumination	0.33	3.58	.01	[-7.08, 7.06]				
Deliberate rumination	12.43	3.95	.41***	[4.79, 21.37]				
Step 2					.17	9.55***	.00	0.29
Constant	45.84	4.75		[37.26, 55.16]				
Intrusive rumination	0.90	3.57	.03	[-6.42, 7.39]				
Deliberate rumination	12.78	4.15	.42***	[4.69, 22.37]				
Intrusions	-1.63	2.52	-.05	[-6.44, 3.08]				
Step 3					.27	10.04***	.10**	9.10
Constant	12.32	10.89		[-8.03, 33.01]				
Intrusive rumination	2.33	3.51	.08	[-5.52, 9.43]				
Deliberate rumination	9.35	4.13	.31**	[0.81, 19.24]				
Intrusions	0.92	2.59	.03	[-4.04, 5.60]				
Friends	4.45	1.35	.28***	[1.68, 7.05]				
Significant others	1.67	1.12	.11	[-0.49, 4.08]				
Step 4					.30	9.61***	.03*	5.70
Constant	-5.86	12.03		[-28.89, 16.18]				
Intrusive rumination	3.36	3.48	.11	[-3.85, 10.31]				
Deliberate rumination	9.40	4.14	.31**	[1.41, 18.81]				
Intrusions	1.85	2.59	.06	[-2.82, 6.66]				
Friends	3.38	1.42	.21**	[0.59, 6.00]				
Significant others	1.06	1.16	.07	[-1.31, 3.67]				
Resilience	0.35	0.15	.20*	[0.07, 0.66]				

Note. Confidence intervals and standard errors based on 1000 bootstrap samples. Total R^2 = .30; Step 1: R^2 = .17, F (2,139) = 14.25, $p < .001$***, Step 2: R^2 = .17, F (3,138) = 9.55, $p < .001$***, R^2 change = .00, $p = .59$, Step 3: R^2 = .27, F (5,136) = 10.04, $p < .001$***, R^2 change = .10, $p < .001$***, Step 4: R^2 = .30, F (6,135) = 9.61, $p < .001$***, R^2 change = .03, $p < .001$*** . BCa CI = Bootstrapped confidence interval, * $p < .05$, ** $p < .01$ *** $p < .001$.

Mediation analysis.

The results illustrated that resilience is a significant predictor of PTG and it was important to ascertain whether resilience helps explain the relationships between the significantly associated psychological variables and PTG in the FD model. Mediation analysis was conducted using the PROCESS method (Hayes, 2013) to examine whether resilience mediated the relationship between deliberate rumination/social support and PTG.

Resilience as a mediator in the relationship between deliberate rumination and PTG.

Simple mediation analysis using ordinary least squares path analysis examined whether resilience mediated the effect of deliberate rumination on PTG. Figure 4 shows that deliberate rumination does not indirectly affect the level of PTG through resilience, *b* = -.93, bootstrapped SE = .75, BCa 95% CI [-3.06, 0.07]. Experience of deliberate rumination was not related to resilience but resilient participants were more likely to experience PTG. Overall, there was no evidence that deliberate rumination influenced the level of PTG independent of its effect on resilience.

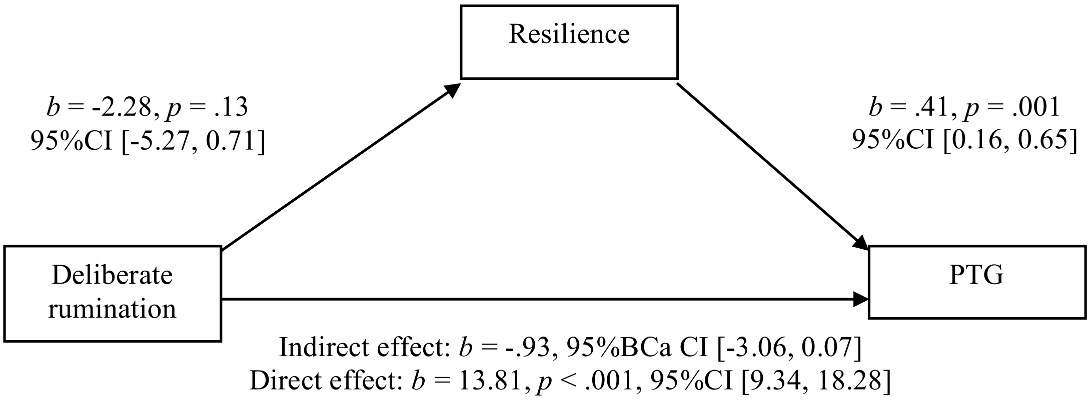


Figure 4. Simple mediational model for the role of resilience on deliberate rumination and PTG.

Resilience as a mediator in the relationship between social support and PTG.

Simple mediation analysis using ordinary least squares path analysis considered whether resilience mediated the effect of social support on PTG. Figure 5 shows social support did not significantly indirectly affect the level of PTG through resilience, *b* = .06, bootstrapped SE = .07, BCa 95% CI [-0.07, 0.24]. Experiencing more social support made participants more likely to be resilient but more resilient participants were not related to experiencing PTG. Overall, there was no evidence that social support influenced the level of PTG independent of its effect on resilience.

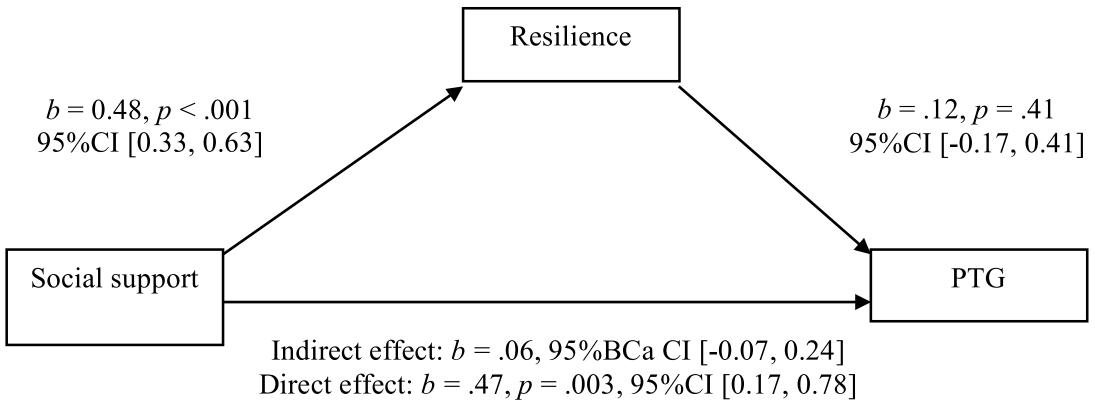


Figure 5. Simple mediational model for the role of resilience on social support and PTG.

2.3.2 Part 2: Qualitative Analysis

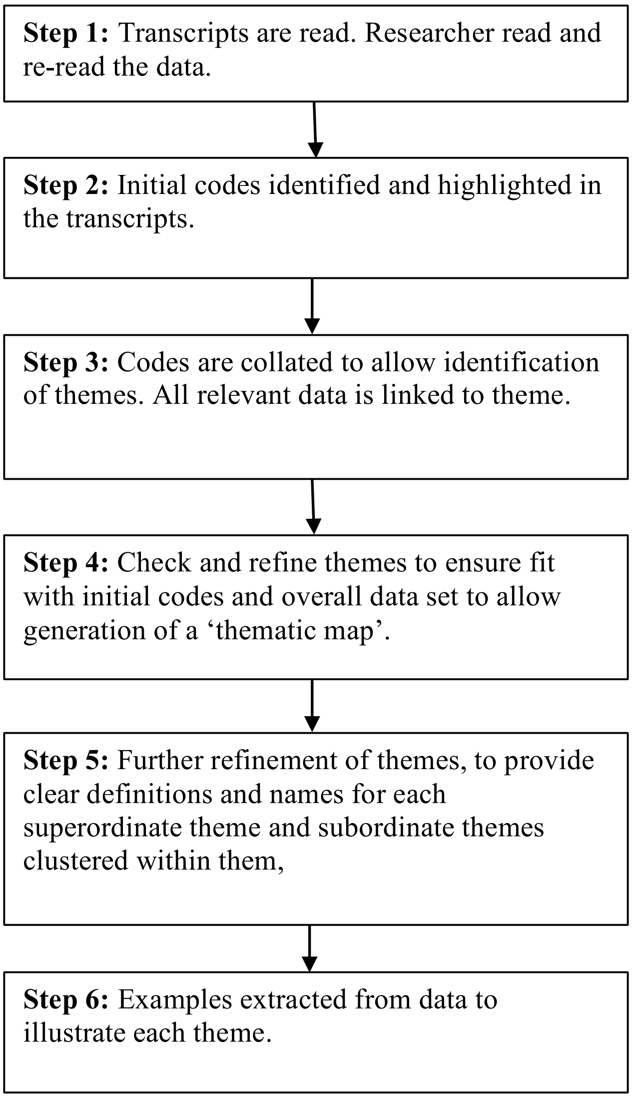
The qualitative component facilitated understanding of the processes that occur along the transplant journey and ensured the themes were grounded in the data. A critical realist epistemological perspective was taken by the researcher (Barker, Pistrang, & Elliott, 2002). This approach suggests that the world is perceived based on individuals' knowledge, beliefs, expectations and context, and it is difficult to obtain absolute truth (Bunge, 1993). Therefore, recipients' responses were examined in their own language, exploration of accounts, and themes emerged from the data.

Coding.

Qualitative analysis explored 12 participants' personal experiences post-transplant and the process of PTG in more detail. Interviews were transcribed and analysed using Braun and Clarke's (2006) six phases to thematic analysis, which is represented in Figure 6. Following immersion and familiarisation of the data, NVivo 10 was used to generate and identify codes and themes. This was a data-driven and inductive process that was conducted with the research question in mind. This approach was applied to other transcripts to ensure the meaning of the data was embedded in the themes (see Appendix R for a sample analysed transcript). A thematic map was developed to capture the story and identify patterns in the data across transcripts. This process enabled superordinate and subordinate themes to emerge as saturation was obtained from the data. Finally, key examples were extracted and documented to reflect the research question (Braun & Clarke, 2006).

Inter-Rater Agreement for Coding.

Three researchers carried out the analysis separately: one was the main author, and the other two researchers were both experienced clinical psychologists working in health, who had proficiency in qualitative research. This process enhanced the credibility and interpretation of the data analysis to ensure that multiple valid perspectives were used to understand individuals' experiences and perspectives (Barker et al., 2002). The researchers maintained close communication to clarify themes and collaboratively agreed on the included themes within the findings. The main author coded all 12 transcripts, and six were coded by a second researcher to establish inter-rater reliability, and there was an overall mean percentage agreement of 90% (range 72-100).



Step 1: Transcripts are read. Researcher read and re-read the data.

Step 2: Initial codes identified and highlighted in the transcripts.

Step 3: Codes are collated to allow identification of themes. All relevant data is linked to theme.

Step 4: Check and refine themes to ensure fit with initial codes and overall data set to allow generation of a ‘thematic map’.

Step 5: Further refinement of themes, to provide clear definitions and names for each superordinate theme and subordinate themes clustered within them,

Step 6: Examples extracted from data to illustrate each theme.

Figure 6. Steps involved in thematic analysis (Braun & Clarke, 2006)

Demographics.

Overall, 12 participants completed the interviews. To ensure anonymity, names have been modified. Participants were interviewed at various places including the hospital clinic (50%), via FaceTime or at home. Table 14 shows participant demographics and illustrates the sample consisted of 58% female and 42% male, and the age range was from 28 to 69 (*M* = 46.83, *SD* = 15.64). The majority of participants were married (41.7%) and employed (58.3%). Most participants had had a bilateral lung transplant (91.7%), the mean time on the transplant waiting list was 8.51 months, ranging from 0.03 to 36 (*SD* = 9.75), and the mean time post-transplant was 30 months, ranging from 8 to 76 (*SD* = 19.50).

Table 14

Participant Demographics

Participant	Age	Relationship status	Employment status	Months on transplant waiting list	Months post-transplant	Type of transplant	Medical condition
Mr A	65	Married	Retired	3	38	Bilateral	COPD
Mr B	63	Co-habiting	Unable to work	36	40	Bilateral	COPD
Mrs C	57	Divorced	Employed	7	19	Bilateral	COPD
Mr D	46	Co-habiting	Not employed	2	15	Bilateral	CF
Mr E	36	Married	Employed	6	76	Bilateral	CF
Mr F	62	Married	Unable to work	6	8	Single	Fibrosing lung disease
Ms G	30	Single	Employed	8	22	Bilateral	CF
Mrs H	44	Divorced	Employed	0.03	38	Bilateral	Primary pulmonary hypertension
Ms I	28	Single	Employed	4	50	Bilateral	CF
Mrs J	69	Married	Retired	8	25	Bilateral	COPD
Mr K	33	Single	Employed	18	19	Bilateral	CF
Mrs L	29	Married	Employed	4	10	Bilateral	CF

Note. CF = Cystic Fibrosis, COPD = Chronic Obstructive Pulmonary Disease

Organisation of themes.

Analysis revealed 15 subordinate themes, grouped into five overarching superordinate themes. Figure 7 presents a thematic map of these relationships and is described in detail within the coding manual (see Appendix S). The themes included window of opportunity; overcoming psychological and physical barriers; steps towards rebuilding life; looking beyond transplant; and the support network. Table 15 presents the frequency of themes across the data. The following section explores these themes in more detail, supported with participant quotes to ensure grounding in the data and to aid reader understanding (Corden & Sainsbury, 2006).

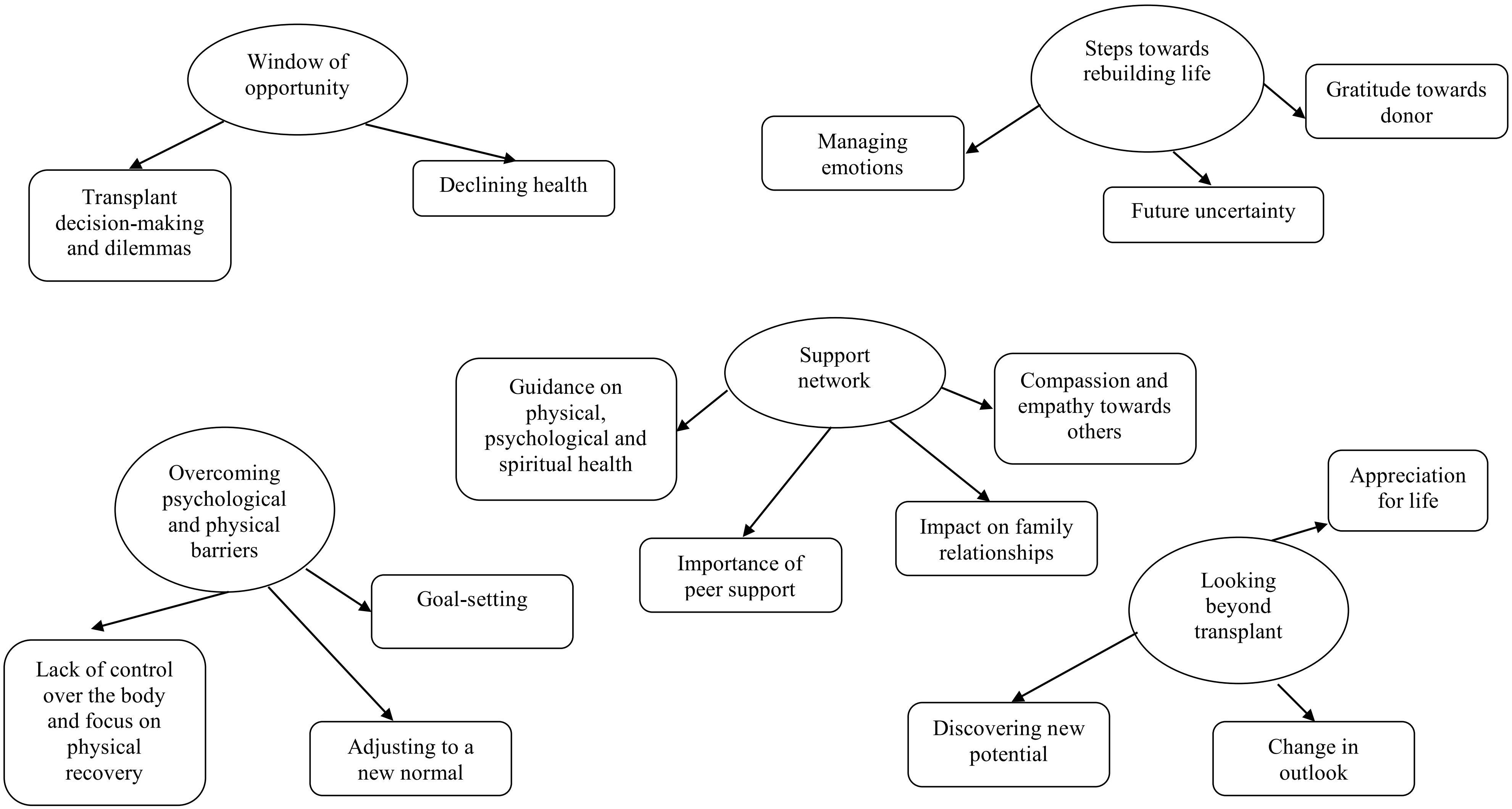


Figure 7. Thematic map of participants experiences of receiving a lung transplant.

Table 15

Frequency of Subordinate Themes for Each Participant.

Subordinate theme	Mr A	Mr B	Mrs C	Mr D	Mr E	Mr F	Ms G	Mrs H	Ms I	Mrs J	Mr K	Mrs L	*N*
Transplant decision-making and dilemmas	✓		✓				✓	✓				✓	5
Declining health	✓	✓	✓	✓	✓	✓			✓	✓	✓		9
Lack of control over the body and focus on physical recovery	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		11
Adjusting to a new normal			✓	✓	✓	✓	✓		✓			✓	7
Goal-setting	✓		✓	✓	✓		✓	✓	✓	✓	✓		9
Managing emotions			✓	✓	✓	✓	✓		✓	✓	✓	✓	9
Uncertainty about future	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	11
Gratitude towards donor	✓		✓	✓	✓		✓	✓				✓	7
Discovering new potential	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	11
Change in outlook	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	11
Appreciation for life	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
Guidance on physical, psychological and spiritual health	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	11
Importance of peer support	✓	✓		✓	✓	✓	✓	✓	✓			✓	9
Impact on family relationships	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	11
Compassion and empathy towards others	✓	✓		✓	✓		✓	✓	✓	✓			8

Note. All names have been changed to protect the anonymity of participants.

Transplant journey.

Across the transplant journey, coping was paramount at each stage of treatment and recovery. Participants appeared to experience loss, and were required to adapt and accept their changing health needs. Some themes were relevant at different times and experiences of coping varied between participants. For example, initially participants were focused on physical recovery and adjusting to their new normal, moving into future uncertainty about their health, and then appraising life differently. Figure 8 provides a diagrammatic illustration of the themes occurring across a timeline. There was some overlap of themes across the timeline; however, this represented a typical path across participants.

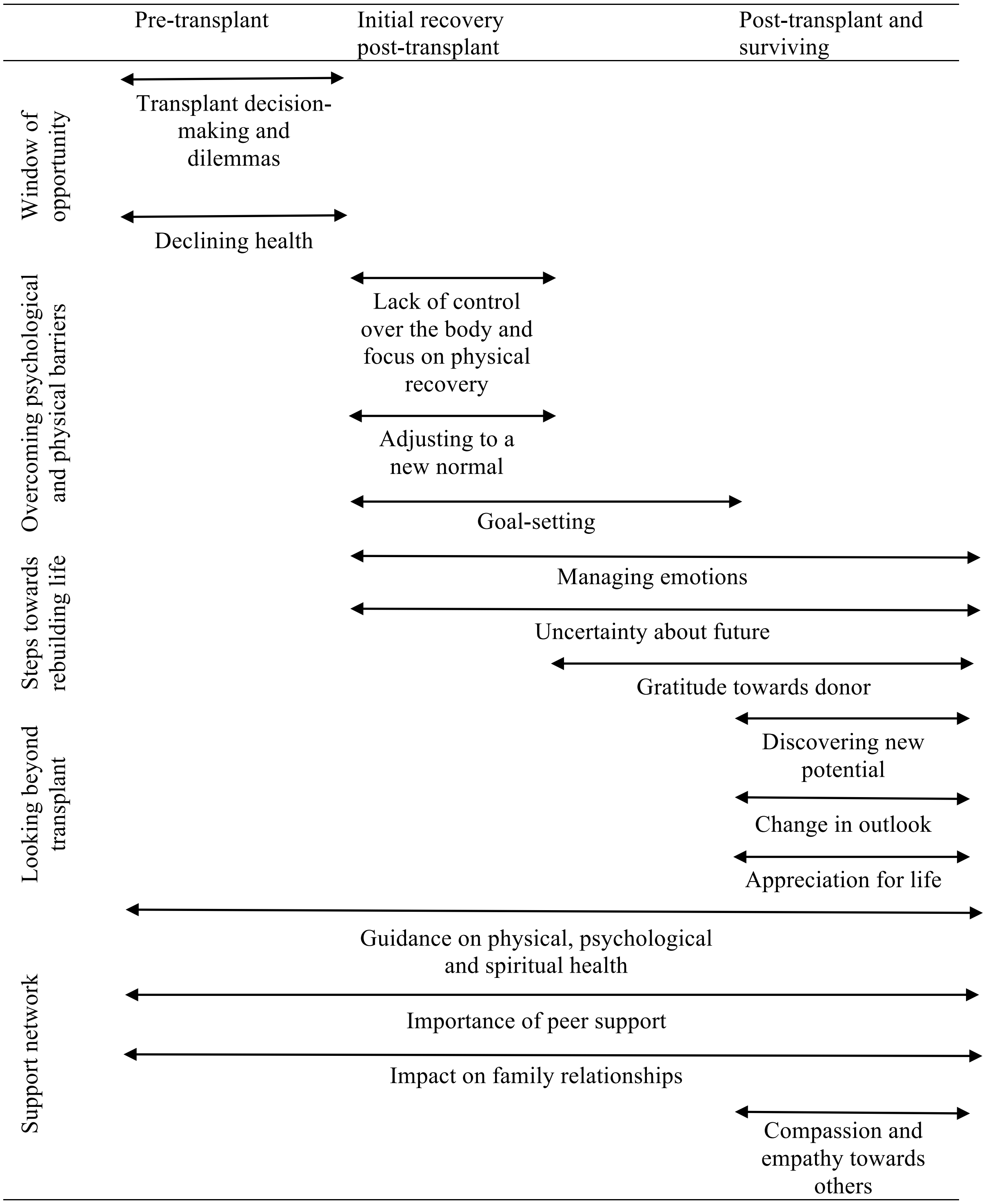


Figure 8. Superordinate and subordinate themes organised across a timeline

Window of opportunity.

Participants highlighted the limited time available to receive a transplant which was influenced by changing health needs and donor availability. While loss of functioning can be gradual, participants were faced with difficult realities about their health: “if you are considering transplant… as a possibility. You should be jumping now because you are getting to the end of the window, you’re not at the beginning of the window, you’re at the end” (Mr A). This was captured by the themes: transplant decision-making and dilemmas, and declining health.

Transplant decision-making and dilemmas.

Prior to transplant, recipients either expressed anxiety or confidence about proceeding with transplant. Feeling of confidence helped them cope with living and dying. The following quotes represent the different experiences of clients such as coping with fear:

> I suppose it was quite a shock when I got told I needed a transplant because I had always been quite healthy. And then literally I just spiralled. In about 2 months I was just really unwell. ...So initially I didn’t really want a transplant. I think the whole idea of it was just a bit scary and something I hadn’t really thought that much about. I knew that lots of people with cystic fibrosis had lung transplants but because I had always been healthy, I’d always been, oh that’s not me. (Mrs L)

> It’s the knowledge of the risk, you know, you lie in bed, the anaesthetist comes up and you sign a piece of paper where one of the possible outcomes are death, d-e-a-t-h. It’s there on the form. And you sign it. And although I’m a religious person, I didn’t want to die. So that was sobering to say the least. (Mr A)

These participants highlighted their rapid loss of function, a degree of denial about needing a transplant, and being faced with the risks associated with major surgery.

In contrast, other participants expressed self-assurance about going forwards: “transplant was my only option, it was no-brainer. I knew I had a limited lifespan but no one could tell me how long I had. And this was my only hope.” (Mrs H) and:

> If you had told me I need the transplant I didn’t really have any kind of - oh do I do it, do I not. My, it was an immediate right I need it. No question about it for me…I wasn’t scared before my transplant at all. It was more excitement because that was the one chance I had at getting the one thing I wanted most. (Ms G)

These quotes also highlight participants desire for a transplant and desperation for a future.

Declining health.

The majority of participants highlighted a deterioration in lung function, an awareness that time was running out, and the impact this deterioration was having on their daily lives, "I just saw my results dropping, year on year" (Mr K), "By 2012 and actually well before that I was down to below 20% and at below 20% you're in trouble and probably on oxygen" (Mr A) and "12 months prior to transplant my health went downhill very quickly; 24-hour oxygen, limited mobility, quite a few hours every day of percussive physiotherapy to clear my chest. Very draining physically, quite draining mentally" (Mr D).

Participants shared the impact on their physical functioning and mental well-being:

> I was on oxygen. It took everything out of me to move from the lounge to the bathroom. I couldn't make it to the end of the drive. I had to have somebody in to clean. We had to have convenience foods, I couldn't cook. Life wasn't easy, it was hard for my husband. (Mrs J)

> I was down to my very last 330ml which isn't a lot. It makes everything that you try and do, it even makes the simplest of tasks – making a cup of tea, putting your shoes on, tying your shoe laces, getting out of bed, having a shower - exhausting, frustrating. And actually yeah quite down-hearted at times ... I had some very, very dark days in the days before my transplant. (Mr E)

These examples illustrate the degree of pressure and stress participants were feeling during this time, as well as another consequence - losing their sense of self: "I didn't know who I was anymore, I'd just knew I was ill, had CF and that was pretty much what it was" (Ms I).

Nevertheless, participants used strategies to manage the emotional turmoil and the reality they were facing:

> I think the month before I kind of lost hope that it was gonna happen and I had gotten so poorly where I kind of thought – well this is it. ...I just remember being really calm but I think it was more because I was really numb and just shocked and didn't really know how to react to be honest. And I thought – well, just stay calm, was my reaction and I did. (Ms I)

Overcoming psychological and physical barriers.

Post surgery transplant recipients referred to overcoming numerous hurdles and managing the uncertain outcome:

> Will I wake up from the operation?. A best friend of mine didn't; couldn't restart the heart. So you've got all the way from there to, another friend of mine is pushing 20 years post-transplant. So there's, there's the book ends as it were of what could happen. So I knew I'd be clearly in that window somewhere. (Mr D)

Subordinate themes (described below) that emerged were lack of control over the body and a focus on physical recovery, adjusting to a new normal, and goal-setting.

Lack of control over the body and focus on physical recovery.

Participants expressed their distress and described struggling to cope with physical restrictions post surgery, which, for some, created dilemmas about their to desire keep fighting: "And, just thinking, I've had enough of all this….And I felt trapped in the physical, and I was physically trapped, it wasn't just the psychological feeling" (Mr A) and "It was so painful. And there were points where I was going, I can't put up with this anymore" (Mrs C).

Participants highlighted that the realities of having a transplant were not all positive, instead they felt fearful and powerless, and needed to overcome feelings of helplessness:

> It's not like a little fairy tale. It's not nice. It's painful. It's emotional. It's hard. I had bowel problems, you know, you're covered in drains which are just full of blood and you just that's scary enough. You wake up and you see these buckets underneath you and you're just like - Oh. (Ms I)

Moreover, these difficulties were precipitated by struggling to communicate with staff:

> When I woke up I discovered that I couldn't talk or walk. The only think I could do was open my eyes, I couldn't even move my finger. And because I had a trachy in I I couldn't ask them what was going on. So it was quite scary. (Mrs H)

Numerous participants reported needing time and motivation to engage in recovery to help them gain physical strength: "I just thought to myself, well it's gonna take time, it a big shock to your system. So it's going to take time now to recover but fortunately I were very patient and I knew it wasn't going to happen overnight" (Mr B) and "You know you take small steps…if you're going to come through, you've got to put your heart into it" (Mr F) and "So it was an element of, you need to get fit again, retrain your muscles, build your muscles up after months and months in a hospital bed. Doing nothing" (Mr E).

Other participants highlighted the need for support from staff to engage in recovery: “if they hadn’t pushed and pushed, I wouldn’t of done anything” (Mrs J).

These examples highlight recipients’ self-determination and the importance of relearning lost skills. However, some participants expressed frustration about their limitations and being faced with further difficulties: “I didn’t really have a lot of mobility after transplant. So it was just swapping one set of restrictions for another” (Mr K).

Adjusting to a new normal.

An important adjustment for participants post-transplant was breathing without difficulties and the realisation that they had received new lungs which transformed their life:

> The hours go by and the days go by and you start being able to, you’re less uncomfortable so you can take deeper breaths, you go – this is brilliant! You know, I can you’re almost like – look! Watch me breathe! (Mr E)

Furthermore:

> The first time I went out I took a breath on my own, in the wind and it was like, “Wow! I can breathe air!” And it didn’t matter what temperature it was. It didn’t matter whether the sun was out. It didn’t matter whether it was raining, as long as I could breathe air with a pair of lungs that actually worked. And that was that was a big gobsmack. (Mrs C)

These examples illustrated participants sense of achievement in completing everyday tasks. Participants also reflected on the changes experienced pre- and post-transplant. This highlighted the impact on mental well-being and the importance of adapting to these new opportunities:

> I just couldn’t get enough air into my lungs. And when you can’t get enough air in, it doesn’t matter how much will you’ve got, you cannot achieve the most simplest things. The transplant came along and it was almost like overnight, you’re given this brand new opportunity and you take a long time to adjust from the physical recuperation but actually there is a huge mental side to that recovery, because when you’ve spent a whole lifetime being unwell, progressively, when you’ve seen loved ones die. You yourself have had three or four years of increased and more debilitating ill-health. It takes a bit, a long while to adjust, to realise you can breathe again. (Mr E)

And:

> I kind of learnt to accept I had been given a really amazing gift and you know although they weren’t my lungs, they were, they were going to become my lungs because obviously they’re the reason I’m alive…Then I started to think

> about all the exciting stuff that I could do once I left and you know the fact that I wasn't struggling. I wasn't dying anymore and that no more machines and tubes and things. (Ms I)

Numerous participants attempted to make up for lost time post-transplant, which made them unwell. This resulted in the consultant encouraging an adjustment to their personal expectations and helping them to realise that they needed to pace themselves:

> And then you start going literally 100 mph and doing everything that you've not been able to do for the last 10 years. And then you find yourself in hospital because you've overdone it. And then you get a talk from your consultant and he gives you, it's a well-known talk amongst transplant recipients. It's known as the superman talk, "Have you had the superman talk yet?", "No, no, no not yet". "Okay. You're get it at some point"… But when they say the superman talk. It's like you get your lungs, and everyone goes from you know 0 to 60 or 0 to 100 like that, and then they basically hit a brick wall because they are so acclimatised or so unfit or so mentally ill-prepared actually for it that they end up in hospital. And the superman talk is that the consultant will come round and go, "Mr E, you're not superman. You know, you've just had a transplant, I know it's really exciting doing all these things but you've got to be realistic and don't try and do everything at once you know". (Mr E)

One recipient also used a speedometer to reflect on their hopes post-transplant. However, poor post-operative outcomes resulted in a loss of functioning, which has made adjustment to the new situation challenging:

> If anything I'm more restricted post-surgery than I was before…I love to cook, I'm even finding that difficult and I've got to pace myself. And I can't, I was always someone who lived life at 110mph and I just can't do that anymore. And I find that a little bit difficult to accept. (Mr F)

Goal-setting.

Almost all participants described setting goals for themselves post-transplant. For many these were small, physical goals which provided recipients with a sense of achievement:

> Looking forward and finding out what I can do and setting goals for myself. And they were mainly physical goals...In the first year I would of liked to of, my goals were to walk up Snowden, Scafell Pike and Ben Nevis. So mainland Britain's top three mountains....And cycling, and hillwalking, so I, another one

> was a 25-mile hike around Brecon beacons. That takes ten and a half hours. Exhausting. Done that. And lots of mountain biking, sea kayaking. (Mr D)

For some participants they wanted to engage in activities they had done previously: "So I was trying to get back to playing sports, playing hockey and yeah, building my strength up was the main, main bit post-transplant for me" (Ms G) and "I was always really determined. I'm quite a positive person I like to think. And I, I wanted to get back to playing golf and I wanted to go back to work" (Mrs H).

For other transplant recipients they needed to engage in self-talk to encourage themselves to pursue their goals:

> I was sitting there, I would go, "Come on Mrs J, come on Mrs J you've got to do this. This is ridiculous. You know. You've got to make yourself do things. You can do it". And you've got to be really determined and "You can do it, you will do it. Come on. Come on. You know, you didn't go through all this for nothing. Come on." And I've made myself, I've pushed myself to do certain things. .. I make myself do it, I have a goal, I make myself do certain things. And you know, I make proper dinners and everything else and it's lovely. (Mrs J)

In contrast, other participants initially struggled to find their purpose in life because for the first time they could pursue hopes and dreams:

> After my transplant I was like, you become a bit lost because you get this new lease of life and you go, "Well what do I do with it?" And my sister said, "Well hang on, you've got a list of things that you said you wanted to do." And I slowly worked my way through that. And as I went through and ticked something off, I put something back on it. ...Even six years later it's constantly setting myself goals and things to look forward and things to go you know what each time I do one of those I realise just how lucky I am that I am in this situation with the opportunities that have presented themselves to be able to go and do these. (Mr E)

These examples illustrate participants desire to achieve small and large goals, ranging from everyday tasks, including cooking, working and shopping, to bucket list aspirations, like travelling the world.

Steps towards rebuilding life.

Participants embarked on a transitional journey as they cognitively processed their transplant experiences. This is encapsulated by the themes of managing emotions, uncertainty about future, and gratitude towards donor.

Managing emotions.

Participants noticed differences in their affect post-transplant, ranging from apathy to anger and attempted to process their experiences. Some participants described themselves as being calmer: “The emotions that I’ve gone through is they have been tempered to some extent. The extremes have been tempered. The negative stuff, that I was thinking and the nastiness of the person that I used to be, a lot of it is down to being so ill. With the improvement that has made me more mellow and pleasant to be around. (Mrs C)

In contrast, another participant felt anger: “I was coping with quite heavy mood swings and I became quite aggressive… And sometimes it would come out and I would end up really offending somebody. And at times I was just constantly ready for a fight. And that’s just not me at all” (Mr K).

Some participants also experienced new emotions: “I’m definitely more emotional that I used to be, that’s true. But I think that was also kind of like, I don’t know, I joke that I’ve adopted emotions since my transplant as well. (Ms G) and “learning to understand my emotions” (Ms I).

Uncertainty about future.

During the process of recovery participants also showed an acute awareness of transplant risks as they attempted to adjust expectations of transplant and trying to focus on living:

> So they say I think the important message they give you is a message that transplantation isn’t a cure. And you sort of look at them inquisitively by that and you go, “What do you mean?” Of course it’s a cure. You know they take away your rubbish lungs and they give you some nice good ones and you can breathe. And they go, “It’s not a cure”. You know, you swap one set of problems for another set of problems and the set of problems is that you can’t breathe. And the new set of problems is that you’ve got a compromised immune system and you’re more of a higher risk of catching things like catching sort of of developing things like cancer or pneumonias and things like that. And it won’t last forever…It’s just mentally preparing me that that’s the situation. (Mr E)

Moreover:

> Cause you you, with a transplant we are all aware that your egg timer has turned over. But it’s an egg timer. And we we look at the numbers of how long

> you've got with a transplant. What things to look out for. So it's not a cure. So you're hyper alert. Almost paranoid about you know – am I doing things right?...Trying to predict the future....In those early, in the first year. And having gone through the first year I've become much more relaxed. (Mr D)

The majority of participants reflected upon transplant not being a cure: "I know the risks of transplant and I know you know that it's not a cure, it was the quality of life for me. And that's and that's why I did it" (Mrs H) and:

> It's not disappointment that's not the right word, it's just, coming to terms with it not being a cure I suppose was what was so difficult. And that yes I'm healthy and I'm well but I still have health issues. So yeah, it's not completely what I expected but it's still amazing. (Mrs L)

Despite being faced with a future, participants were also uncertain about whether to allow themselves to make plans in the face of their recognition of having a reduced life expectancy: "you've got your life back for a period. You know, we know and I know the average survival rate for a lung transplant patient is five years and I've had three. And so I know the facts" (Mr A) and:

> I think for me is there is a psychological aspect is that you don't know how long it's going to last... I think for me the worst thing is, you are more susceptible to things going wrong quite quickly. And you don't know if that's going to happen tomorrow, in six months' time, in a years' time, in two years' time, in five years' time. (Mr E)

These examples illustrate the psychological dilemmas recipients experience in the knowledge of their susceptibility to infection and rejection, as well as their struggle to tolerate future uncertainty.

Gratitude towards donor.

Most participants expressed a sense of connection with their donor and felt fortunate that they had received a transplant: "I'm so lucky. I'm so lucky that that family made that decision at that point. And I was in the right place to be able to benefit from that" (Mr E).

This resulted in a desire to express their appreciation towards the donor and their family: "I am the steward of somebody who couldn't use these lungs anymore. I'm the steward of these lungs. So I've gotta I've gotta do a good job" (Mr A).

Other participants engaged in a degree of cognitive processing and subsequently actively engaged in life differently:

> Cause you're kind of enjoying yourself now for two people. You've got to think about the donor who, make the donor proud of what you're doing. Take

> the new lungs to mountains perhaps those lungs never went to before. Experiences those old lungs never had before. Carry that, carry the soul of the other person around with you. Make them proud of you. And so and my adventures and my explorations and what I get up to, I'm doing it not just for me, I'm doing it for the set of lungs, for my partner. It's nice to come back with stories of look what I've done. (Mr D)

These examples illustrate participants' sense of responsibility and duty to their donor.

Looking beyond transplant.

Following post-operative recovery, participants noticed changes in their mental perspective towards themselves, others and the future: "You've got to be adaptable and I think I I I adapted downwards and sort of gradually adapted upwards" (Mr A). This was encapsulated by discovering new potential, change in outlook and appreciation for life.

Discovering new potential.

All participants reflected on the freedom that a transplant had provided and that the transplant gave them the ability to pursue interests and achieve tasks they had never expected: "Just go somewhere new. Try something new. Even if it's just something little. It's more about pushing the boundaries after transplant than getting used to the new boundaries" (Mr K).

For some this manifested in spending time with their grandchildren and doing simple day-to-day tasks:

> I mean if you wanted me to give a serious but trivial response, it would be putting out the rubbish at seven o'clock on a cold wet November morning. You know the thought that I can do that is astonishing. You know, I mean it could be flying to Italy or going up the cape Dolomites or a million big things but actually being able to put the rubbish out at seven o'clock in the morning is is is I I almost enjoy it because it's so astonishing that I can do that and be out in cold weather and it doesn't take my breath. (Mr A)

For others it was related to:

> I've always wanted to live on my own, I've always wanted to be independent. I always just wanted to have normal life, go to work, come home, have friends, go out, socialise with my friends. You know, have meals out, takeaways. And just things that people do and don't really think about. But for me, they were like massive. It's normality isn't it. (Ms I)

Furthermore:

> I've got a new life. It's a lot better than what I had before, well it was 100% better than what I had before. All I looked forward to was death before. I really

> didn't have much time, I know I didn't. But now, woah, oh I don't know. And I can fly, I'm allowed to go flying. Well, in an aeroplane. Whereas before, because I was on oxygen I couldn't fly. (Mrs J)

These examples illustrate the importance of feeling independent and experiencing normal life. For some participants it was also important to return to their previous level of activity:

> I guess I've got the life that I had before back and probably a bit more in the fact that I can do more exercise without getting out of breath. And I'm not quite so paranoid about getting quite as ill or being near people that are ill. I know obviously I need to be careful but before like if somebody even sniffed I was like completely paranoid. (Mrs L)

Other participants with CF highlighted the realisation of having a future they never expected, which created dilemmas: "Suddenly made me realise that it's okay, you can have plans for the future now. And it was as if, that was like a watershed moment having been told that. It made me have a bit more confidence" (Mr K) and:

> I all of a sudden, was faced with the fact that I had a future I didn't think I was gonna have and I didn't know what I was going to do….I just thought – what do I do? What is it that I want to do actually more than anything? It's kind of like being reborn and I had to rediscover who I was, and that and that was really emotional actually. (Ms I)

Change in outlook.

All participants reappraised their perspective on life. This theme was most clearly related to PTG, and was illustrated by participants describing more positive feelings and having a different mindset following adversity. Recipients described engagement in positive self-talk:

> You know, no matter how bad things can get, take that opportunity, take that positive that's there, grab onto it and make the most of that because if you can keep yourself working towards something that keeps your mind focused at even at the hardest of times it's incredibly powerful tool. (Mr E)

Other participants reiterated the importance of positive cognitions:

> You can remain as a vegetable if you want, just sitting there, not doing a lot, and you can gradually deteriorate and go downhill but positive thoughts mean that that you're more likely to be able to get through it and improve your life and gain a greater quality of life that you did before. Just because of your own

> personal drive, your own will. The more you achieve the more competent you become. (Mrs C)

Some participants reflected on the impact that the transplant had made to their physical and mental well-being:

> Changes are easy to handle if you can breathe. If you've got, if you feel, every breath, you're not thinking about too much which means you've got energy which gives you energy and mental space to make decisions that were were so hard before. So I guess most things that are thrown at me these days, I can handle very well. I'm resilient to surprises, to change, to a lot of things that have happened over the last year. I take it in my stride. I'm quite cavalier about sort of a lot of things that. I like mountain biking, I go a bit faster these days….I'm still pushing boundaries and where and what I can do, and adventures and what have you. So yeah, it's all go. It's all positive. (Mr D)

Another participant described the way in which he coped with the transplant process influenced his outlook on life in a meaningful way, which helped create a life mantra:

> So you have a hope, have a plan and no regrets. And I think you know the hope… no matter how bad things seem you know, how bad the prognosis is, there is a positive in that message that you're been given and you've just got to take that positive and make the absolute most of it. And focus on that because you're mental wellbeing has, for me had such a strong link between my physical wellbeing and I needed to be able to stay mentally happy and mentally focused and positive to believe that I could get through to getting the transplant. So you know there's having the hope, believing that I could do something, no matter how bad it was, taking that positive and run with it. Having a plan is as I say the bucket list. You know, I needed to know what success was going to be, how could I make some sort of success, have something to look forward to. And then the last one was don't have any regrets, have no regrets. Don't leave it too late to do those things that you want to do because that is the worst thing in the world is that phrase: 'I wish I'd done this when I had the chance'. And that you know that, those three lessons for me are something that you know I do regularly think about and regularly remind myself that those are the three things that I almost live by now. (Mr E)

Appreciation for life.

All participants acknowledged the significance of their health problems and developed strategies to cope by accepting the past and living in the here-and-now:

> I didn't wanna dwell on my bad, it is was a tough experience that I went through, and I didn't want to dwell on that. I I wanted to accept it's happened and it was horrible and I would never wish it on my worst enemy. Because it is a, it really is a hard journey. (Mrs H)

Some participants advised:

> Don't fight things when they come along. Go with the flow. Just accept them and let them drift in and let them drift out of your life, without getting hung up about things. And just make the most of the time you've got. Try to think positive, always try and think positive. (Mr B)

Another participant illustrated acceptance during his reflection on his limited lifespan:

> I take each day as it comes. You know, because I've got to get through another bit of major surgery. It's nice cause I've seen the fifth of my grandchildren born. You you feel sad because you know that you're not going to see them grow up. You know, I'm already 60. I've got important, significant diseases and I'm not going to make old bones. But that's life. You you know you just have to accept it. (Mr F)

These examples illustrate how participants recognised the importance of adjusting and accepting the positive and negative experiences in life.

Support network.

Participants identified their support network as an important vehicle influencing their post-transplant experiences. Subordinate themes included guidance on physical, psychological and spiritual health; the importance of peer support; impact on family relationships; and compassion and empathy towards others.

Guidance on physical, psychological and spiritual health.

Participants valued the medical expertise and quality of care provided by the hospital staff. Participants described feeling safe and cared for: "I remember the quality of nursing care. What I was hearing when they didn't think I was conscious was, to say it was professional is to minimise, I mean it was just wonderful, the commitment that you felt of the staff" (Mr A) and "I felt really, really secure…So that helped, because the nurses were really, really good" (Mr B).

Recipients also shared the highs and lows of the transplant journey with staff. The following examples highlight the importance of these relationships in shaping people's experiences and the investment of staff in recipients' recovery: "I've become an outlier, you know they'll all disappointed by the way, you know all the things that have happened and the way I have been left" (Mr F).

Moreover:

> For the medical team here, if they get to hear what I've done, that's gotta make them feel good. Look at what we did. They made a difference. They made a huge difference. And I like to make it nice and clear how much of a difference they've made. By climbing mountains and getting into all sorts of mischief. Then they can see what they've done. Look at what you made me do. (Mr D)

Some participants referred to the psychological support they received, which supported them in managing change and expectations both pre- and post-transplant. These quotes illustrate the importance of the psychological provision that aided participants' mental well-being:

> I spent some time seeing a clinical psychologist at my transplant centre post-transplant and that was to help me deal with some changes that happened in my life pre-transplant with relationships and things like that. I had a bit of a rough ride and this psychologist helped me manage these changes and just set expectations and realise that you know, things can change but you ultimately have that, you are in total control of what you do and you choose how you live your life and what you do and what you don't do. (Mr E)

Furthermore:

> I don't think, anyone can prepare you for it. ...And I know X [clinical psychologist] said to me before transplant she said, "It's, it's not going to be easy. And think of your worst nightmare and then treble it. And then that's what it's going to be like." And even though she said those words, you try and think like that but it still doesn't come to the… (Mrs H)

Other participants wanted further information relating to the physical and psychological implications of a transplant to help prepare themselves:

> And so when you wake up, it isn't so scary. Perhaps a bit more chat on the drugs, I mean I just had such bad hallucinations in there. That was awful. I thought people were trying to kill me. (Mrs H)

And:

> But I think, we have so many discussions about the things that can go wrong and all the treatments and you know your limitations afterwards, that you're immunosuppressed and you have two days' worth of talks when you're just being constantly being told all these things. Actually psychological implications of it, you know the fact that some of us have literally come from the brink of death and you're just this is your only hope, it's that that all of a sudden you've got a future. That is quite a big thing to get your head around and just coming to terms with everything that's happened. (Ms I)

Participants also sought spiritual guidance to aid their decision-making and coping throughout the transplant process. The following quotes emphasise the important role religion and spirituality played in recipients lives at every stage of the transplant journey:

> As part of the assessment process actually I wrote to, I'm a devote Christian and I wanted to work through my head, the ethics. Although I worked with it and I felt very positive about it as an employee, I wanted to work through it for myself.… And I wrote to somebody… the head of kidney transplant at Queen's Nottingham is a lay reader in the Anglican church and I didn't know him, he didn't know me but I wrote to him…I had a tremendously helpful letter back from him. (Mr A)

> … my faith is important to me and it's not just going to church, singing hymns, reading the creed. You know I I do believe that there is a God who is you know who if you like has numbered my days and I am in his hands. But that doesn't take away my respect and gratitude for the surgeons who may be atheists for all I know and great for them. You know they are brilliant. (Mr A)

> I'm heavily into the church. ...You can always ring up, get help. Also I believe in the power of prayer to be quite honest….And to be quite honest I believe that's why I'm here….I was having prayer from all over the world. I know people in many, many parts of the world and I was getting a lot of prayer whilst I was having all this done. ...So really I mean, I guess I shouldn't really be be here. But for some reason I am. And this is why I feel I have to give back, because I feel that God has given me a new life. But that's how I personally feel. (Mrs J)

Importance of peer support.

Transplant recipients valued peer support from both patients and non-patients. There are parallels with the quantitative analysis, which revealed that more support from friends was associated with higher levels of PTG.

Reciprocal support with other patients was important. Participants experienced benefits from receiving help from others either personally or via social media:

> You're fully aware and you're prepared, and you have other friends that go through the same thing at the time, and things like social media, at the time of the transplant was so invaluable for just getting other people's experiences of their own journey that have gone through transplant. (Mr E)

This support provided both practical information and emotional support, and some participants preferred to talk to people who had shared their experiences:

> Use other transplant patients for their experiences. .... And the chat forums, like X [hospital] transplant club, sometimes if I wanna put a question on there, that I'm not sure about and I don't wanna speak to a clinical person. And sometimes you can go on there and just give them a bit of guidance and that helps a lot. And then you start chatting to them and then you meet them in clinic and then you build a relationship and you can share experiences, and and sometimes calm people down. (Mrs H)

Participants also wanted to inspire other patients with their achievements:

> I've got a friend who's actually still in here now. She was debating whether to have a transplant. And I wanted to encourage her, you know this is this is the potential of the difference in life between before and after a transplant. And I wanted to set a good example for her to encourage her to put herself on the list....so I'm hoping in some small way I you know showed that person where things could go. (Mr D)

Furthermore, participants wanted to be realistic and share their experiences about the transplant process: "And I was quite honest with them because I felt like that was important to be really honest. To try and explain exactly what they're going to face. And also, answer questions like going to the toilet for example". (Mrs H)

Another important source of emotional and physical support were non-patient friendships:

> My friends have probably always been my, for my personally my strongest support group…And they were there throughout the whole thing when I was

> getting ill… And you know they would help me out and my old housemate would sort of do all my night time feeds and prepare them for me if I was too tired to do them myself. And yeah my friends still now like help me with anything that I need. So I think my friendships, my friends are sort of my main source of support. (Ms G)

Some participants also suggested avenues for additional support including a support group and/or mentoring system, to create a space to share recovery challenges:

> I think like a mentoring sort of system. So when you get people post-transplant that can talk to people pre. People would probably I suppose you've got to be quite together yourself…But it's maybe having that is something more real you know from somebody's whose been through it and can say, "Actually you know what, I really struggled". And particularly, if you read blogs, people I think tend to romanticise what they've been through, they'll be like, "Oh that first breath is amazing". That first breath was awful. I was in so much pain...., that's real because a lot of people that I've spoken to have woken up expecting to have that first breath that's so amazing. And then they don't get it…Actually that's normal, that's what it should feel like because you've just been through major surgery. So I think it's that, just being really real, talking to somebody that will, or you know whether it's like having a leaflet written by patients post-transplant or you know face-to-face is quite difficult because of infection risks. But some sort of way where actually could be more real about what does happen in those first few days. (Ms I)

Impact on family relationships.

Prior to transplant, most participants described being dependent on family members for support and they expressed concern about the strain on their family:

> It was difficult for my family as well because you know that it it just hard. It's bad enough to go through major surgery but to watch from the side-lines when somebody you love is getting multiple complications it it's hard for them. (Mr F)

Post-transplant participants described wanting to give something back to family members:

> She put in the investment, the effort, the time, that my partner put in to keeping me alive, to keep me going for my transplant. Just paying that back. Seeing the smile on her face. Being part of her life. ...Keeping her happy. That is the best

> thing about having the transplant. Being, helping reward someone else for all their effort. And myself. (Mr D)

For other participants there have been opportunities to engage with grandchildren, which was not previously possible:

> She's mentioned it a couple of times, "oh it's so much nicer now you're okay. You can move around Nanny. We can do this, and we can do that". And I said, "Yeah okay then. I will have a go"….But it's it's so nice that I can interact with the kids now. Whereas before, some of the things I couldn't do, and they'd noticed. (Mrs J)

However, some participants reflected on the impact their mobility difficulties had had on their relationship, which changed their roles and in some cases led to their relationship ending:

> We went through so much together and you know 10 years is a long time to be with somebody and he had literally become my carer. And I, that changes a relationship, I think....It's not the same after that. It's difficult to feel attractive or anything when the person you're with is literally seeing you at your worst. They had to clean you, wash you, help you dress. You know, it changed things a lot, even for him, he became so protective of me and I think he felt more like a carer than he did a partner as well (Ms I).

Furthermore:

> It was just coming up three years, my husband left me...Which was hard because I know transplant has had an impact of that…It was very difficult for X [husband] and I'm sure it's had a major part in it. Because he was my carer for so long, especially after transplant, I've always been quite an independent person, but after transplant because of my mobility issues, he really had to look after me, literally wipe my bottom. And, and that must of affected things, and also obviously had an effect on my sex life. And I don't look the same anymore under my clothing. So I've got massive scars and massive drain sites. (Mrs H)

Compassion and empathy towards others.

Post-transplant participants described a desire to engage in instrumental and emotional support:

> I've got a cousin who has probably got cancer and is dying from cancer, I visit him regularly, and I feel because I've been at the back end of life I don't feel

> like I can tell him what, to think, what to feel or what to do but I can empathise in a way probably that some people can't. (Mr A)

Some participants said:

> You just feel that you can give something back again like try and do, I don't do as much as I used to do but I do try to do as much fundraising for this hospital as I can. And that's really important to me because of how much they have helped me…, and we are doing a volunteering project next year to decorate [the hospital]. (Mrs H)

> I'm making garments for very premature babies….But it's really nice to be able to do something, to give back. And I've been able to go back to church. And it it's really nice that I can do different things. I'm helping with the Foodbank. ...And that's part of our church. But it's all something to get out there and give a bit back. You know, a lots been given to me, my life has been given to me. I don't want to waste it by sitting in here all the time. I've got to get out. (Mrs J)

These quotes illustrated participants' compassion towards others after being given a future and their hope that they could influence other people: "if I can inspire people in some small way, that's a bonus" (Mr D) and "So I've done and I've gone and held some little stalls and tried to get people to sign up to be organ donors, on the anniversary of my donor". (Mr E) as well as "promoting organ donation and things like that. Not, not to feel worthy but to make, I don't quite know" (Ms G).

2.4 Discussion

The primary aim of this study was to examine components of the functional-descriptive model of PTG (Tedeschi & Calhoun, 2004) by investigating the relationships between cognitive processing, distress, social support and PTG in a lung transplant population. A secondary aim was to ascertain whether PTG increased over time post-transplant. The study also examined the role played by resilience and examined whether resilience mediated the relationship between the psychological variables being studied and PTG. The quantitative and qualitative components were used to enable triangulation and further explore recipients' experiences of the transplant process. These findings, clinical implications, limitations and areas for further research are discussed in more detail below.

2.4.1 Presence of PTG in Lung Transplant

Consistent with previous literature, transplant recipients experienced positive change across all domains: relating to others, new possibilities, appreciation of life, personal strength and spiritual change. In the present study, the mean PTG scores were 64.15, which is very similar to the average scores of 64.7 in bone marrow transplant recipients (Widows et al., 2005) and higher than other studies examining PTG in cancer (Steel et al., 2008) and cardiovascular disease (Sheikh & Morotta, 2005) with mean scores of 51 and 56.84 respectively. However, it was not possible to make comparisons with other transplant populations due to the limited evidence-base and variation in measures used. Qualitative findings highlighted recipients' new 'appreciation for life' that occurred following another person's loss of life that had enabled them to receive new lungs. This led to feelings of responsibility and a desire to make the most of their lives post-transplant (Thomsen & Jensen, 2009).

There was no evidence to support the hypothesis that PTG was higher the longer the participant was post-transplant. However, previous research found that the relationship with PTG was moderated by time since the trauma, rather than being a predictor variable (Helgeson et al, 2006). The FD model suggests that the different psychological variables within the model interact to influence the development of PTG and for some individuals this process may occur over time, whereas for others it may taper off (Tedeschi & Calhoun, 2004). Conversely, there may be some variation in the sequential time frames for the processes involved in PTG between individuals (Frazier et al., 2001). However, further longitudinal studies are needed to examine these relationships in more detail.

There was no association between age or gender and PTG in this study. However, previous evidence found that women and younger people are more likely to experience PTG (Linley & Joseph, 2004) possibly due to more engagement in positive reappraisal and self-talk (Tamres et al., 2002). Interestingly, the objective measures of physical well-being, including lung function and

BMI were unrelated to PTG. Other studies have found that subjective appraisal rather than objective health indicators are more strongly associated with PTG (Helgeson et al., 2006).

2.4.2 Cognitive Processing and PTG

Consistent with the FD model, the results showed that deliberate rumination was a significant statistical predictor of PTG. Intrusive rumination had a significant positive association with PTG; however, it was not a significant predictor of PTG in the regression analysis when entered with deliberate rumination. The FD model suggests that intrusive rumination occurs initially after a trauma and that over time individuals switch to deliberate rumination, which in turn promotes PTG. However, given that the measure of cognitive processing asks individuals about their current levels of intrusive and deliberate rumination, it was not possible to identify whether intrusive rumination has already occurred and individuals are predominantly engaging in deliberate rumination.

When individuals switch from intrusive to deliberate rumination this may facilitate integration of trauma-related experiences. The FD model proposes that this occurs through individuals' search for meaning and development of a coherent narrative of the event (Tedeschi & Calhoun, 2004). This process may provide a means for producing schema change. These processes are reflected in the Event Related Rumination Inventory (ERRI) used to measure cognitive processing, with questions including: deliberately spending time thinking about the transplant experience and finding new meaning for the future, which may have facilitated individuals' experience of PTG. Schema and behavioural change are reflected in the qualitative themes: 'goal-setting' and 'appreciation for life'. Individuals acknowledged the significance of their experiences and recognised the importance of adjusting and accepting the positive and negative experiences in life. This led to individuals' 'discovering new potential' and experiencing a 'change in outlook'.

2.4.3 Distress and PTG

There is some debate about whether PTG is an outcome or process. Evidence suggests that PTG is not a static outcome but rather an ongoing process, which is evident in the relationship between distress and PTG (Tedeschi & Calhoun, 2004). Findings showed distress was not a significant statistical predictor of PTG. PTSD intrusions were positively associated with PTG but not related to global distress, depression, anxiety and stress. Similarly, Fox et al. (2014) found limited evidence for an association between these difficulties and PTG. These results are consistent with the FD model which suggests negative intrusive thoughts and images are related to PTG and are an essential component of the PTG process (Tedeschi & Calhoun, 2004). Consistent with previous review findings, the current results illustrate that different measures of distress have varying relationships with PTG due to different approaches that have been used to conceptualise distress (Helgeson et al., 2006).

However, it is important to highlight that only 10% of the current sample were in the clinical range for PTSD and only 13% were in the moderate to extremely severe range for depression, anxiety and stress. This demonstrates that although individuals experience distress post-transplant, this distress is not always reflected in the relationship with PTG. These findings can be understood by the proposal that PTG and distress are separate dimensions. Therefore, an increase in PTG may not prevent distress from occurring and is dependent on the perceived threat of the experience (Calhoun & Tedeschi, 1998).

The qualitative findings provided support for the model's hypothesised relationships between distress and PTG. In the early stages of recovery distress was present in the themes: 'Lack of control over the body and focus on physical recovery' and 'managing emotions', which reflected attempts to cope with feelings of fear, helplessness and anger, which eventually led to individuals 'looking beyond transplant'. The FD model suggests distress is a precursor to PTG and acknowledges that PTG may not lead to reductions in psychological distress (Tedeschi & Calhoun, 2004). Empirical evidence has also suggested distress and PTG may vary dependent on the stage of emotional processing (Helgeson et al., 2006). These findings showed that early reports of PTG were positively correlated with distress but negatively correlated with later reports of distress (Helgeson et al., 2006). However, it was not possible to establish the direction of these relationships in the current cross-sectional study.

2.4.4 Social Support and PTG

Consistent with previous research, social support was a significant statistical predictor of PTG. More specifically, friends were the only significant independent predictor of PTG in this population. There were also positive associations between support from significant others with PTG. The qualitative study complemented these findings by highlighting a superordinate theme of 'support network'. Thus both components of the study are consistent with the theoretical role given to social support in the FD model of PTG (Tedeschi & Calhoun, 2004). The model suggests that self-disclosure is the mechanism through which social support has its effect. Self-disclosure may operate by helping and/or allowing people to create narratives about their experiences, which could in turn provide new perspectives that can be integrated into their changed belief system (Neimeyer, 2001). Within the current study, lung transplant recipients particularly valued peer support from other patients both for practical information and emotional support due to their understanding and awareness of the transplant journey. The importance of 'friend support' is also consistent with previous lung transplant studies, which showed that higher social support from friends led to higher levels of PTG at long-term follow up (Fox et al., 2014). However, it is not clear whether social support facilitates PTG, or is a consequence, or if they interact.

Interestingly, family and significant others were not significant independent predictors of PTG. The qualitative component of the study suggested that recipients were concerned about the 'impact on family'. Therefore, they did not engage in so much self-disclosure with family in an attempt to manage the emotional impact of their difficulties on others. However, there is a potential cost to limiting self-disclosure; Lepore and Helgeson (1998) showed that it resulted in a stronger relationship between intrusive thoughts and depression, preventing PTG.

2.4.5 Resilience and PTG

Previous literature has suggested that resilience may play an important role in the development of PTG; however, it has not been included as a part of the FD model. Therefore, another aim of this research was to ascertain whether resilience might play a role in PTG and therefore need to be included in the model. In this study, although resilience significantly predicted PTG, it did not act as a mediator between deliberate rumination/social support and PTG. These results support previous theories of the conceptual relationship between resilience and PTG and potentially reflect the hypothesis that PTG reflects dynamic processes occurring over time (Lepore & Revenson, 2006). Resilience has three components: recovery, resistance and reconfiguration which together encapsulate positive and negative adaptations in the face of stressful life events. However, PTG reflects a reconfiguration process involving positive transformation following trauma (Lepore & Revenson, 2006). This suggests that PTG may be captured within resilience, as resilience reflects both positive and negative coping strategies following a significant event.

The failure to find a mediation effect suggests that, although resilience is important, social support and cognitive reappraisal are vital to the development of PTG. An explanation for these findings is individuals may engage in less avoidant coping and the presence of supportive social environments provide the resources to cope more effectively post-transplant (Lepore & Revenson, 2006). However, it is difficult to establish the direction of these relationships and higher levels of PTG may increase resilience. Moreover, the sample size may have been insufficient for a small effect and these relationships warrant further exploration with longitudinal studies and structural equation modelling.

2.4.6 Experiences of Transplant

One strength of this study was its use of mixed methods. The interviews conducted in the qualitative component of the study reflected many of the psychological processes identified within the FD model as contributors to the development of PTG and have been discussed in detail. Consistent with previous research (Salick & Auerbach, 2006), participants transitioned through different stages towards integration of the trauma and its reappraisal. Coping was paramount at each stage of the transplant journey and the affective tone in the narratives changed over time. The primary focus post-transplant was on 'overcoming psychological and physical barriers', shifting towards 'future uncertainty' and finally reappraising life. Participants experienced loss, and had to adapt and accept their changing health needs. The current findings that are specific to lung transplant accord well with the qualitative literature on PTG in physical health more generally

(Hefferon, Grealy, & Mutrie, 2009), which emphasises that recovering and thriving following illness creates a new awareness and an increased importance of the body.

2.4.7 Limitations and Directions for Further Research

Inevitably there are some methodological limitations that need to be considered. Firstly, the cross-sectional design was useful for exploring the relationships between the psychological variables and PTG. However, this limits the potential to infer causality and provide supporting evidence for the PTG model. To rectify this, a longitudinal study would be required to establish causal relationships, and to test predictions about hypotheses related to PTG.

The recruitment approach may have led to sampling bias, which could limit external validity to the wider lung transplant population. Participants were predominantly approached in outpatient clinics while attending for ongoing monitoring. Most of the participants were very willing and motivated to contribute to the study. However, participants who were not approached or who declined may have been more avoidant or have been experiencing more distress. Interestingly, in an age of growing internet use, none of the participants completed the questionnaires online. This may have been related to convenience issues, privacy fears, or to not getting the physical prompt provided by a questionnaire pack.

The PTGI is a valid and reliable tool, which measures perceptions of growth and change. However, this ignores negatively evaluated processes of change and creates a risk of individuals' responding in a manner that is socially desirable (Wittmann & Büchi, 2010). It would be valuable to utilise a valid and reliable measure that assesses perceived positive and negative change after a trauma, such as the Psychological Well-Being – Post Traumatic Changes Questionnaire (PWB-PTCQ; Joseph et al., 2012) and to develop performance-based measures of PTG to ascertain actual growth at different points. However, the PWB-PTCQ has not been validated in physical health conditions, whereas the PTGI is a widely used measure that allows comparisons across different experiences of trauma.

The qualitative findings provided valuable insights into recipients' transplant experiences. The majority of the participants experienced a positive transplant outcome; however, their motivation to share their experiences may have created a positive bias in the findings. Therefore, these results may not accurately reflect recipients who have significant post-transplant complications. However, the interview schedule attempted to flexibly allow participants to describe their experiences and one participant did express significant ongoing difficulties. Nevertheless, in general participants in the qualitative component described a process of change from struggling to adjust and accept their experiences to positive change. These findings illustrate the complex processes that occur for lung transplant recipients and complement the quantitative outcomes from the study.

2.4.8 Clinical Implications

Given that this is a cross-sectional study, any clinical recommendations must remain tentative. However, the discovery that both deliberate rumination and social support facilitated PTG, and that resilience was an independent predictor of PTG suggest that all three constructs may have benefits in preparing for, and recovering from, lung transplants. At the moment there are few interventions aimed at promoting the development of PTG because we do not have clear evidence about exactly how it develops. However, this study adds to emerging evidence suggesting that deliberate rumination rather than involuntary rumination may be important for the development of PTG. Clinicians need, at least, to be aware of the distinction between these two types of rumination and to recognise their potentially differing effects. They could test the impact of switching from intrusive to deliberate rumination by either using single case study methodology to evaluate benefits or testing the effect within patients using behavioural experiments. Other areas worth exploring in treatment include providing opportunities for disclosure and examining ways of enhancing deliberate rumination. This work may be facilitated within individual therapy or group environments.

Treatments used for PTSD may be usefully employed to support the process of deliberate rumination. Based on the cognitive model of PTSD developed by Ehlers and Clark (2000), clinical psychologists can engage clients in a process of revisiting their trauma memories through exposure. This involves creating a trauma timeline and reliving, by putting into words their experiences to help elaborate and contextualise the trauma memory (Foa & Riggs, 1993). Clients are then supported to engage with verbal and imagery cognitive restructuring, and encouraged to reclaim their lives with engagement in meaningful activities and social contact. This trauma-focused cognitive-behavioural therapy intervention has an excellent evidence-base and could be considered a form of deliberate rumination. However, this intervention would need to be carefully evaluated to ascertain whether this was an appropriate intervention to promote deliberate rumination and PTG.

Given the important relationships between resilience and PTG, the current findings highlight the potential importance of increasing resilience to facilitate PTG. It would be useful to explore the predictors of resilient outcomes following lung transplant and to ascertain whether resilience-building interventions are appropriate for improving resilience. One of the research sites is considering assessing resilience prior to transplant as a potentially useful measure of transplant outcome, which could highlight less resilient individuals who might benefit from resilience-building skills. Padesky and Mooney (2012) have developed a strengths-based cognitive-behavioural therapy model to support people to build and strengthen personal resilience. This four-step model encourages individuals to search for strengths, construct a personal model of resilience, apply this personal model to areas of life they are finding difficult, and practise resilience. This approach may also have significant clinical utility for clinical psychologists; however, this would of course need to be evaluated.

The qualitative findings provided additional valuable insights into recipients' experiences of support across the transplant process. Clinicians would benefit from an awareness of differential coping strategies occurring at different time points and knowing when additional support is required. Pre-transplant education and information was important for recipients; however, participants wanted more information relating to the physical and psychological consequences to help prepare themselves for the transplant process. Therefore, a comprehensive information pack on the transplant journey based on the experiences shared by recipients would be a valuable resource. Recipients also expressed a need for mentoring/transplant peer support groups. Other patients are valuable resources for sharing knowledge and beliefs, and should be used in the education process both pre- and post-transplant to help facilitate revision of schemas and promote PTG. This may support recipients' emotional and mental well-being as they adjust and cope with transplant. Given possible infection risk, signposting to online forums may provide another avenue of support for transplant recipients. However, this warrants further research.

2.4.9 Conclusions

This is the first study to investigate the role played by cognitive processing, distress, social support, resilience on the development of PTG in a lung transplant population. The findings provided some support for Tedeschi and Calhoun's (2004) model of PTG and demonstrated the importance of cognitive processing, social support and resilience for positive psychological change. This sample has been neglected within the PTG evidence-base and it was valuable to address this gap in the literature to aid understanding of people's experiences following a significant event such as transplant. This research will provide a platform for further research in this area and encourage professionals to consider these constructs to facilitate positive outcomes on the transplant journey.

Appendix A: Reflections on Research Process

These reflections are dedicated to the research process, encompassing seeking ethical approval and data collection and analysis.

Ethical Approval

The ethical approval process felt extremely challenging. Significant changes made to the approval process and difficulties with internal processes, resulted in delays in receiving ethical approval. Initially I commenced this process in February 2016 and obtained approval and contract set up in October 2016. These difficulties made me feel very frustrated and concerned I would have insufficient time for data collection. However, during this period I gained some valuable experiences that I will take forward for the future. Primarily, I learnt valuable knowledge and experience of the processes involved in obtaining ethical approval. I further developed my leadership skills and learnt the importance of regularly liaising with other professionals and following up identified issues. This helped develop my confidence in being assertive but respectful to other professionals.

Data Collection

Data collection required travelling to two research sites across the country. This required a considerable time commitment and without the research block this would not have been possible. From visiting these sites, I gained useful insights into the role of a clinical psychologist in a health setting. I noticed psychology are highly valued within the multi-disciplinary team and vital for aiding recovery and adjustment following transplant. I felt very aware by the strong relationships between the staff and patients as well as the sense of community. I felt this aided communication and helped patients feel supported in their medical care and transplant journey. My regular presence at the sites also supported engagement with staff and patients, enabling identification of appropriate participants. I found participants were highly motivated to take part in the research and desired to contribute to the field. Many participants expressed wanting to share their experiences and help other transplant recipients, which was reflected in the high response rate.

When I commenced the qualitative interviews, I was instantly struck by how much people valued having the opportunity to share their story. The information shared was rich in detail and I felt humbled to have the opportunity to hear their experiences. In the interviews, I needed to manage my own clinical curiosity with professionalism. It was difficult not to engage in therapeutic conversations and comment with language that may influence the information participants shared, and ensure I remained neutral. However, I found it important to strike a balance between being warm and empathic, as well as exploring their experiences as a researcher in a non-judgemental way.

During the interviews and data analysis I felt very moved by participants' experiences, both touched by their honesty and hearing how their lives have been transformed from before and after transplant. It was also inspiring to hear how participants coped and their subsequent achievements.

Summary

This research was an incredible learning experience for me and allowed me to gain insights into the experiences of a neglected population. On reflection, I acknowledge this was an ambitious project, which entailed a significant amount of work, both with the quantitative and qualitative components. However, I feel these aspects complemented each other and the qualitative interviews provided support for the quantitative results. This research will hopefully provide a platform for further work in this area and help shape patient care for future transplant recipients.

Appendix B: COSMIN taxonomy of measurement properties (Adapted from Mokkink et al., 2010a)

Note. HR-PRO = Health-related patient reported outcome.

Appendix C: Quality criteria for measurement properties of health status questionnaires (Terwee et al., 2007)

Property	Definition	Quality criteria
Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire	+ A clear description is provided of the measurement aim, the target population, the concepts that are being measured, and the item selection AND target population and (investigators OR experts) were involved in item selection; ? A clear description of above-mentioned aspects is lacking OR only target population involved OR doubtful design or method; - No target population involvement; 0 No information found on target population involvement.
Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct	+ Factor analyses performed on adequate sample size (7 * # items and ≥100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95; ? No factor analysis OR doubtful design or method; - Cronbach's alpha(s) < 0.70 or > 0.95, despite adequate design and method; 0 No information found on internal consistency.
Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard	+ Convincing arguments that gold standard is ''gold'' AND correlation with gold standard ≥0.70; ? No convincing arguments that gold standard is ''gold'' OR doubtful design or method; - Correlation with gold standard < 0.70, despite adequate design and method; 0 No information found on criterion validity.
Construct validity	The extent to which the scores on repeated measures are close to each other (absolute measurement error)	+ Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses; ? Doubtful design or method (e.g., no hypotheses); - Less than 75% of hypotheses were confirmed, despite adequate design and methods; 0 No information found on construct validity.
Reproducibility		
Agreement	The extent to which the scores on repeated measures are close to each other (absolute measurement error)	+ MIC < SDC OR MIC outside the LOA OR convincing arguments that agreement is acceptable; ? Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable); - MIC ≥ SDC OR MIC equals or inside LOA, despite adequate design and method; 0 No information found on agreement.

Property	Definition	Quality criteria
Reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)	+ ICC or weighted Kappa ≥ 0.70; ? Doubtful design or method (e.g., time interval not mentioned); - ICC or weighted Kappa < 0.70, despite adequate design and method; 0 No information found on reliability.
Responsiveness	The ability of a questionnaire to detect clinically important changes over time	+ SDC or SDC < MIC OR MIC outside the LOA OR RR > 1.96 OR AUC ≥ 0.70; ? Doubtful design or method; - SDC or SDC ≥ MIC OR MIC equals or inside LOA OR RR ≤ 1.96 OR AUC < 0.70, despite adequate design and methods; 0 No information found on responsiveness.
Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	+ ≤15% of the respondents achieved the highest or lowest possible scores; ? Doubtful design or method; - >15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods; 0 No information found on interpretation.
Interpretability	The degree to which one can assign qualitative meaning to quantitative scores	+ Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined; ? Doubtful design or method OR less than four subgroups OR no MIC defined; 0 No information found on interpretation.

Note. MIC = minimal important change; SDC = smallest detectable change; LOA = limits of agreement; ICC = Intraclass correlation; SD = standard deviation. + = positive rating; ? = indeterminate rating; - = negative rating; 0 = no information available. Doubtful design or method = lacking of a clear description of the design or methods of the study, sample size smaller than 50 subjects (should be at least 50 in every (subgroup) analysis), or any important methodological weakness in the design or execution of the study.

Appendix D: COSMIN checklist with 4-point scale (adapted from Terwee et al., 2012)

Instructions

This version of the COSMIN checklist is recommended for use in systematic reviews of measurement properties. With this version it is possible to calculate overall methodological quality scores per study on a measurement property. A methodological quality score per box is obtained by taking the lowest rating of any item in a box (‘worse score counts’). For example, if for a reliability study one item in the box ‘Reliability’ is scored poor, the methodological quality of that reliability study is rated as poor. The Interpretability box and the Generalizability box are mainly used as data extraction forms. We recommend to use the Interpretability box to extract all information on the interpretability issues described in this box (e.g. norm scores, floor-ceiling effects, minimal important change) of the instruments under study from the included articles. Similar, we recommend to use the Generalizability box to extract data on the characteristics of the study population and sampling procedure. Therefore no scoring system was developed for these boxes.

Step 1. Evaluated measurement properties in the article

Internal consistency	Box A
Reliability	Box B
Measurement error	Box C
Content validity	Box D
Structural validity	Box E
Hypotheses testing	Box F
Cross-cultural validity	Box G
Criterion validity	Box H
Responsiveness	Box I

Step 2. Determining if the statistical method used in the article are based on CTT or IRT

Box General requirements for studies that applied Item Response Theory (IRT) models

	excellent	good	fair	poor
1. Was the IRT model used adequately described? e.g. One Parameter Logistic Model (OPLM), Partial Credit Model (PCM), Graded Response Model (GRM)	IRT model adequately described	IRT model not adequately described		
2. Was the computer software package used adequately described? e.g. RUMM2020, WINSTEPS, OPLM, MULTILOG, PARSCALE, BILOG, NLMIXED	Software package adequately described	Software package not adequately described		
3. Was the method of estimation used adequately described? e.g. conditional maximum likelihood (CML), marginal maximum likelihood (MML)	Method of estimation adequately described	Method of estimation not adequately described		
4. Were the assumptions for estimating parameters of the IRT model checked? e.g. unidimensionality, local independence, and item fit (e.g. differential item functioning (DIF))	assumptions of the IRT model checked	assumptions of the IRT model partly checked	assumptions of the IRT model not checked or unknown	

To obtain a total score for the methodological quality of studies that use IRT methods, the ‘worse score counts’ algorithm should be applied to the IRT box in combination with the box of the measurement property that was evaluated in the IRT study. For example, if IRT methods are used to study internal consistency and item 4 in the IRT box is scored fair, while the items in the internal consistency box (box A) are all scored as good or excellent, the methodological quality score for internal consistency will be fair. However, if any of the items in box A is scored poor, the methodological quality score for internal consistency will be poor.

Step 3. Determining if a study meets the standards for good methodological quality

Box A. Internal consistency				
	Excellent	Good	Fair	Poor
1. Does the scale consist of effect indicators, i.e. is it based on a reflective model?				
Design requirements				
2. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
3. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
4. Was the sample size included in the internal consistency analysis adequate?	Adequate sample size (≥100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (<30)
5. Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?	Factor analysis performed in the study population	Authors refer to another study in which factor analysis was performed in a similar study population	Authors refer to another study in which factor analysis was performed, but not in a similar study population	Factor analysis NOT performed and no reference to another study
6. Was the sample size included in the unidimensionality analysis adequate?	7* #items and ≥100	5* #items and ≥100 OR 6-7* #items but <100	5* #items but <100	<5* #items
7. Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?	Internal consistency			Internal consistency

Box A. Internal consistency	Excellent	Good	Fair	Poor
	statistic calculated for each subscale separately			statistic NOT calculated for each subscale separately
8. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
Statistical methods				
9. for Classical Test Theory (CTT), continuous scores: Was Cronbach's alpha calculated?	Cronbach's alpha calculated		Only item-total correlations calculated	No Cronbach's alpha and no item-total correlations calculated
10. for CTT, dichotomous scores: Was Cronbach's alpha or KR-20 calculated?	Cronbach's alpha or KR-20 calculated		Only item-total correlations calculated	No Cronbach's alpha or KR-20 and no item total correlations calculated
11. for IRT: Was a goodness of fit statistic at a global level calculated? E.g. χ^2, reliability coefficient of estimated latent trait value (index of (subject or item) separation)	Goodness of fit statistic at a global level calculated			Goodness of fit statistic at a global level NOT calculated

Note. Item 1 is used to determine whether internal consistency is relevant for the instrument under study. It is not used to rate the quality of the study.

Box B. Reliability: relative measures (including test-retest reliability, inter-rater reliability and intra-rater reliability)	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (<30)
4. Were at least two measurements available?	At least two measurements			Only one measurement
5. Were the administrations independent?	Independent measurements	Assumable that the measurements were independent	Doubtful whether measurements independent	Measurements were NOT independent
6. Was the time interval stated?	Time interval stated		Time interval NOT stated	
7. Were patients stable in the interim period on the construct to be measured?	Patients were stable (evidence provided)	Assumable that patients were stable	Unclear if patients were stable	Patients were NOT stable
8. Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval appropriate	Time interval was NOT appropriate

Box B. Reliability: relative measures (including test-retest reliability, inter-rater reliability and intra-rater reliability)	Excellent	Good	Fair	Poor
9. Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions	Test conditions (evidence provided)	Assumable that test conditions were similar	Unclear if test conditions were similar	Test conditions were NOT similar
10. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
Statistical methods				
11. for continuous scores: Was an intraclass correlation coefficient (ICC) calculated?	ICC calculated and model or formula of the ICC is described	ICC calculated but model or formula of the ICC not described or not optimal. Pearson or Spearman correlation coefficient calculated with evidence provided that no systematic change has occurred	Pearson or Spearman correlation coefficient calculated WITHOUT evidence provided that no systematic change has occurred or WITH evidence that systematic change has occurred	No ICC or Pearson or Spearman correlations calculated
12. for dichotomous/nominal/ordinal scores: Was kappa calculated?	Kappa calculated			Only percentage agreement calculated

Box B. Reliability: relative measures (including test-retest reliability, inter-rater reliability and intra-rater reliability)	Excellent	Good	Fair	Poor
13. for ordinal scores: Was a weighted kappa calculated?	Weighted Kappa calculated		Unweighted Kappa calculated	Only percentage agreement calculated
14. for ordinal scores: Was the weighting scheme described? e.g. linear, quadratic	Weighted scheme described	Weighted scheme NOT described		

Box C. Measurement error: absolute measures	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (<30)
4. Were at least two measurements available?	At least two measurements			Only one measurement
5. Were the administrations independent?	Independent measurements	Assumable that measurements were independent	Doubtful whether the measurements were independent	Measurements NOT independent
6. Was the time interval stated?	Time interval stated		Time interval NOT stated	
7. Were patients stable in the interim period on the construct to be measured?	Patients were stable (evidence provided)	Assumable that patients were stable	Unclear if patients were stable	Patients were NOT stable
8. Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval was appropriate	Time interval NOT appropriate
9. Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions	Test conditions were similar (evidence	Assumable that test	Unclear if test conditions were similar	Test conditions were NOT similar

Box C. Measurement error: absolute measures	Excellent	Good	Fair	Poor
	provided)	conditions were similar		
10. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
Statistical methods				
11. For CTT: Was the Standard Error of Measurement (SEM), Smallest Detectable Change (SDC) or Limits of Agreement (LoA) calculated?	SEM, SDC, or LoA calculated	Possible to calculate LoA from the data presented		SEM calculated based on Cronbach's alpha, or on SD from another population

Box D. Content validity (including face validity)	Excellent	Good	Fair	Poor
General requirements				
1. Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?	Assessed if all items refer to relevant aspects of the construct to be measured		Aspects of the construct to be measured poorly described AND this was not taken into consideration	NOT assessed if all items refer to relevant aspects of the construct to be measured
2. Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)	Assessed if all items are relevant for the study population in adequate sample size (≥10)	Assessed if all items are relevant for the study population in moderate sample size (5-9)	Assessed if all items are relevant for the study population in small sample size (<5)	NOT assessed if all items are relevant for the study population OR target population not involved
3. Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)	Assessed if all items are relevant for the purpose of the application	Purpose of the instrument was not described but assumed	NOT assessed if all items are relevant for the purpose of the application	
4. Was there an assessment of whether all items together comprehensively reflect the construct to be measured?	Assessed if all items together comprehensively reflect the construct to be measured		No theoretical foundation of the construct and this was not taken into consideration	NOT assessed if all items together comprehensively reflect the construct to be measured
5. Were there any important flaws in the design or methods of the study?	No other important methodological		Other minor methodological flaws in the	Other important methodological flaws in the

Box D. Content validity (including face validity)	Excellent	Good	Fair	Poor
	flaws in the design or execution of the study		design or execution of the study	design or execution of the study

Box E. Structural validity	Excellent	Good	Fair	Poor
1. Does the scale consist of effect indicators, i.e. is it based on a reflective model?				
Design requirements				
2. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
3. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
4. Was the sample size included in the analysis adequate?	7* #items and ≥100	5* #items and ≥100 OR 5-7* #items but <100	5* #items but <100	<5* #items
5. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. rotation method not described)	Other important methodological flaws in the design or execution of the study (e.g. inappropriate rotation method)

Box E. Structural validity	Excellent	Good	Fair	Poor
Statistical methods				
6. or CTT: Was exploratory or confirmatory factor analysis performed?	Exploratory or confirmatory factor analysis performed and type of factor analysis appropriate in view of existing information	Exploratory factor analysis performed while confirmatory would have been more appropriate		No exploratory or confirmatory factor analysis performed
7. for IRT: Were IRT tests for determining the (uni-) dimensionality of the items performed?	IRT test for determining (uni)dimensionality performed			IRT test for determining (uni)dimensionality NOT performed

Box F. Hypotheses testing	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥100 per analysis)	Good sample size (50-99 per analysis)	Moderate sample size (30-49 per analysis)	Small sample size (<30 per analysis)
4. Were hypotheses regarding correlations or mean differences formulated a priori (i.e. before data collection)?	Multiple hypotheses formulated a priori	Minimal number of hypotheses formulate a priori	Hypotheses vague or not formulated but possible to deduce what was expected	Unclear what was expected
5. Was the expected *direction* of correlations or mean differences included in the hypotheses?	Expected direction of the correlations or differences stated	Expected direction of the correlations or differences NOT stated		
6. Was the expected absolute or relative *magnitude* of correlations or mean differences included in the hypotheses?	Expected magnitude of the correlations or differences stated	Expected magnitude of the correlations or differences NOT stated		
7. for convergent validity: Was an adequate description provided of the comparator instrument(s)?	Adequate description of the constructs	Adequate description of most of the	Poor description of the constructs	NO description of the constructs measured by the

Box F. Hypotheses testing

	Excellent	Good	Fair	Poor
	measured by the comparator instrument(s)	constructs measured by the comparator instrument(s)	measured by the comparator instrument(s)	comparator instrument(s)
8. or convergent validity: Were the measurement properties of the comparator instrument(s) adequately described?	Adequate measurement properties of the comparator instrument(s) in a population similar to the study population	Adequate measurement properties of the comparator instrument(s) but not sure if these apply to the study population	Some information on measurement properties (or a reference to a study on measurement properties) of the comparator instrument(s) in any study population	No information on the measurement properties of the comparator instrument(s)
9. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. only data presented on a comparison with an instrument that measures another construct)	Other important methodological flaws in the design or execution of the study

Box F. Hypotheses testing	Excellent	Good	Fair	Poor
Statistical methods				
10. Were design and statistical methods adequate for the hypotheses to be tested?	Statistical methods applied appropriate	Assumable that statistical methods were appropriate, e.g. Pearson correlations applied, but distribution of scores or mean (SD) not presented	Statistical methods applied NOT optimal	Statistical methods applied NOT appropriate

Box G. Cross-cultural validity	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	CTT: 7* #items and ≥100 IRT: ≥200 per group	CTT: 5* #items and ≥100 OR 5-7* #items but <100 IRT: ≥200 in 1 group and 100- 199 in 1 group	CTT: 5* #items but <100 IRT: 100-199 per group	CTT: <5* #items IRT: (<100 in 1 or both groups
4. Were both the original language in which the HR-PRO instrument was developed, and the language in which the HR-PRO instrument was translated described?	Both source language and target language described			Source language NOT known
5. Was the expertise of the people involved in the translation process adequately described? e.g. expertise in the disease(s) involved, expertise in the construct to be measured, expertise in both languages	Expertise of the translators described with respect to disease, construct, and language	Expertise of the translators with respect to disease or construct poor or not described	Expertise of the translators with respect to language not described	
6. Did the translators work independently from each other?	Translators worked independent	Assumable that	Unclear whether translators	Translators worked NOT independent

Box G. Cross-cultural validity	Excellent	Good	Fair	Poor
		the translators worked independent	worked independent	
7. Were items translated forward and backward?	Multiple forward and multiple backward translations	Multiple forward translations but one backward translation	Multiple forward translations but one backward translation	Only a forward translation
8. Was there an adequate description of how differences between the original and translated versions were resolved?	Adequate description of how differences between translators were resolved	Poorly or NOT described how differences between translators were resolved		
9. Was the translation reviewed by a committee (e.g. original developers)?	Translation reviewed by a committee (involving other people than the translators, e.g. the original developers)	Translation NOT reviewed by (such) a committee		
10. Was the HR-PRO instrument pre-tested (e.g. cognitive interviews) to check interpretation, cultural relevance of the translation, and ease of comprehension?	Translated instrument pre-tested in the target population	Translated instrument pre- tested, but unclear if this was done in the target population	Translated instrument pre-tested, but NOT in the target population	Translated instrument NOT pre-tested
11. Was the sample used in the pre-test adequately described?	Sample used in the pre-test		Sample used in the pre-test	

Box G. Cross-cultural validity	Excellent	Good	Fair	Poor
	adequately described		NOT (adequately) described	
12. Were the samples similar for all characteristics except language and/or cultural background?	Shown that samples were similar for all characteristics except language /culture	Stated (but not shown) that samples were similar for all characteristics except language /culture	Unclear whether samples were similar for all characteristics except language /culture	Samples were NOT similar for all characteristics except language /culture
13. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
Statistical methods				
14. for CTT: Was confirmatory factor analysis performed?	Multiple-group confirmatory factor analysis performed			Multiple-group confirmatory factor analysis NOT performed
15. for IRT: Was differential item function (DIF) between language groups assessed?	DIF between language groups assessed			DIF between language groups NOT assessed

Box H. Criterion validity

	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (<30)
4. Can the criterion used or employed be considered as a reasonable 'gold standard'?	Criterion used can be considered an adequate 'gold standard' (evidence provided)	No evidence provided, but assumable that the criterion used can be considered an adequate 'gold standard'	Unclear whether the criterion used can be considered an adequate 'gold standard'	Criterion used can NOT be considered an adequate 'gold standard'
5. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study

Box H. Criterion validity

	Excellent	Good	Fair	Poor
Statistical methods				
6. for continuous scores: Were correlations, or the area under the receiver operating curve calculated?	Correlations or AUC calculated			Correlations or AUC NOT calculated
7. for dichotomous scores: Were sensitivity and specificity determined?	Sensitivity and specificity calculated			Sensitivity and specificity NOT calculated

Box I. Responsiveness	Excellent	Good	Fair	Poor
Design requirements				
1. Was the percentage of missing items given?	Percentage of missing items described	Percentage of missing items NOT described		
2. Was there a description of how missing items were handled?	Described how missing items were handled	Not described but it can be deduced how missing items were handled	Not clear how missing items were handled	
3. Was the sample size included in the analysis adequate?	Adequate sample size (≥100)	Good sample size (50-99)	Moderate sample size (30-49)	Small sample size (<30)
4. Was a longitudinal design with at least two measurement used?	Longitudinal design used			No longitudinal design used
5. Was the time interval stated?	Time interval adequately described			Time interval NOT described
6. If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described?	Anything that occurred during the interim period (e.g. treatment) adequately described	Assumable what occurred during the interim period	Unclear or NOT described what occurred during the interim period	
7. Was a proportion of the patients changed (i.e. improvement or deterioration)?	Part of the patients were changed (evidence provided)	NO evidence provided, but assumable that part of the patients were changed	Unclear if part of the patients were changed	Patients were NOT changed

Box I. Responsiveness	Excellent	Good	Fair	Poor
Design requirements for hypotheses testing				
For constructs for which a gold standard was not available:				
8. Were hypotheses about changes in scores formulated a priori (i.e. before data collection)?	Hypotheses formulated a priori		Hypotheses vague or not formulated but possible to deduce what was expected	Unclear what was expected
9. Was the expected *direction* of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?	Expected direction of the correlations or differences stated	Expected direction of the correlations of differences NOT stated		
10. Were the expected absolute or relative *magnitude* of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?	Expected magnitude of the correlations or differences stated	Expected magnitude of the correlations or differences NOT stated		
11. Was an adequate description provided of the comparator instrument(s)?	Adequate description of the constructs measured by the comparator instrument(s)		Poor description of the constructs measured by the comparator instrument(s)	NO description of the constructs measured by the comparator instrument(s)
12. Were the measurement properties of the comparator instrument(s) adequately described?	Adequate measurement	Adequate measurement	Some information on measurement	NO information on the measurement

Box I. Responsiveness	Excellent	Good	Fair	Poor
	properties of the comparator instrument(s) in a population similar to the study population	properties of the comparator instrument(s) but not sure if these apply to the study population	properties (or a reference to a study on measurement properties) of the comparator instrument(s) in any study population	properties of the comparator instrument(s)
13. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study (e.g. only data presented on a comparison with an instrument that measures another construct)	Other important methodological flaws in the design or execution of the study
Statistical methods				
14. Were design and statistical methods adequate for the hypotheses to be tested?	Statistical methods applied appropriate		Statistical methods applied NOT optimal	Statistical methods applied NOT appropriate
Design requirement for comparison to a gold standard				
For constructs for which a gold standard was available:				
15. Can the criterion for change be considered as a reasonable gold standard?	Criterion used can be considered	No evidence provided, but	Unclear whether the	Criterion used can NOT be

Box I. Responsiveness	Excellent	Good	Fair	Poor
	an adequate ‘gold standard’ (evidence provided)	assumable that the criterion used can be considered an adequate ‘gold standard’	criterion used can be considered an adequate ‘gold standard’	considered an adequate ‘gold standard’
16. Were there any important flaws in the design or methods of the study?	No other important methodological flaws in the design or execution of the study		Other minor methodological flaws in the design or execution of the study	Other important methodological flaws in the design or execution of the study
Statistical methods				
17. for continuous scores: Were correlations between change scores, or the area under the Receiver Operator Curve (ROC) curve calculated?	Correlations or area under the ROC curve (AUC) calculated			Correlations or AUC NOT calculated
18. for dichotomous scales: Were sensitivity and specificity (changed versus not changed) determined?	Sensitivity and specificity calculated			Sensitivity and specificity NOT calculated

Interpretability

We recommend to use the Interpretability box to extract all information on the interpretability issues described in this box of the instruments under study from the included articles.

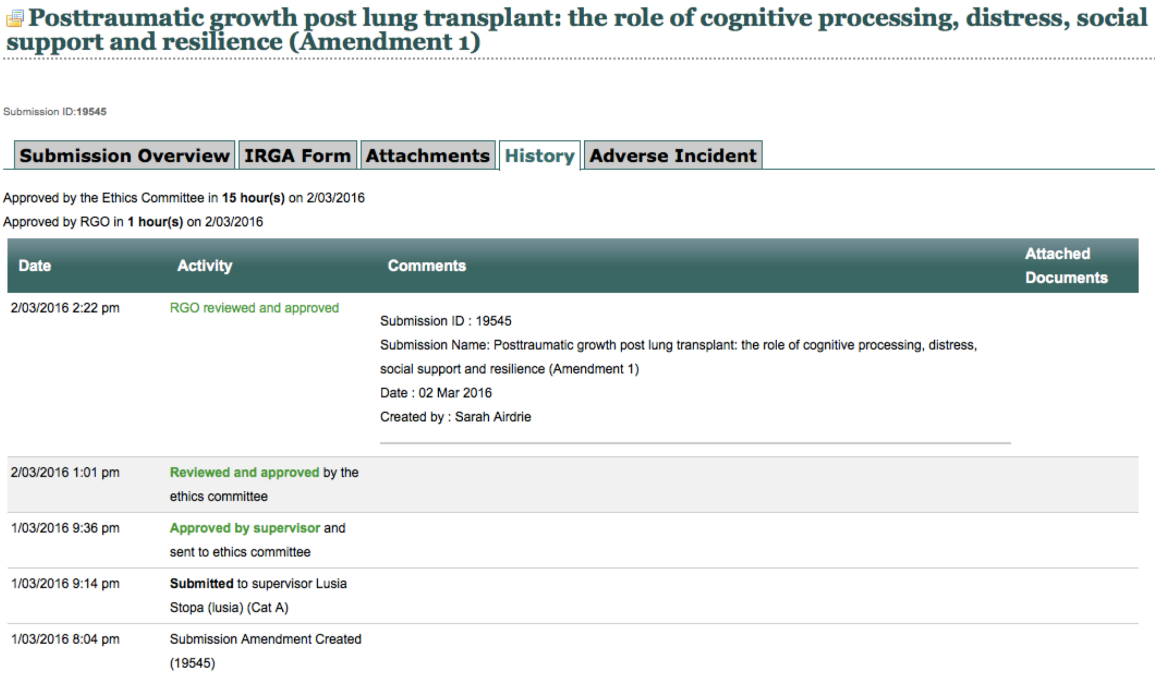
Box Interpretability	Study information
Percentage of missing items	
Description of how missing items were handled	
Distribution of the (total) scores	
Percentage of the respondents who had the lowest possible (total) score	
Percentage of the respondents who had the highest possible (total) score	
Scores and change scores (i.e. means and SD) for relevant (sub) groups, e.g. for normative groups, subgroups of patients, or the general population	
Minimal Important Change (MIC) or Minimal Important Difference (MID)	

Generalisability

We recommend to use the Generalisability box to extract data on the characteristics of the study populations and sampling procedures of the included studies.

Box Generalisability	Study information
Median or mean age (with standard deviation or range)	
Distribution of sex	
Important disease characteristics (e.g. severity, status, duration) and description of treatment	
Setting(s) in which the study was conducted (e.g. general population, primary care or hospital/rehabilitation care)	
Countries in which the study was conducted	
Language in which the HR-PRO instrument was evaluated	
Method used to select patients (e.g. convenience, consecutive, or random)	
Percentage of missing responses (response rate)	

Appendix E: University Ethical Approval



Posttraumatic growth post lung transplant: the role of cognitive processing, distress, social support and resilience (Amendment 1)

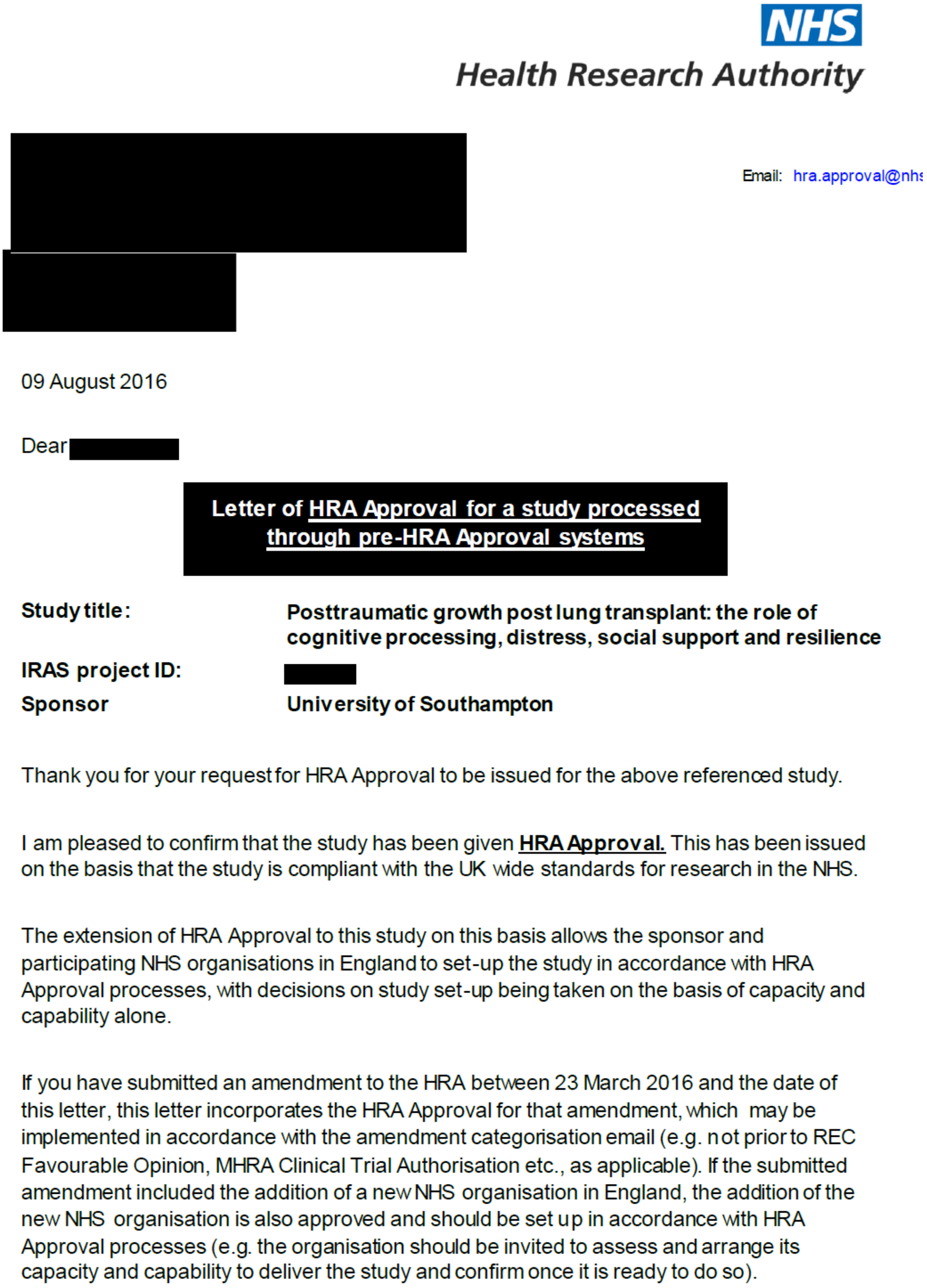
Submission ID:**19545**

Approved by the Ethics Committee in **15 hour(s)** on 2/03/2016

Approved by RGO in **1 hour(s)** on 2/03/2016

Date	Activity	Comments	Attached Documents
2/03/2016 2:22 pm	RGO reviewed and approved	Submission ID : 19545 Submission Name: Posttraumatic growth post lung transplant: the role of cognitive processing, distress, social support and resilience (Amendment 1) Date : 02 Mar 2016 Created by : Sarah Airdrie	
2/03/2016 1:01 pm	**Reviewed and approved** by the ethics committee		
1/03/2016 9:36 pm	**Approved by supervisor** and sent to ethics committee		
1/03/2016 9:14 pm	**Submitted** to supervisor Lusia Stopa (lusia) (Cat A)		
1/03/2016 8:04 pm	Submission Amendment Created (19545)		

Appendix F: HRA Approval Letter



NHS
Health Research Authority

[redacted]

Email: hra.approval@nhs

09 August 2016

Dear [redacted]

Letter of HRA Approval for a study processed through pre-HRA Approval systems

Study title:	**Posttraumatic growth post lung transplant: the role of cognitive processing, distress, social support and resilience**
IRAS project ID:	[redacted]
Sponsor	**University of Southampton**

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **HRA Approval.** This has been issued on the basis that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).

Participation of NHS Organisations in England

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with HRA Approval Processes. It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate Statement of Activities and HRA Schedule of Events. The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study. If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA..

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

After HRA Approval

ADD option if study required a REC Favourable Opinion In addition to the document, *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the HRA website.

Your IRAS project ID is 198067. Please quote this on all correspondence.

Yours sincerely

HRA Approval Team

Email: hra.approval@nhs.net

Copy to: [redacted]
[redacted]

Appendix G: Demographic Information

1. What is your gender?

☐ Female

☐ Male

2. What is your age?

…………………………

3. What is the highest level of education you have completed?

☐ Less than high school degree
☐ O Levels, GCSEs (or equivalents)
☐ A Levels (or equivalents)
☐ Vocational training certificate(s) (e.g., City and Guilds, NVQ)
☐ Bachelor's degree
☐ Master's degree
☐ Doctoral degree
☐ Higher professional qualifications (e.g., accountancy, law, etc)
☐ Other

4. Which of the following best describes your relationship status?

☐ Married
☐ Widowed
☐ Single
☐ Divorced
☐ Civil partnership
☐ Co-habiting

5. Which of the following categories best describes your employment status?

☐ Employed
☐ Not employed
☐ Unable to work
☐ Retired

6. What is your ethnicity?

☐ White
☐ Black-Caribbean
☐ Black-African
☐ Black-Other
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Other (please specify) ………………

7. How long did you wait on the lung transplant waiting list?

…………Years…………….Months

8. How long has it been since your lung transplant?

…………Years…………….Months

9. What type of transplant did you have?

☐ Unilateral (single) lung transplant

☐ Bilateral (double) lung transplant

10. What primary medical condition did you have that meant you required the transplant?

☐ Cystic Fibrosis (CF) and bronchiectasis
☐ Chronic Obstructive Pulmonary Disease (COPD) and emphysema
☐ Fibrosing lung disease
☐ Primary pulmonary hypertension

11. What is your height?

…………cm or …………in

12. What is your weight?

…………kg or …………st

13. What is your current FEV1 lung function?

…………..%

Appendix H: Questionnaire Information Sheet

Questionnaires Participant Information Sheet

(Version 4; 12.05.2016)

Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience

Researchers' names: Sarah Airdrie, Dr Melissa Sanchez and Dr Lusia Stopa

Thank you for being interested in our study. I am a Trainee Clinical Psychologist at University of Southampton. As part of my training I am conducting research into people's experiences of having a lung transplant. Before you decide whether you would like to take part, please take the time to read the following information carefully and discuss with others if you wish. If there is anything that is not clear, or if you would like more information, please feel free to contact me on the contact details provided below.

What is the research about?

We are interested in understanding people's experiences of positive life change (known as posttraumatic growth) after having a lung transplant. We are also interested in the relationship between your thinking, social support, positive and negative coping, and aspects that helped you to recover from having a lung transplant.

Why is the study being done?

Having a lung transplant can improve people's physical health and quality of life. Research suggests people who have a transplant are less likely to have mental health difficulties. Therefore, it is out hope that this research will help us gain an understanding of people's experience of positive life change after this significant life event.

Why have I been invited?

You have been invited because you have had a lung transplant. You are eligible to take part if you are aged 18 years and older, have had a single or double lung transplant in the last 10 years (and not within a month of surgery).

Do I have to take part?

You are free to decide whether or not to take part in this study. After reading the information sheet, we will ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason. If you chose not to take part or withdraw, this will not affect the care you get from your doctors.

What will happen to me if I take part?

If you agree to take part in this study, you will be asked to complete 6 questionnaires about your experiences after your lung transplant. The questionnaires will take approximately 30 to 45 minutes.

After completing the questionnaires, you will be asked if you would like to take part in an interview about your experiences. This will give you an opportunity to share your experiences in more detail. The interview will take approximately 30 to 45 minutes and it will be audio-recorded and transcribed. You do not have to decide now whether you want to take part. If you are interested in taking part we will ask you to provide your contact details after completing the questionnaires.

What are the possible benefits of taking part?
We hope that with your help we will find ways to improve follow up care people receive after having a lung transplant. Although there will be no immediate benefit for the people taking part in the study, we hope that their participation will be beneficial to other people in the future.

What are the possible disadvantages and risks of taking part?
We have tried to ensure that the questions in this study do not cause any distress. However, it is not uncommon to experience some anxieties or concerns when completing questionnaires about the impact of your transplant on your well-being. Therefore, information about additional support will be provided in the debrief. The University of Southampton Research Ethics Committee (REC) and South Central – Hampshire B REC, have approved this study.

What if there is a problem?
If you have a question or concern about any aspect of this study you should ask to speak to one of the researchers, Sarah Airdrie who will do their best to answer your questions [redacted]

If you remain unhappy and wish to complain formally you can do this through the Chair of the Faculty of Social and Human Sciences Ethics Committee (Phone: 023 8059 3856, Email: fshs-rso@soton.ac.uk).

Will my taking part in the study be kept confidential?
All information collected about you during the research will be kept strictly confidential. All paper data will be stored in a locked cabinet, accessed only by the research team. Research data will be made anonymous and given a research code and electronic data will be stored on a password protected computer known only to the researcher. This will make sure the study complies with the Data Protection Act (1998). All information will be kept confidential unless we are concerned about yourself or others' safety. If this is identified, your clinical staff team will be informed.

The University of Southampton policy recommend research data is kept for a minimum of 10 years and then disposed of securely. This will be followed in this study.

What will happen if I don't carry on with the study?
Your participation is voluntary and you may change your mind at any time, without giving a reason. If you withdraw from the study all the information and data collected from you, to date, will be destroyed and your name will be removed from all the study files. This will not affect the care you receive from your doctors in the future.

Who is organising or sponsoring the research?
The University of Southampton is sponsoring this research study.

Further information and contact details:
If you would like additional information about taking part in research please look at British Lung Foundation website (https://www.blf.org.uk) who can provide advice and support.

If you would like specific information about this research project please contact: Sarah Airdrie [redacted]

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

Appendix I: Questionnaire Opt In Form

Opt in sheet - questionnaires
(Version 4; 12.05.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez and Dr Lusia Stopa

My name is ……………………………………..

Please tick one box below as appropriate:

I would be interested taking part in the research ☐
or
I do not wish to be contacted about this again ☐

If you are interested in taking part please provide your contact details below and the researcher will contact you about taking part:

Name: __________________
Address: __________________
____
City __________________
Postcode __________________

Email address: __________________
Telephone number: __________________

Please tick your preferred method of communication:
☐ Post ☐ Email ☐ Telephone

Please return to clinic administrator or member of clinical team FAO Sarah Airdrie or [redacted]

Appendix J: Questionnaire Consent Form

Questionnaire Consent Form
(Version 5; 02.06.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez and Dr Lusia Stopa

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (12.05.2016/version 4). I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. ☐

I agree for my data to be used for the purpose of this study, and the information collected about me may be shared anonymously with other researchers. ☐

I understand my participation is voluntary and I may withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

I agree to take part in this research project. ☐

Name of Participant (print name)	Signature	Date
Name of Person taking consent	Signature	Date

Appendix K: Questionnaire Debrief

Questionnaire Debriefing Statement
(Version 5; 02.06.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez and Dr Lusia Stopa

Thank you for participating in this research! The aim of this research was to gain a greater understanding of positive life change (known as posttraumatic growth) after having a lung transplant. We were also interested in the relationship between your thinking, social support, positive and negative coping, and aspects that helped you to recover from having a lung transplant.

Your data will help us to understand your views and experiences post transplant. This has hopefully provided you with an opportunity to voice your experiences. This will help us to be aware of ways we need to improve follow up service you receive.

We have tried to ensure that the questions in this study do not cause any distress. However, if you felt upset or distressed by the content, please do not hesitate to contact a member of your clinical staff team at the hospital.

If you would like further therapeutic support please contact your GP to discuss possible therapeutic interventions or psychological therapies such as Improving Access to Psychological Therapies (IAPT).

You may wish to seek support from charities including:

- **British Lung Foundation** (https://www.blf.org.uk/): Tel: 03000 030 555. Lines are open 9am to 5pm.
- **Mind** (https://www.mind.org.uk/): Tel: 0300 123 3393. Lines are open 9am to 6pm, Monday to Friday (except for bank holidays). Email: info@mind.org.uk; Text: 86463

If you require urgent support:

- Please contact you **GP** or 101. **NHS 101** is a NHS non-emergency number to talk to a health-care advisor. This is available 24 hours a day, 365 days a year.

Once again results of this study will not include your name. Thank you for your participation in this research.

Researcher's Signature ________________________________
Date ___________________

Appendix L: Interview Opt in

Further research involvement?

In addition we would like to interview a number of people about their experiences of having a lung transplant.

This would involve meeting with you for 30 to 45 minutes and asking you a number of questions about your experiences. This would be done at a convenient time or place to coincide with your hospital clinic appointments, at home (if you live in the local Hampshire area), on the University of Southampton premises, or via Skype. I will audio-record our conversations and transcribe them. After this, all personal identifiable information will be removed to make the data anonymous.

If you are interested in taking part, please complete your details below. The researcher will then contact you with further information about taking part.

Name: ___________________

Address: ___________________

____

City ___________________

Postcode ___________________

Email address: ___________________

Telephone number: ___________________

Please tick your preferred method of communication:

☐ Post ☐ Email ☐ Telephone

Please return to clinic administrator or member of clinical team FAO Sarah Airdrie or [redacted]

Appendix M: Interview Information Sheet

Interview Participant Information Sheet
(Version 4; 12.05.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez and Dr Lusia Stopa

Thank you for being interested in our study. I am a Trainee Clinical Psychologist at University of Southampton. As part of my training I am conducting research into people's experiences of having a lung transplant. Before you decide whether you would like to take part, please take the time to read the following information carefully and discuss with others if you wish. If there is anything that is not clear, or if you would like more information, please feel free to contact me on the contact details provided below.

What is the research about?
We are interested in understanding people's experiences of positive life change (known as posttraumatic growth) after having a lung transplant. We are also interested in the relationship between your thinking, social support, positive and negative coping, and aspects that helped you to recover from having a lung transplant.

Why is the study being done?
Having a lung transplant can improve people's physical health and quality of life. Research suggests people who have a transplant are less likely to have mental health difficulties. Therefore, it is out hope that this research will help us gain an understanding of people's experience of positive life change after this significant life event.

Why have I been invited?
You have been invited because you have had a lung transplant. You are eligible to take part if you are aged 18 years and older, have had a single or double lung transplant in the last 10 years (and not within a month of surgery).

Do I have to take part?
You are free to decide whether or not to take part in this study. After reading the information sheet, we will ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason. If you chose not to take part or withdraw, this will not affect the care you get from your doctors.

What will happen to me if I take part?
If you agree to take part in this study, you will take part in a single semi-structured interview about your views and experiences. The researcher will meet with you when you have your next clinic appointment or on Skype. If you live in the Hampshire area it is possible to meet you at home or on the university premises. This interview will take up to 30 to 45 minutes and will be audio-recorded and transcribed.

What are the possible benefits of taking part?
We hope that with your help we will find ways to improve follow up care people receive after having a lung transplant. Although there will be no immediate benefit for the people taking part in the study, we hope that their participation will be beneficial to other people in the future. You will also receive a £20 Amazon voucher for your time and effort.

What are the possible disadvantages and risks of taking part?
We have tried to ensure that the questions in this study do not cause any distress. However, it is not uncommon to experience some anxieties or concerns when completing questionnaires about the impact of your transplant on your well-being. Therefore, information about additional support will be provided in the debrief. The University of Southampton Research Ethics Committee (REC) and South Central – Hampshire B REC, have approved this study.

What if there is a problem?
If you have a question or concern about any aspect of this study you should ask to speak to one of the researchers, Sarah Airdrie who will do their best to answer your questions [redacted]

If you remain unhappy and wish to complain formally you can do this through the Chair of the Faculty of Social and Human Sciences Ethics Committee (Phone: 023 8059 3856, Email: fshs-rso@soton.ac.uk).

Will my taking part in the study be kept confidential?
All information collected about you during the research will be kept strictly confidential. All paper data will be stored in a locked cabinet, accessed only by the research team. Research data will be made anonymous and given a research code. The audio recording of your interview will be deleted from the device as soon as possible and transferred to a password-protected computer known only to the researchers. The recording will be transcribed, your name will be removed from the interview, and the audio recording will be deleted. This will make sure the study complies with the Data Protection Act (1998). All information will be kept confidential unless we are concerned about yourself or others' safety. If this is identified, your clinical staff team will be informed.

The University of Southampton policy recommend research data is kept for a minimum of 10 years and then disposed of securely. This will be followed in this study.

What will happen if I don't carry on with the study?
Your participation is voluntary and you may change your mind at any time, without giving a reason. If you withdraw from the study all the information and data collected from you, to date, will be destroyed and your name will be removed from all the study files. This will not affect the care you receive from your doctors in the future.

Who is organising or sponsoring the research?
The University of Southampton is sponsoring this research study.

Further information and contact details:
If you would like additional information about taking part in research please look at British Lung Foundation website (https://www.blf.org.uk) who can provide advice and support.

If you would like specific information about this research project please contact: Sarah Airdrie [redacted]

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

Appendix N: Interview Consent Form

Interview Consent Form
(Version 5; 02.06.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez Dr Lusia Stopa

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (12.05.2016/version 4). I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. ☐

I agree for my data to be used for the purpose of this study, and the information collected about me may be shared anonymously with other researchers. ☐

I understand my participation is voluntary and I may withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

I consent to the interview being audio-recorded and that the researcher can use anonymous quotes from my interview when reporting the study. ☐

I agree to take part in this research project. ☐

____________________	____________________	____________________
Name of Participant (print name)	Signature	Date
____________________	____________________	____________________
Name of Person taking consent	Signature	Date

Appendix O: Interview Topic Guide

Interview Topic Guide
(Version 3; 01/03/2016)

Questions:

1. Could you tell me a little about your experience of having a lung transplant?
2. What thoughts crossed your mind after having your transplant?
   (Did these change or not change over time?)
3. Can you tell me if you feel differently since having the transplant? Happy/sad/worried?
4. What is the best/worst thing about having a transplant?
5. Did you have any expectations of how life would be after having a transplant?
6. Can you tell me if your life has changed? In what way? How do you handle these changes? What helps you cope?
7. What kinds of things do you think about when you think about your future?
8. What are some of the important relationships in your life? Who do you turn to when you are not feeling well, or going through a hard time?
9. What advice would you give to other people who are adjusting to life after having a lung transplant?
10. Is there anything that you would like to tell me that you think is important that I haven’t asked about?

Appendix P: Interview Debrief

Interview Debriefing Statement
(Version 5; 02.06.2016)
Posttraumatic growth post transplant: the role of cognitive processing, distress, social support and resilience
Researchers' names: Sarah Airdrie, Dr Melissa Sanchez, Dr Lusia Stopa

Thank you for participating in this research! The aim of this research was to explore participant's experiences after having a lung transplant and the development of positive life change, known as posttraumatic growth.

Your data will help us to understand your views and experiences post transplant. This has hopefully provided you with an opportunity to voice your experiences. This will help us to be aware of ways we need to improve follow up service you receive.

We have tried to ensure that the questions in this study do not cause any distress. However, if you felt upset or distressed by the content, please do not hesitate to contact a member of your clinical staff team.

If you would like further therapeutic support please contact your GP to discuss possible therapeutic interventions or psychological therapies such as Improving Access to Psychological Therapies (IAPT).

You may wish to seek support from charities including:

- **British Lung Foundation** (https://www.blf.org.uk/): Tel: 03000 030 555. Lines are open 9am to 5pm.
- **Mind** (https://www.mind.org.uk/): Tel: 0300 123 3393. Lines are open 9am to 6pm, Monday to Friday (except for bank holidays). Email: info@mind.org.uk; Text: 86463

If you require urgent support:

- Please contact you **GP** or 101. **NHS 101** is a NHS non-emergency number to talk to a health-care advisor. This is available 24 hours a day, 365 days a year.

Once again results of this study will not include your name. Thank you for your participation in this research.

Researcher's Signature ________________________________
Date ____________________

Appendix Q: Additional Information about Data Analysis

Parametric test assumptions were examined. Total scores and subscales were non-normally distributed except for the total CDRISC and deliberate subscale for the ERRI. Total PTGI and PTGI subscales were slightly negatively distributed and total MSPSS and MSPSS subscales were negatively distributed. Intrusive subscale was slightly positively skewed and total DASS-21, total IES and subscales for the respective scales were positively skewed. On the DASS-21, IES, MSPSS, and CDRISC outliers were identified and these values were substituted with values 2 standard deviations above or below the mean. Log, square root and reciprocal transformation variables were computed, which slightly improved the distributions for some variables. However, the recommended criteria for kurtosis and skew were not met (Field, 2009). The relatively large sample size permitted bootstrapping to ensure bias corrected accelerated 95% confidence intervals for the regression analysis and ensure robustness of statistical analysis (Field, 2009). The scatter plots were linear.

Hierarchical multiple regression test assumptions were met. The variance inflation factor showed that multi-collinearity was not an issue. The assumption of independent errors was met illustrated by the Durbin-Watson test being close to 2. Homoscedasticity was also demonstrated by the residuals being normally distributed. The standardised residuals considered possible outliers in the model and revealed 95% cases did not have absolute values above two and 99% cases did not have absolute values above 2.5 which suggested it was unlikely there were extreme cases affecting the accuracy of the regression model.

Appendix R: Sample Analysed Transcript

Transcribed Interview: Mr D

Interview details

Project Title: Posttraumatic growth post lung transplant

Interview date, time, location: 21.11.2016, 12.30, Clinic

Interviewer: SA ('I')

Interviewee: Participant 4 ('Mr D')

Interview Transcript:

I: I'm SA and I'm a Trainee Clinical Psychologist and I'm aiming to explore peoples' experiences of having a lung transplant. And I am interested in your views and experiences of that. This will involve taking part in a single semi-structured interview, and that will probably last between 30 to 45 minutes. The interview will be audio-recorded and transcribed later, and I'm just going to ask you a number of questions about those experiences. Personal information will not be released or viewed by any other person not involved in the project and the results will not include your name or any other identifying characteristics. Although I do need to say, if there is anything that you might say that puts yourself or others at risk from harm, I will need to contact a member of the clinical team, if that's okay to think about any other ways that might be useful to support you. Your participation is voluntary and you can withdraw at any time. Do you have any questions?

Mr D: The audio-recording is it available to for me to have later or?

I: Wouldn't probably plan to have that but if you wanted it then you would be welcome and I could try to find a way of getting it you if you would really like it.

Mr D: I will decide at the end if that's okay?

I: Yes of course. It's your recording so I guess I see no reason why I couldn't do that. Okay. Are there any other questions?

Mr D: Not so far.

I: Brilliant. Okay. First of all, could you tell me a little bit about your experience of having a lung transplant?

Declining lung function
Impact on mental health

Mr D: Okay. So having cystic fibrosis, reaching the age of about 43/44 reasonably healthy. Then let's say, 12 months prior to transplant my health went downhill very quickly. 24-hour oxygen, limited mobility, quite a few hours every day of percussive physiotherapy to clear my chest. Very draining physically, quite draining mentally. It was January of 2015 I was, the discussion about being on the transplant list was put forward and between my local hospital and [hospital] lots of tests were done. I think I was, came to [hospital] first in the May of 2-15. And I was, agreed to be on the transplant list and I was on the transplant list for about six to eight weeks. First call was successful.

I: Great.

Mr D: And I had the transplant.

I: Excellent. And what's life been like since having the transplant?

Mr D: It's been the best 16 months of my healthy adult life.

I: Okay.

Dramatic change in physical health + functioning

Mr D: So I've never been so healthy, fit, done as much, felt I could do as much, potential there is great. I haven't exhausted the potential yet.

I: There's still time.

Mr D: Yeah. It's still quite unreal.

I: Okay.

Breathing without difficulties

Mr D: Because the breathing part, the I don't think about breathing. And for the past 20 or so years prior to transplant there were every three months, sometimes more often into hospital for two weeks for intravenous antibiotics. There was the coughing, there was the all sorts, there was the last say 5/10 years there was a lot of percussive physiotherapy. So a lot of freedom has been given me and I've got a taste of what it can be like to be normal. I've got diabetes, I've got to take tablets.

But compared to what I had before, that is a minor convenience as worst.

I: Okay.

Mr D: There's the odd trip up to [name] hospital, seven and a half hour maybe round trip.

I: Yeah.

Mr D: But again, it's it's unreal, it's it's unreal.

I: Okay, that's really good to hear. And kind of what thoughts crossed your mind after having the transplant? Can you take yourself back to around that time or even up to now?

Mr D: Well I had many thoughts. So what are you looking for I mean we all have thoughts about?

I: Yeah. All kinds of thoughts. So I guess thoughts about of having had that transplant and kind of things that came to your mind immediately or about the transplant?

Difficulties post surgery

Mr D: First week was tough. Cause I think I was having a reaction to the, might be a normal reaction to the anaesthetics so I was away with the fairies for, some nasty hallucinations so that was whilst I was in ITU.

I: Yeah.

Concerns about transplant success

Mr D: So that was the first week to eight/nine days and there were a lot of doubts about was the transplant successful in my mind. No one else's.

I: Yeah.

Mr D: In my mind. And I kept on checking what what are my saturation levels? What are this? What are that? So after the first eight/nine days of being almost paranoid that things weren't right and that was partly because of my mental state.

I: Yeah.

Task-setting

Mr D: Having such a big thing. It's quite common. After that, once I became myself again, I think everything was positive. Focused on getting out of hospital. There were there were requirements for me, physical requirements for me to do before I could be discharged, walking for a certain distance or time, and flight of steps. So I adhered

Physical goals

to what the physiotherapists were were you know instructing me to do my exercises cause you're left for maybe hours in the day you know to do stuff. So, doing the exercises like arms and legs and what have you. So the first, so after the first 9/10 days, then it was another week or so to 10 days on the I think it was [name] ward. So the recovery ward. So it was, that was graft. And I was out of here in three weeks in total. So I'm pleased with that. They were as well. Then, went home, we were quite nervous, my partner and I, a lot you know a lot of medications to take, important ones, things to watch out for. So, we were home for two days, we were back in for clinic. So the first say four to six weeks it's twice a week for the clinic. So you're quite, your head is still in hospital mode.

Concern about medication

I: Yeah, definitely.

Mr D: But within that, I was very weak, my legs were quite weak. It was tough to get up a flight of stairs. Doable. Cause the muscle wastage in the legs, that's the biggest shock for me was how much I had sort of lost my strength in the legs as well as arms. But your body goes through quite a lot in those, in those first few weeks.

Patience with recovery

I: Yeah. And then kind of six weeks I guess you're now at home, can you recall any of the particular thoughts that you might of had then about the transplant?

Mr D: I get flashbacks about a lot about those first weeks or 10 days in ITU because that was mentally tough.

I: Yeah.

Accept difficult experiences have happened

Mr D: But it was then more changing it to looking forward, having been through an ordeal.

I: Yeah.

Physical goals

Mr D: Looking forward and finding out what I can do and setting goals for myself. And they were mainly physical goals.

I: Yeah. And what kind of, can you give me an example of some those goals?

Mr D: Yes. In the first year I would of liked to of, my goals were to walk up Snowden, Scafell Pike and

Ben Nevis. So mainland Britain's top three mountains.

I: Yeah.

Mr D: So we bagged all those. That was good.

Mr D: Brilliant.

Physical goals

Mr D: And cycling, and hillwalking, so I, another one was a 25-mile hike around Brecon beacons. That takes then and a half hours. Exhausting. Done that. And lots of mountain biking, sea kayaking. So there were lots of things that my goals to what what would I of wanted to do in a few years prior to the transplant. And it's, so I wanted to do that for myself, for my partner and for the for the to tell other people – this is what happens, the change between before and after transplant.

Give back to family members

I: Yeah.

Inspiring Others

Mr D: And I had, I've got a friend whose actually still in here now. She was debating whether to have a transplant. And I wanted to encourage her, you know this is this is the potential of the difference in life between before and after a transplant. And I wanted to set a good example for her to encourage her to put herself on the list.

I: Yeah.

Mr D: And luckily enough she had a transplant five weeks ago. She's upstairs now.

I: Ah great.

Mr D: And so I'm hoping in some small way I you know showed that person where things could go.

I: Yeah, definitely.

Mr D: So but mostly, challenge myself, set myself goals.

I: Yeah.

Mr D: So I'm quite a sort of focused person.

I: Brilliant. And what kind of emotions did you feel? Did you feel differently since having the transplant?

Mr D: Oh blimey.

I: Were they happy? Was it worry? Sad? What kind of things?

Limited time available

Not a cure

Mr D: Concern. I wouldn't go with worry. I tend not to be a worrier too much but concern. Cause you you, with a transplant we are all aware that your egg timer has turned over. But it's an egg timer. And we we look at the numbers of how long you've got with a transplant. What things to look out for. So it's not a cure. So you're hyper alert. Almost paranoid about you know – am I doing things right? So I think probably for the first six to nine months. I think the consultants would agree that I was overly concerned with figures, with statistics. Where am I on this list? Trying to predict the future.

I: Yeah.

Calmer post transplant

Mr D: In these early, in the first year. And having gone through the first year I've become much more relaxed. But the reason I'm up here today and two weeks ago is because I have a slight concern with a drop in lung function, and there was a slight rattling in the throat. So I wanted to check that. So there is, I'm not so blasé where I'm not ignoring the feedback.

I: Yeah.

Mr D: So I'm, I'm much more easy going the longer I'm going into it. I think the first year you're very aware of you know where am I on the statistics?

I: Yeah, understandable.

Mr D: Yes. Yes I had mixed emotions. I don't think I've experienced, imagine I've experienced any emotions of thoughts that many other people haven't. I don't think I've been particularly moody or particularly happy. I tend to be fairly unemotional. I'm not ecstatic and I'm not you know very depressed, I'm somewhere in the middle but I'm my emotions tend not to stray much from the from the centre line.

I: Yeah, okay. Thank you. And what is the best thing about having had a transplant?

Breathing without difficulties

Mr D: Breathing. Without thinking about it.

I: Yeah.

Mr D: Having time to do things. And being alive for my partner.

I: Yeah.

Give back to family members

Mr D: She put and the investment, the effort, the time, that my partner put in to keeping me alive, to keep me going for my transplant. Just paying that back. Seeing the smile on her face. Being part of her life.

I: Yeah.

Give back

Mr D: Keeping her happy. That is the best thing about having the transplant. Being, helping reward someone else for all their effort. And myself. Other things would be experiencing things that I've never experienced before in the 45 years prior to having the transplant.

I: Yeah.

Accept difficult experiences have happened

Mr D: The energy. The possibilities. I'm not looking too far ahead but a future but that was kind of looking bleak for a time.

I: Yeah.

Ability to make decisions

Mr D: Having space mentally to enjoy things that there wasn't space before. It was all about treatment and lack of energy and sleeping and just where's the breath coming from. And not having discomfort, not having pain. I could go on but, yeah.

I: Sounds like life is really different.

Mr D It is the most transforming thing that I have had ever done. You're looking before and after. Yeah it's unbelievable. It's magic trick.

I: Amazing. Okay. And thinking on the other side what is the worst thing about having a transplant?

Reduced life expectancy

Mr D: Not really thought about it. That's not a question that's that's ever come to mind, so now you're posing it. Having a different condition that I can probably do less about. Rejection. You can't treat rejection quite often with anything.

I: No.

Mr D: And knowing that, where cystic fibrosis your decline was more linear. You could probably say, Not a cure

however ill I am now I've got a year, two years before things get naughty. And then there's maybe another option, I'm already on that last option. So I'm not having a standby. If your transplant fails, knowing that quite possibly you couldn't have another transplant, that that's not that that's not a certainty. This might be, you might only have six months, or a year or depending on the speed of decline with this new condition I've got. I suppose, that, the potential for that to happen, I know of course it will, transplants don't last forever. So you you're wary of that.

I: Yeah.

Mr D: And that's in the back of the mind that you can't fully relax. Cause I've got this new condition that there's no plan B.

I: Right.

Mr D: Or hardly, rarely a plan B. So yeah, there's that addition to, that that's on the plate as well as my cystic fibrosis and whatever else I've got.

I; And has that come up recently?

Mr D: No.

I: Okay. But that that's on our minds before the transplant.

I: The rejection?

Limited time available

Mr D: Rejections. Well, it's your last your last kind of roll of the dice as it were. As it's something that I'm aware of that a few people tried to put off going on the transplant list. Trying to eek out as much as they can with the old set of lungs knowing that there's the stopwatch starts, once you've had a transplant. And keeping that as long as you can before you need start that stopwatch or turn the egg timer over.

I: Yeah.

Support on social media

Mr D: So there's that sort of, there's that way of thinking. It's it's been there for a while before transplant but it's more real after transplant and then through social media, Facebook, and the like you can't help but get told by other people that such and such had a year, such and such had two years, and somebody needs another, a redo.

I: Yeah.

Mr D: Somebody had a transplant from our local hospital within a month or two months of myself, has needed another one for another six months, has been on the redo list.

I: Right, okay.

Realisation of a future

Mr D: So and that's a potential. That's always there. I guess that was never there before. I've was never in that position before transplant. So that was the reality of that possible outcome is now with me.

I: Yeah, yeah.

Mr D: Well it's one of those things you try and stuff at the back of the cupboard.

I: Okay. Yeah. Fair enough.

Mr D: Don't bring it out and dust it often.

I: Okay. We will leave it there then in that area. And did you have any expectations of how life would be after having a transplant?

Mr D: I tried not to.

I: Okay.

Mr D: I was hoping for a break from the exhaustive, draining regime.

I: Yeah.

Impact on physical functioning

Family strain

Uncertainty about transplant surgery

knowledge of risks

Mr D: The discomfort, the pain. I was having an end to that and for what it was causing for other people around me. I wanted, I was hoping for that. And I was kind of presuming if I was having a transplant I wouldn't have all the treatments, so time consuming, I would have more energy. So there were basic ones. And that's a presumption looking at other people who've not had, you come from the stage of, "Will I wake up from the operation?". A best friend of mine didn't. Couldn't restart the heart. So you've got all the way from there to. Another friend of mine is pushing 20 years post-transplant. So there's there's the book ends as it were of what could happen. So I knew I'd be clearly in that window

Mr D: That that's my relationships at the moment. It takes care of probably 100% of sort of the relationship aspect of life.

I: And who do you turn to when you're having a difficult time or?

Mr D: My partner. I think most of my, what what's the phrase? Eggs are in one basket.

I: Yeah.

Mr D: So yeah there is a lot effort. We passed each other within about two miles cause she just flew back from New York this morning.

I: Oh right, okay.

Mr D: I was just driving past [location] and I think she was touching down.

I: Oh, okay.

Mr D: So I think we were passing in the early morning there otherwise she would have been here with me.

I: Oh okay. And what advice would you give to other people who are adjusting to life after a transplant?

Mr D: Relax.

I: Yeah.

Mr D: There's nothing you can do about if anything goes wrong, you can't do anything. Be pragmatic. Don't get emotional. If you've got worries, voice them straight away. What happens happens. If you're alive six months after your transplant and it's going reasonably well then you're up on the game. Cause usually you wouldn't be around, well depending on how fast you go downhill I wouldn't I wouldn't of been around probably about a month/two months if I hadn't had my transplant when I did. Winter was coming. I was finding it tough. So for me, once I got home, relax and enjoy. Work hard to enjoy yourself. Focus on that and don't let, even though my first year was kind of, concerned about the figures and what's this? What's that? Is that cough right? Am my blows a bit down or? Just be vigilant but relax and

Medical advice and treatment

Loosing hope

Limited time available

enjoy yourself. It's more important that you're enjoying yourself now more than ever.

I: Yeah.

Appreciation towards donor

Mr D: Cause you're kind of enjoying yourself now for two people. You've got to think about the donor who, make the donor proud of what you're doing. Take the new lungs to mountains perhaps those lungs never went to before. Experiences those old lungs never had before. Carry that, carry the soul of the other person around with you. Make them proud of you. And so and my adventures and my explorations and what I get up to, I'm doing it not just for me, I'm doing it for the set of lungs, for my partner. It's nice to come back with stories of look what I've done.

I: Absolutely.

Inspiring Others

Mr D: Look what I've got away with. So you know and I can inspire people in some small way, that's a bonus. I don't do it for that. I do it for me, I'm a bit selfish. My fun is for me. And so enjoy life. I'm not of a religion that I'm going to come back around again. This is my only stab at it. So yeah, enjoy myself.

I: Brilliant.

Fortunate

Mr D: And also for the medical team here, if they get to hear what I've done, that's gotta make them feel good. Look at what we did. They made a difference. They made a huge difference. And I like to make it nice and clear how much of a difference they've made. By climbing mountains and getting into all sorts of mischief. Then they can see what they've done. Look at what you made me do.

I: Yeah. Brilliant. And is there anything else that you would like to tell me that you think is important that I haven't asked you?

Reduced life expectancy

Mr D: Yeah. Just because I'm 16 months post, doesn't mean to say that I haven't resolved any issues mentally. What if I started going downhill, how am I going to mentally cope with that in the future? Will I start to worry a lot? I don't know. So, I'm not going to say it's going to be plain sailing from here on in. So I don't know what the futures going to hold. So I can't be I can't ever be

Adapting + adjusting to new opportunities

too relaxed. I've still got a very serious thing going on for me, I've got my cystic fibrosis which I will always have, diabetes, ditto, plus the transplant issues. I guess it's just trying to adapt to everything and just keep positive.

I: Yeah.

Mr D: And that might not be a, it's something I've got to think about. It might not come natural, I don't think it comes naturally, naturally for me to just to be so blasé about life. I didn't get, I don't think I got to 45 without having a lot of thought in what I was doing. I was fairly active, I would say I was pretty compliant with my drugs. And I think adhering to advice and thinking about what's happening physically and my health wise, that's got me to having my transplant and I've got to keep vigilant in the future with that. I don't let anything slide, keep my eye on the ball. So I think yeah, so I don't know what is going to be thrown at me in the future so I've just got to be kind of prepared for whatever, whatever is coming, which is difficult. Who knows. Yeah. That that's that's for the future I think, be aware, things can change.

Symptom acceptance

I: Yeah, okay. Well thank you very much for answering all my questions.

END OF INTERVIEW.

Appendix S: Coding Manual

Theme	Subordinate theme and description	Codes included	Description	Examples
Window of opportunity	**Transplant decision-making and dilemmas:** Prior to having a transplant decision-making and concerns of individuals	Knowledge of risks	Trying to cope with the awareness of transplant surgery risks	It's the knowledge of the risk, you know, you lie in bed, the anaesthetist comes up and you sign a piece of paper where one of the possible outcomes are death, d-e-a-t-h. It's there on the form. And you sign it. And although I'm a religious person, I didn't want to die. So that was sobering to say the least. (Mr A)
		Shock needed transplant surgery	Coping with not expecting to need transplant	I suppose it was quite a shock when I got told I needed a transplant because I had always been quite healthy. And then literally I just spiralled. In about 2 months I was just really unwell. ...So initially I didn't really want a transplant. I think the whole idea of it was just a bit scary and something I hadn't really thought that much about. I knew that lots of people with cystic fibrosis had lung transplants but because I had always been healthy, I'd always been, oh that's not me. (Mrs L)
		Certainty about transplant	Assured and clear about having transplant	Transplant was my only option, it was no-brainer. I knew I had a limited lifespan but no one could tell me how long I had. And this was my only hope. (Mrs H)
	Declining health: Deterioration in physical and mental health	Declining lung function	Lung function capacity reducing	I just saw my results dropping, year on year. (Mr K)
		Impact on physical functioning	Physical limitations impacting on day-to-day tasks	I was on oxygen. It took everything out of me to move from the lounge to the bathroom. I couldn't make it to the end of the drive. I had to have somebody in to clean. We had to have convenience foods, I couldn't cook. Life wasn't easy, it was hard for my husband. (Mrs J)
		Impact on mental health	Physical limitations impacting mental well-being	12 months prior to transplant my health went downhill very quickly; 24-hour oxygen, limited mobility, quite a few hours every day of percussive physiotherapy to clear my chest. Very draining physically, quite draining mentally. (Mr D)

Theme	Subordinate theme and description	Codes included	Description	Examples
Overcoming psychological and physical barriers		Loosing self	Loosing sense of self and defined by illness	I didn't know who I was anymore, I'd just knew I was ill, had CF and that was pretty much what it was. (Mrs I)
		Loosing hope	Loosing hope that receive transplant	I think the month before I kind of lost hope that it was gonna happen and I had gotten so poorly where I kind of thought – well this is it. ...I just remember being really calm but I think it was more because I was really numb and just shocked and didn't really know how to react to be honest. And I thought – well, just stay calm, was my reaction and I did. (Mrs I)
	Lack of control over body and focus on physical recovery: individuals described being restricted and out of control, as well as focused on mobilisation	Desire to give up	Not wish to carry on with recovery	It was so painful. And there were points where I was going, I can't put up with this anymore. (Mrs C)
		Difficult realities post-surgery	Difficulties coming to terms with the realities of post-surgery	It's not like a little fairy tale. It's not nice. It's painful. It's emotional. It's hard. I had bowel problems, you know, you're covered in drains which are just full of blood and you just that's scary enough. You wake up and you see these buckets underneath you and you're just like - Oh. (Mrs I)
		Unable to communicate	Unable to talk to others and ask questions or for assistance	When I woke up I discovered that I couldn't talk or walk. The only think I could do was open my eyes, I couldn't even move my finger. And because I had a trachy in I I couldn't ask them what was going on. So it was quite scary. (Mrs H)
		Patience with recovery	Aware of slow recovery and needing to tolerate the difficulties	I just thought to myself, well it's gonna take time, it a big shock to your system. So it's going to take time now to recover but fortunately I were very patient and I knew it wasn't going to happen overnight. (Mr B)
		Difficulties managing restrictions	Difficult to cope with lack of control and limitations	I didn't really have a lot of mobility after transplant. So it was just swapping one set of restrictions for another. (Mr K)
		Encouragement to engage with recovery	Others supported recipients to commence recovery	If they hadn't pushed and pushed, I wouldn't of done anything. (Mrs J)

Theme	Subordinate theme and description	Codes included	Description	Examples
	Adjusting to a new normal: Coping with a new life	Breathing without difficulties	Being able to breathe without problems	The hours go by and the days go by and you start being able to, you're less uncomfortable so you can take deeper breaths, you go – this is brilliant! You know, I can you're almost like – look! Watch me breathe! (Mr E)
		Adapting and adjusting to new opportunities	Coping with changes in life situation	I kind of learnt to accept I had been given a really amazing gift and you know although they weren't my lungs, they were, they were going to become my lungs because obviously they're the reason I'm alive…Then I started to think about all the exciting stuff that I could do once I left and you know the fact that I wasn't struggling. I wasn't dying anymore and that no more machines and tubes and things. (Mrs I)
		Pacing	Importance of learning how to pace themselves	And then you start going literally 100 mph and doing everything that you've not been able to do for the last 10 years. And then you find yourself in hospital because you've overdone it. And then you get a talk from your consultant and he gives you, it's a well-known talk amongst transplant recipients. It's known as the superman talk, "Have you had the superman talk yet?", "No, no, no not yet". "Okay. You're get it at some point"… But when they say the superman talk. It's like you get your lungs, and everyone goes from you know 0 to 60 or 0 to 100 like that, and then they basically hit a brick wall because they are so acclimatised or so unfit or so mentally ill-prepared actually for it that they end up in hospital. And the superman talk is that the consultant will come round and go, "P5, you're not superman. You know, you've just had a transplant, I know it's really exciting doing all these things but you've got to be realistic and don't try and do everything at once you know". (Mr E)
	Goal-setting: Focussed on setting tasks to achieve	Physical goals	Focused on achieving physical tasks	Looking forward and finding out what I can do and setting goals for myself. And they were mainly physical goals...In the first year I would of liked to of, my goals were to walk up Snowden, Scafell Pike and Ben Nevis. So mainland Britain's top three mountains....And cycling, and hillwalking, so I, another one was a 25-mile hike around Brecon beacons. That takes 10 ½ hours. Exhausting. Done that. And lots of mountain biking, sea kayaking. (Mr D)
		Self-talk	Encouraging self to achieve goals	I was sitting there, I would go, "Come on P10, come on P10 you've got to do this. This is ridiculous. You know. You've got to make yourself do things. You can do

Theme	Subordinate theme and description	Codes included	Description	Examples
Steps towards rebuilding life				it". And you've got to be really determined and "You can do it, you will do it. Come on. Come on. You know, you didn't go through all this for nothing. Come on." And I've made myself, I've pushed myself to do certain things. .. I make myself do it, I have a goal, I make myself do certain things. And you know, I make proper dinners and everything else and it's lovely. (Mrs J)
		Task-setting	Creating lists of tasks hoping to achieve	After my transplant I was like, you become a bit lost because you get this new lease of life and you go, "Well what do I do with it?" And my sister said, "Well hang on, you've got a list of things that you said you wanted to do." And I slowly worked my way through that. And as I went through and ticked something off, I put something back on it. ...Even six years later it's constantly setting myself goals and things to look forward and things to go you know what each time I do one of those I realise just how lucky I am that I am in this situation with the opportunities that have presented themselves to be able to go and do these. (Mr E)
	Managing emotions: coping with affect post-transplant	Calmer post-transplant	Noticed less volatile	The emotions that I've gone through is they have been tempered to some extent. The extremes have been tempered. The negative stuff, that I was thinking and the nastiness of the person that I used to be, a lot of it is down to being so ill. With the improvement that has made me more mellow and pleasant to be around. (Mrs C)
		Fluctuations in mood	Changes in emotions	I was coping with quite heavy mood swings and I became quite aggressive… And sometimes it would come out and I would end up really offending somebody. And at times I was just constantly ready for a fight. And that's just not me at all. (Mr K)
		New emotions	Experienced emotions that differed to pre-transplant	I'm definitely more emotional that I used to be, that's true. But I think that was also kind of like, I don't know, I joke that I've adopted emotions since my transplant as well. (Mrs G) and "learning to understand my emotions. (Mrs I)
	Uncertainty about future: need to cope with not knowing future health outcomes	Limited time available	Awareness that life could be limited and attempt to focus on living	Cause you you, with a transplant we are all aware that your egg timer has turned over. But it's an egg timer. And we we look at the numbers of how long you've got with a transplant. What things to look out for. So it's not a cure. So you're hyper alert. Almost paranoid about you know – am I doing things right?...Trying to

Theme	Subordinate theme and description	Codes included	Description	Examples
Looking beyond transplant				predict the future....In those early, in the first year. And having gone through the first year I've become much more relaxed. (Mr D)
		Not a cure	Transplant does not cure health	I know the risks of transplant and I know you know that it's not a cure, it was the quality of life for me. And that's and that's why I did it. (Mrs H)
		Reduced life expectancy	Awareness of limited survival time and risks of deterioration in health	You've got your life back for a period. You know, we know and I know the average survival rate for a lung transplant patient is five years and I've had three. And so I know the facts. (Mr A)
	Gratitude towards donor: thankful for the choices made by the donor	Fortunate	Thankful for being able to receive new lungs from donor	I'm so lucky. I'm so lucky that that family made that decision at that point. And I was in the right place to be able to benefit from that. (Mr E)
		Appreciation towards donor	Recognition of important role to play as recipient of new lungs	I am the steward of somebody who couldn't use these lungs anymore. I'm the steward of these lungs. So I've gotta I've gotta do a good job. (Mr A)
	Discovering new potential: realisation and engagement with new possibilities that previously not possible	Pursue new interests	Ability to explore and try out interests that had not previously been able to do	Just go somewhere new. Try something new. Even if it's just something little. It's more about pushing the boundaries after transplant than getting used to the new boundaries. (Mr K)
		Simple day-to-day tasks	Recipients appreciation being able to everyday tasks and activities that take for granted	I mean if you wanted me to give a serious but trivial response, it would be putting out the rubbish at seven o'clock on a cold wet November morning. You know the thought that I can do that is astonishing. You know, I mean it could be flying to Italy or going up the cape Dolomites or a million big things but actually being able to put the rubbish out at seven o'clock in the morning is is is I I almost enjoy it because it's so astonishing that I can do that and be out in cold weather and it doesn't take my breath. (Mr A)
		Get life back	Realisation that able to do things again that had not been	I guess I've got the life that I had before back and probably a bit more in the fact that I can do more exercise without getting out of breath. And I'm not quite so paranoid about getting quite as ill or being near people that are ill. I know obviously

Theme	Subordinate theme and description	Codes included	Description	Examples
			possible after deterioration in health	I need to be careful but before like if somebody even sniffed I was like completely paranoid. (Mrs L)
		Realisation of a future	Recognition that life has changed and now have hope for a future to make plans	I all of a sudden, was faced with the fact that I had a future I didn't think I was gonna have and I didn't know what I was going to do….I just thought – what do I do? What is it that I want to do actually more than anything? It's kind of like being reborn and I had to rediscover who I was, and that and that was really emotional actually. (Mrs I)
	Change in outlook: changed perspective and view on life	Positive self-talk	Recipients focused on talking positively to self to help maintain a focused mindset	You know, no matter how bad things can get, take that opportunity, take that positive that's there, grab onto it and make the most of that because if you can keep yourself working towards something that keeps your mind focused at even at the hardest of times it's incredibly powerful tool. (Mr E)
		Ability to make decisions	Without physical limitations, able to think about life decision more clearly and make choices	Changes are easy to handle if you can breathe. If you've got, if you feel, every breath, you're not thinking about too much which means you've got energy which gives you energy and mental space to make decisions that were were so hard before. So I guess most things that are thrown at me these days, I can handle very well. I'm resilient to surprises, to change, to a lot of things that have happened over the last year. I take it in my stride. I'm quite cavalier about sort of a lot of things that. I like mountain biking, I go a bit faster these days….I'm still pushing boundaries and where and what I can do, and adventures and what have you. So yeah, it's all go. It's all positive. (Mr D)
		Life mantra	Positive characteristics that guide how to live and to make the most out of life	So you have a hope, have a plan and no regrets. And I think you know the hope… no matter how bad things seem you know, how bad the prognosis is, there is a positive in that message that you're been given and you've just got to take that positive and make the absolute most of it. And focus on that because you're mental wellbeing has, for me had such a strong link between my physical wellbeing and I needed to be able to stay mentally happy and mentally focused and positive to believe that I could get through to getting the transplant. So you know there's having the hope, believing that I could do something, no matter how bad it was,

Theme	Subordinate theme and description	Codes included	Description	Examples
				taking that positive and run with it. Having a plan is as I say the bucket list. You know, I needed to know what success was going to be, how could I make some sort of success, have something to look forward to. And then the last one was don't have any regrets, have no regrets. Don't leave it too late to do those things that you want to do because that is the worst thing in the world is that phrase: 'I wish I'd done this when I had the chance'. And that you know that, those 3 lessons for me are something that you know I do regularly think about and regularly remind myself that those are the 3 things that I almost live by now. (Mr E)
	Appreciation for life: changed view on the importance of life and what able to achieve	Accept difficult experiences have happened	Accept struggle with transplant experience	I didn't wanna dwell on my bad, it is was a tough experience that I went through, and I didn't want to dwell on that. I I wanted to accept it's happened and it was horrible and I would never wish it on my worst enemy. Because it is a, it really is a hard journey. (Mrs H)
		Symptom acceptance	A sense of 'I'm used to it now' and need to get on with life as this is part of life	I take each day as it comes. You know, because I've got to get through another bit of major surgery. It's nice cause I've seen the fifth of my grandchildren born. You you feel sad because you know that you're not going to see them grow up. You know, I'm already 60. I've got important, significant diseases and I'm not going to make old bones. But that's life. You you know you just have to accept it. (Mr F)
Support network	**Guidance on physical, psychological and spiritual health:** Receiving support from others to support their physical health, mental and spiritual well-being	Medical advice and treatment	Recognised and valued advice given and support received from medical staff throughout treatment	For the medical team here, if they get to hear what I've done, that's gotta make them feel good. Look at what we did. They made a difference. They made a huge difference. And I like to make it nice and clear how much of a difference they've made. By climbing mountains and getting into all sorts of mischief. Then they can see what they've done. Look at what you made me do. (Mr D)
		Psychological support	Importance of support from clinical psychology in preparing and recovering from transplant	I spent some time seeing a clinical psychologist at my transplant centre post-transplant and that was to help me deal with some changes that happened in my life pre-transplant with relationships and things like that. I had a bit of a rough ride and this psychologist helped me manage these changes and just set expectations and realise that you know, things can change but you ultimately have that, you are in total control of what you do and you choose how you live your life and what you do and what you don't do. (Mr E)

Theme	Subordinate theme and description	Codes included	Description	Examples
		Desired further information	Recipients wanted more information pre-transplant on side effects	And so when you wake up, it isn't so scary. Perhaps a bit more chat on the drugs, I mean I just had such bad hallucinations in there. That was awful. I thought people were trying to kill me. (Mrs H)
		Religious and spiritual support	Importance of religious and spiritual beliefs in process	… my faith is important to me and it's not just going to church, singing hymns, reading the creed. You know I I do believe that there is a God who is you know who if you like has numbered my days and I am in his hands. But that doesn't take away my respect and gratitude for the surgeons who may be atheists for all I know and great for them. You know they are brilliant. (Mr A)
	Importance of peer support: Recipients valued peer support from both patients and non-patients	Support on social media	Positive comments and support from others on social media to make process easier	You're fully aware and you're prepared, and you have other friends that go through the same thing at the time, and things like social media, at the time of the transplant was so invaluable for just getting other people's experiences of their own journey that have gone through transplant. (Mr E)
		Shared experiences	Other transplant recipients understand the journey, providing both practical and emotional support, and friendships develop	Use other transplant patients for their experiences. .... And the chat forums, like X [hospital] transplant club, sometimes if I wanna put a question on there, that I'm not sure about and I don't wanna speak to a clinical person. And sometimes you can go on there and just give them a bit of guidance and that helps a lot. And then you start chatting to them and then you meet them in clinic and then you build a relationship and you can share experiences, and and sometimes calm people down. (Mrs H)
		Inspiring others	Expressed desire to encourage others to have transplant demonstrated through own achievements	I've got a friend who's actually still in here now. She was debating whether to have a transplant. And I wanted to encourage her, you know this is this is the potential of the difference in life between before and after a transplant. And I wanted to set a good example for her to encourage her to put herself on the list....so I'm hoping in some small way I you know showed that person where things could go. (Mr D)

Theme	Subordinate theme and description	Codes included	Description	Examples
		Emotional and physical support	Importance of friends providing practical and emotional support	My friends have probably always been my, for my personally my strongest support group…And they were there throughout the whole thing when I was getting ill… And you know they would help me out and my old housemate would sort of do all my night time feeds and prepare them for me if I was too tired to do them myself. And yeah my friends still now like help me with anything that I need. So I think my friendships, my friends are sort of my main source of support. (Mrs G)
		Suggestions for additional support	Expressed desire for additional support to help manage realistic expectations of transplant process	I think like a mentoring sort of system. So when you get people post-transplant that can talk to people pre. People would probably I suppose you've got to be quite together yourself…But it's maybe having that is something more real you know from somebody's whose been through it and can say, "Actually you know what, I really struggled". And particularly, if you read blogs, people I think tend to romanticise what they've been through, they'll be like, "Oh that first breath is amazing". That first breath was awful. I was in so much pain...., that's real because a lot of people that I've spoken to have woken up expecting to have that first breath that's so amazing. And then they don't get it…Actually that's normal, that's what it should feel like because you've just been through major surgery. So I think it's that, just being really real, talking to somebody that will, or you know whether it's like having a leaflet written by patients post-transplant or you know face-to-face is quite difficult because of infection risks. But some sort of way where actually could be more real about what does happen in those first few days. (Mrs I)
	Impact on family relationships: awareness of positive and negative effect on family members and these relationships	Family strain	Awareness of the stress on family members during the transplant process	It was difficult for my family as well because you know that it it just hard. It's bad enough to go through major surgery but to watch from the side-lines when somebody you love is getting multiple complications it it's hard for them. (Mr F)
		Give back to family members	Recognition of the impact of physical health on	She put and the investment, the effort, the time, that my partner put in to keeping me alive, to keep me going for my transplant. Just paying that back. Seeing the smile on her face. Being part of her life. ...Keeping her happy. That is the best thing

Theme	Subordinate theme and description	Codes included	Description	Examples
			relationships and desire to work hard show gratitude	about having the transplant. Being, helping reward someone else for all their effort. And myself. (Mr D)
		Opportunities to spend time with family	Physically able to and other people noticing that able to spend quality time with them	She's mentioned it a couple of times, "oh it's so much nicer now you're okay. You can move around Nanny. We can do this, and we can do that". And I said, "Yeah okay then. I will have a go"….But it's it's so nice that I can interact with the kids now. Whereas before, some of the things I couldn't do, and they'd noticed. (Mrs J)
		Change in relationship roles	Physical illness had negative impact and changed romantic relationships	We went through so much together and you know 10 years is a long time to be with somebody and he had literally become my carer. And I, that changes a relationship, I think....It's not the same after that. It's difficult to feel attractive or anything when the person you're with is literally seeing you at your worst. They had to clean you, wash you, help you dress. You know, it changed things a lot, even for him, he became so protective of me and I think he felt more like a carer than he did a partner as well. (Mrs I)
	Compassion and empathy towards others: Desire to alleviate difficulties and support other people	Emotional support to others	Providing emotional support to other people with difficulties	I've got a cousin who has probably got cancer and is dying from cancer, I visit him regularly, and I feel because I've been at the back end of life I don't feel like I can tell him what, to think, what to feel or what to do but I can empathise in a way probably that some people can't. (Mr A)
		Engagement in community by supporting others	Desire to give back to other people in the wider community	I'm making garments for very premature babies….But it's really nice to be able to do something, to give back. And I've been able to go back to church. And it it's really nice that I can do different things. I'm helping with the Foodbank. ...And that's part of our church. But it's all something to get out there and give a bit back. You know, a lots been given to me, my life has been given to me. I don't want to waste it by sitting in here all the time. I've got to get out. (Mrs J)
		Encourage others to be donors	Actively promote other people to become organ donors	If I can inspire people in some small way, that's a bonus. (Mr D)

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