

Submitted in partial fulfillment of the Lancaster University Doctorate in Clinical Psychology

June 2019

**Doctoral Thesis**

**Experiences of Supporting Organ Transplant Recipients**

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**Table of Word Count**

<b>Thesis Section</b>	<b>Text</b>	<b>Appendices (including tables, figures, references)</b>	<b>Total</b>
<b>Abstract</b>	<b>277</b>	<b>N/A</b>	<b>277</b>
<b>Literature Review</b>	<b>7,993</b>	<b>16,720</b>	<b>24,713</b>
<b>Research Paper</b>	<b>8,000</b>	<b>5,228</b>	<b>13,228</b>
<b>Critical Appraisal</b>	<b>3,886</b>	<b>571</b>	<b>4,457</b>
<b>Ethics Section</b>	<b>4,704</b>	<b>6,956</b>	<b>14,338</b>
<b>Total</b>	<b>24,860</b>	<b>29,475</b>	<b>54,335</b>

## **Thesis Abstract**

Close family members of organ transplant recipients are frequently implicated in supporting their loved one through their transplant journey and have a crucial role to play in the patient's recovery and adjustment posttransplant. Given this, there is a need to fully understand their personal experiences to ensure their needs are fully realized and met within clinical services. This doctoral thesis explores how significant family members experience the process of solid organ transplantation within a paediatric and adult context. It includes a systematic literature review of qualitative research regarding parents' experiences of organ transplant; a research paper exploring spouses' experiences of heart transplant; a critical appraisal; and an ethics section.

The literature review synthesized qualitative research regarding parents' experiences of organ transplant. A meta-ethnography of seventeen studies resulted in three interpretative conceptual themes: 'parenting in the context of uncertainty', 'assimilating to new roles and responsibilities' and (3) 'an opportunity for renewal and growth'. These findings are discussed in relation to the previous literature as well as discussing clinical implications and future research.

The research paper explored spouses' experiences of heart transplant using interpretative phenomenological analysis. The experiences of seven wives and two husbands of heart transplant recipients were analyzed, resulting in three overarching themes explicating their experiences: 'driven by a sense of responsibility', 'striving for togetherness', and 'wrestling with the prospect of them dying'. Similarly, each are discussed in relation to the previous literature, clinical implications and future research.

The critical appraisal presents a continued discussion on the research paper including the strengths and challenges experienced in this research. Reflections on aspects of the research process are considered. Potential areas of future research are discussed further.

## **Declaration**

This thesis reports research undertaken between January 2017 and June 2019 for the Lancaster University Doctorate in Clinical Psychology. The work presented with here is my own, except where otherwise stated. This thesis has not been submitted for the award of a higher degree elsewhere.

Name: Jessica Sheffield (née Morley)

Signed:

Date:

## **Acknowledgments**

I would like to firstly thank the participants who so generously volunteered their time to take part in this research, as well as the members of the transplant teams who have supported along the way. Additionally, I would like to thank Dr Craig Murray who has supervised me and helped me navigate through this process. I have really valued your continued support over the years I have been on the course and returning from maternity leaves. A big thank you to my friends and family, especially my mum and Nev who have always checked in with me and been there through the really difficult times. And to my husband Ross who has taken on so much of our life loads to help me dedicate the time needed to complete this work. And finally, the biggest thanks of all to my two sons Atticus and Keziah who have inspired me to stay strong and focus on the end goal.

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Running Head: PARENTS' EXPERIENCES OF PEDIATRIC ORGAN TRANSPLANT

**Section One: Literature Review**

**Parents' Experiences of Pediatric Organ Transplantation: A Metasynthesis of Qualitative studies**

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Word Count: 7,993

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Prepared for submission to Qualitative Health Research<sup>1</sup>

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<sup>1</sup> The manuscript was prepared in line with author guidelines for Qualitative Health Research (see Appendix 1-A). Where these guidelines have not been followed, Lancaster University thesis guidelines have been followed. Of note, the word count is in line with University guidance.

### **Abstract**

Parents of pediatric organ transplant recipients play a crucial role supporting their child through transplant and posttransplant care. However, they are vulnerable to psychological strain which can compromise their ability to cope and their capacity to support. Ensuring that parents are understood and supported has important implications both for the parent and the child's wellbeing. Therefore, the current review aimed to synthesize existing qualitative research on parents' experiences of organ transplant. Seventeen studies were identified through a systematic literature search of five electronic databases. Using meta-ethnography, three interpretative conceptual themes were derived: 'parenting in the context of uncertainty', 'assimilating to new roles and responsibilities', and 'an opportunity for renewal and growth'. The findings provide a conceptual understanding of the experiences of parenting a child with organ transplant important for clinical services responsible for supporting pediatric transplant recipients and their parents/ families.

**Keywords:** *meta-ethnography; metasynthesis; parenting; transplantation; pediatrics*

Organ transplant is an important lifesaving and life-transforming treatment option for patients with end-stage organ failure (Burra & De Bona, 2007; Fine, Webber, Harmon & Kelly, 2007). In 2018, the number of people receiving an organ transplant in the United Kingdom (UK) reached a record high at 5,090; approximately 5% ( $n = 283$ ) of which were pediatric patients (National Health Service [NHS] Blood and Transplant, 2018a; NHS Blood and Transplant 2018b). In the United States, the annual figure of pediatric organ transplants in 2018 was 1,895, approximately 14% of all organ transplants performed (Health Resource and Services Administration [HRSA], 2018). Ongoing developments in perioperative procedures and immunosuppressive drugs continue to contribute to better posttransplant outcomes and long-term survival rates in patients, transforming and prolonging the lives of many children affected by life-limiting disease (Gummert, Ikonen & Morris, 1999; Kim & Marks, 2014).

Although organ transplant can lead to dramatic functional improvements in patients compared to before, it is not necessarily curative and patients face living with a severe chronic condition (Rana, et al., 2015; Wilhelm, 2015). Adapting to life as a transplant recipient can be difficult and is fraught with both psychosocial as well as physical challenges (Forsberg, Backman & Moller, 2000; Peyrovi, Raiesdana & Mehrdad, 2014; Sadala & Stolf, 2008). Transplant recipients live with the ongoing threat of transplant rejection and posttransplant complications (Ingulli, 2010). Transplant recipients must therefore adhere to a set of life-long self-care behaviors and medical management to ensure ongoing healthy outcomes (Dew et al., 1999; Schrem, Barg-Hock, Strassburg, Schwarz & Klempnauer, 2009). Pediatric patients have expressed their difficulties in adapting to the day to day demands and restrictions that come with life as an organ transplant recipient (Olauson et al., 2006).

In consideration of the pediatric population, parents play a crucial role in supporting their child with posttransplant daily care and health management (Mavis, Ertl, Chapman, Cassidy & Lerret, 2015). This can be demanding and impact on the family's quality of life and wellbeing. For example, empirical research has found that parents of pediatric organ transplant recipients are vulnerable to high levels of stress, burnout and psychological distress (Alonso et al., 2008; Cousino, Rae, Schumacher, Magee & Fredericks, 2017; Farley et al. 2007; Kikuchi et al., 2015; Young, et al., 2003; Zelikovsky, Schast & Jean-Francois, 2007). In pediatric organ transplant, high levels of stress within a family have been linked to poor posttransplant medical adherence (Griffin & Elkin, 2001).

Nonadherence to immunosuppressant medications has been linked with almost all chronic rejection episodes in pediatric transplant recipients (Berquist et al., 2008; Shemesh et al., 2004).

Findings linking parental outcomes with medical adherence in pediatric patients must be considered within the wider context to avoid potential 'victim-blaming' inferences made when research links parental distress with adverse child outcomes (Young, Dixon-Woods & Heney, 2002). Nevertheless, including the family system to formulate around family functioning and parental stress in pediatric transplant psychosocial assessment is recommended (Shemesh, 2008). The literature indicates that pediatric organ transplant can negatively impact the psychological wellbeing and coping of the child as well the parents. Therefore, ensuring that parents are coping in their role of parenting a child with a transplanted organ is essential for both the parent and child's health and wellbeing status.

Quantitative research is limited in its ability to address research questions focused on understanding the full complexity of lived experiences, personal meaning and internal perspectives. Conversely, qualitative methods are strongly positioned when the purpose is to understand how people make sense of the world, experience events and manage certain situations, concerned with "bringing humanity to the human health dilemma" (Thorne, 2019, p.5). It is argued that qualitative research has an important contribution in broadening the evidence-base for clinical practice (Barbour, 2000; Green & Britten, 1998). Gaining rich descriptions of individual subjective experiences can generate novel insights into the process and outcomes of psychological services (Silcerstein, Auerbach & Levant, 2006).

Qualitative metasynthesis is a recognized approach to rigorously analyzing data across qualitative studies in an area of specific investigative interest (Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004; Walsh & Downe, 2005). This involves synthesizing authors' interpretation (2<sup>nd</sup> order constructs) which have been derived from participant data (1<sup>st</sup> order constructs) to produce novel, integrated findings (3<sup>rd</sup> order constructs). The aim of this is to move beyond describing qualitative research results to uncover in-depth knowledge, reinterpret the findings as a whole, offering new understanding and insight (Britten et al., 2002; Thorne, 2019).

Although there are a number of syntheses that have been conducted on parents' experiences of parenting a child with chronic illness (Coffey, 2006; Heath, Fare & Shawe, 2017; Knafl & Gilliss, 2002; Tong, Lowe, Sainsbury & Craig, 2008; Tyerman, Eccles & Gray, 2017), there are none to the authors knowledge that have been conducted specifically regarding the experiences of parents of pediatric transplant recipients. Although there might be some similarities in these experiences, research is needed to illuminate the specific experiences of parenting in the context of organ transplant. To understand the experiences of parents whose children have received an organ transplant in the depth necessary for informing psychosocial interventions and strategies aimed at supporting the whole family, a metasynthesis of published qualitative research in this area is required. Therefore, the present review is a synthesis of parents' experience of pediatric organ transplantation. The outcome of such rigorous synthesis holds potential benefits to clients, clinicians and policy makers (Cahill, Robinson, Pettigrew, Galvin & Stanley, 2018).

## **Method**

### **Search Strategy**

The databases Academic Search Complete (1989-present), Cumulative Index to Nursing and Allied Health Literature (CINAHL; 1990-present), PsycINFO (1947-present), PsychARTICLES (1894-present) and MEDLINE (1983-2019) were searched in September 2018 for literature related to parents' experiences of children who have had an organ transplant. The research interests of these databases were applicable to the topic and aims of the current review and were therefore deemed appropriate for inclusion within the search strategy. A topic specialist librarian was consulted before finalizing search terms and the search strategy. EBSCO host thesaurus was utilized with recognized search terms along with free text words to combine search terms grouped into three key areas: (1) organ transplant, (2) parent, and (3) qualitative research. A comprehensive list of search terms can be found in Table 1. Terms were truncated to search for variant spellings and possible pluralization of that term. For example, the truncation 'transplant\*' was used to ensure articles using the term 'transplantation' were included; the truncation 'card\* transplant\*'" was used to include articles using the term 'cardiac transplant' and 'cardiothoracic transplant'.

INSERT TABLE 1 ABOUT HERE



### **Selection Criteria**

Studies were considered eligible for this review if: (a) articles were published in English; (b) articles included the use of an inductive method of qualitative analysis; (c) articles were published in a peer reviewed journal; (d) articles gathered data through interview or focus group; (e) articles included thematic interpretations in the findings and evidenced these interpretations using original quotes. As there is a paucity of qualitative research in this area, no date limiters were applied.

Although the experiences of parenting vary depending on the child's current age (Herbert, 2004), parenting in pediatric organ transplant is an area of limited qualitative research and the current review aimed to capture the experiences of parents within this context, regardless of their child's age. Therefore, the current study did not exclude articles in relation to the reported ages of the pediatric transplant so long as they were considered pediatric at the time of transplant (<18 years old). It is also noted that parents' experiences might vary depending on their child's diagnosis leading up to transplant and the type of organ transplantation received. However, metasynthesis of qualitative research regarding patient experiences of organ transplant have elicited themes that have successfully conceptualised the phenomenon in the broader sense inclusive of different organs (Tong, Morton, Howard & Craig, 2009). Therefore, the current review took a similar approach and was not restricted to a specific pre-transplant diagnosis or type of organ transplant. However, to increase the generalizability of findings to a clinical population, the current review focused specifically on solid organ transplant (e.g., heart, lung, liver, kidney, pancreas) as opposed to hollow organ, bone marrow or stem-cell transplantation. Articles in which participants were parental live-donors (e.g., live-kidney or partial liver) were excluded as it is likely that the experiences of these parents hold fundamental differences compared to non-donor parents (Forsberg, Nilsson, Krantz & Olausson, 2004; Thys et al., 2015). As this is the first attempt to review the literature specific to parents' experiences of pediatric organ transplant, articles using an inductive method of analysis were eligible from various methodological and epistemological positions, so long as the findings were interpretive, thematic and included illustrative quotes.

A systematic search of the five chosen databases was conducted in September 2018. This resulted in a total of 2220 articles (Academic Search Complete, 484; CINAHL, 256; PsychINFO, 214;

PsychARTICLES, 11; MEDLINE, 1255). All titles and abstracts were screened and discarded if they did not satisfy the selection criteria. Any duplicates were removed at this stage. The remaining studies were retrieved for full-text review and assessed in more detail for eligibility. Uncertainties regarding eligibility were discussed with the supervising researchers. Finally, a process of 'back-chaining' was adopted whereby references of articles included in the review were hand-searched for relevant titles. Of the five articles identified at this stage, one satisfied the inclusion criteria. Examples of excluded studies can be found in Table 2. The most common reasons for exclusion were because the study was not qualitative research, did not include parents as participants or was not concerned with solid organ transplants. Following this, a total of seventeen articles were included in the metasynthesis (see Figure 1).

INSERT TABLE 2 ABOUT HERE

INSERT FIGURE 1 ABOUT HERE

### **Appraising the Quality of the Selected Studies**

The use of quality appraisal tools to evaluate qualitative research is a controversial issue and one which presents a diverse range of conflicting positions (Dixon-Woods, Shaw, Agarwal & Smith, 2004; Spencer & Ritchie, 2012). Nevertheless, assessing the validity and reliability of research continues to hold significant power regarding whether research gains ethical approval, funding, and credence and impacts the influence findings have on driving change (le Roux, 2017; Majid, Vanstone & Majid, 2018). Considering this, the current review adopted the use of The Critical Skills Appraisal Programme (CASP; Public Health Research Unit, 2006) to critically appraise the strengths and weaknesses of articles included in the review.

The CASP includes ten areas which are deemed relevant for appraising qualitative research in terms of credibility, rigor and relevance. These include appraisal of research design, research strategy, data collection, reflexivity, ethical consideration, data analysis, findings and value of the research. Following two initial screening items, each study was scored in accordance with Duggleby et al's., (2010) suggestion as either "1" weak, "2" moderate or "3" strong for the remaining eight items. All the studies passed the CASP screening criteria and each article was given a score out of 24, which are collated in Table 3. Toye et al., (2013) caution against excluding studies from a qualitative synthesis

using methodological criteria. Therefore, the resultant scores were not used to exclude articles but enabled the researcher to ensure that themes derived from the meta-ethnography were not overly represented by articles appraised as being of poorer quality. For instance, the theme 'assimilating to new roles and responsibilities' was contributed by four articles that received the lowest CASP scores (15 and 16) in this sample of articles, but also by three articles that received the highest CASP score (22). Additionally, although the third theme 'an opportunity for renewal and growth' was represented by the least number of articles (n=5), the quality of these articles in terms of average CASP rating was the highest.

INSERT TABLE 3 ABOUT HERE

### **Characteristics of the Selected Studies**

Seventeen articles were included in the final review (Adams, Evangelini, Lunnon-Wood & Burch, 2014; Anthony et al., 2009; Green, McSweeney, Ainley & Bryant, 2008; Green, Meaux, Huett & Ainley, 2009; Lerret, Johnson & Haglund, 2017; Lerret, et al., 2014; Lochridge, Wolff, Oliva, & O'Sullivan-Oliveira, 2013; Mantulak, 2014; Mantulak & Cadell, 2018; Mantulak & Nicholas, 2016; Meaux et al., 2014; Stubblefield & Murray, 1998, 1999, 2000, 2001, 2002; Wright, Elwell, McDonagh, Kelly & Wray, 2016). These seventeen articles represented findings from ten distinct studies. For instance, Stubblefield and Murray (1998, 1999, 2000, 2001, 2002) used interview data from one study (fifteen parents) to address five specific research questions in their analysis which resulted in five published articles. Similarly, the findings from Green, et al., (2008) and Green, et al., (2009) have been obtained from the same study sample; and the findings from Mantulak (2014), Mantulak and Nicholas (2016) and Mantulak and Cadell (2008) have also been obtained from the same study sample. In reading the articles it was determined that the focus of them examined different aspects of parental experiences, giving an overall richer description of the study sample interview data. It was therefore concluded that the articles contained enough variation in topic focus to avoid a biased analysis and were therefore all included as separate articles in the current review.

The final seventeen articles were published between 1998 and 2018 and came from three different countries: United States, UK, and Canada. They included qualitative data from 164 participants consisting of 129 mothers and 35 fathers, the majority of which were parents to children

with a heart transplant (45%), followed by liver (26%), kidney (16%), lung (3%) and multi-visceral (3%). Fourteen of the articles focused exclusively on parental experiences specific to one type of organ transplantation (heart = 5; lung = 5; kidney = 3; liver = 1); and the remaining three included parents of children with varying types of organ transplant. Five of the articles explored the experiences of parents whose children were adolescents/ young adults; two articles explored the experiences of parents whose children were primary school aged; and the remaining ten articles included parents whose children's ages ranged from infancy through to adolescence. A summary of the demographic and descriptive data regarding the participants and methods within the studies is presented in Table 4.

INSERT TABLE 4 ABOUT HERE

### **Data Synthesis**

A meta-ethnographic approach was used to extract and synthesize the data within the current review to produce an interpretative analysis of the experiences of parents of pediatric transplant recipients. Originally developed by Noblit and Hare (1998), meta-ethnography is an interpretive approach to synthesizing qualitative research that aims to develop new conceptual understandings of the phenomenon under investigation (Shaw, 2012). This method is commended for its potential to provide a higher order interpretation, generate new research questions and reduce duplication of research (Atkins et al., 2008). The current synthesis followed the seven phases detailed by Noblit and Hare (1998, p.26-29) which include (1) getting started, (2) deciding what is relevant, (3) reading the studies, (4) determining how the studies are related, (5) translating the studies into one another, (6) synthesizing the translations, and (7) expressing the synthesis. Although written in a step-by-step manor, the expectation is that many of these stages overlap and are revisited before concluding the synthesis. The process in adherence with these steps is described in more detail below.

Following the selection of the final articles included in the review, the researcher became familiar with each article by reading each one several times. The main findings from each of the articles were identified and summarized in Table 5. A data extraction table was completed for each article where second order constructs (the authors) interpretations) contained within each theme were compiled along with a supportive illustrative participant quotation (first order constructs; see

Appendix 1 - B for example). At this stage the researcher made a list of the key metaphors, phrases and ideas from the data; or as Atkins et al., (2008) referred to them as, “key concepts” (p.133). The key concepts were then compared across articles and grouped into an overall concept (through an iterative process of re-reading, comparing and contrasting). The relationship between the studies was determined as reciprocal in nature where “the concepts of one study could be easily encompassed by those of another” (Shaw, 2012, p.16). Using this assumption, the key concepts of the first study were compared with the second study. The synthesis of this comparison allowed additional organization of the emerging third-order conceptual categories. Subsequent articles were then individually compared to these findings and the process continued until all articles had been compared (translated into previous studies). The result of this ended with the construction of third order interpretations summarized into three overarching themes. Final tables were compiled detailing the key concepts from each article that contributed to the third order interpretive themes (see Table 6, 7, 8). These were subsequently scrutinized in terms of how well they reflected the original themes from each article. The final expression of this synthesis is presented below.

INSERT TABLE 5 ABOUT HERE

INSERT TABLE 6 ABOUT HERE

INSERT TABLE 7 ABOUT HERE

INSERT TABLE 8 ABOUT HERE

### **Results**

The aim of the meta-ethnography was to produce an interpretative synthesis of the qualitative research exploring the experiences of parents of children who have received a solid organ transplant. The analysis led to three themes: four of the articles contained all three themes, nine of the articles contained two of the themes, and four of the articles contained one of the themes (Table 9). The three themes developed through the analysis were labelled ‘parenting in the context of uncertainty’, ‘assimilating to new roles and responsibilities’, and ‘an opportunity for renewal and growth’. Each of these themes will be discussed.

INSERT TABLE 9 ABOUT HERE

#### **Theme 1: Parenting in the Context of Uncertainty**

Eleven of the articles (representing data from seven studies) contributed to the theme 'parenting in the context of uncertainty' (Green et al., 2008; Green et al., 2009; Lerret et al., 2017; Lerret et al., 2014; Mantulak, 2014; Mantulak & Nicholas, 2016; Meaux et al., 2014; Stubblefield & Murray, 1998, 2000, 2002; Wright et al., 2016). The theme included two distinct aspects of this experience encapsulated within the subthemes, 'inescapable fear and uncertainty', and 'managing the unknown'.

#### *Inescapable Fear and Uncertainty*

For participants in the articles reviewed, parenting in the context of pediatric organ transplant meant acknowledging their child's fragility and vulnerability and looking toward a future with a more poignant sense of uncertainty. In the day-to-day lives of parents, the risk to their child posed by the threat of infection and organ-rejection created a constant sense of trepidation and apprehension to contend with: As one parent states, "there's always concern about rejection and infection" (Stubblefield & Murray, 1998, p.379). For parents of children with heart, liver and lung disease, fear of future threat stemmed from the fatal and "catastrophic consequences" organ rejection could have to their child (Meaux, 2014, p.230). For parents of children with kidney disease (Mantulak, 2014; Mantulak & Nicholas, 2016), experiences of fear in relation to liver graft failure were closely linked with their experiences of dialysis before their child was transplanted and "foreshadows the uncertainty of what the future may bring" (Mantulak & Nicholas, 2016, p.590).

For some parents the impact of this relented as time passed (Meaux et al., 2014) but inherently this concern was incessant and chronic (Green, et al., 2009; Lerret, et al., 2017; Meaux et al., 2014; Stubblefield & Murray, 2000) and essentially inescapable, illustrated in participant quotes such as "it never completely goes away. You know, it's in the back of your head the whole time" (Green, et al., 2009, p.124); and, "you're always worried for that, like that constant little 'what if?'" (Mantulak & Nicholas, 2016, p.587).

Parenting in the context of uncertainty created a state of emotional turmoil in parents plagued by fearing the worst was inevitable, or as Manulak (2014) described, being "existentially trapped in a future that belongs to the changing needs of the present" (p.23). Essentially, it was difficult for parents to set aside their all-consuming worries and recontextualize their experiences beyond the sphere of

uncertainty and fear. For example, as one parent remarks, “I guess the hardest thing is not freaking out over every little thing. Try to remember the big picture – not everything is transplanted related” (Lerret, et al., 2017, p.6).

### *Managing the Unknown*

Parenting in the context of uncertainty involved ascertaining ways to manage experiences related to the unknown which for some meant taking control to minimize threat. For example, parents engaged in preventative, risk averse measures, or as Mantulak (2014) described, “daily rituals embedded with the fear of transplant rejection” (p.22), that minimized the likelihood of posttransplant complications. Examples of this included being “strict” with posttransplant medical care (Green, et al., 2008, p.53), protecting the recipient by limiting and restricting exposure to potentially risky situations (Green, et al., 2008; Wright, et al., 2017), and maintaining constant vigilant monitoring of their child and the environment (Green, et al., 2009; Lerret, et al., 2017; Stubblefield & Murray, 1998).

In contrast to this, some parents managed the fear of the unknown by accepting it as ‘the unknowable’ (Lerret et al., 2014; Mantulak 2014; Stubblefield & Murray, 1998). This contributed to parents’ experiences of coping in the context of uncertainty (Mantulak, 2015). Accepting that uncertainty remains inescapable provided parents the opportunity for new hope. For example, parents in Stubblefield and Murray’s (1998) study viewed transplantation as “a new lease on life” (p.373).

## **Theme 2: Assimilating to New Roles and Responsibilities**

Sixteen articles (representing data from all ten studies) contributed to the theme ‘assimilating to new roles and responsibilities’ (Adams et al., 2014; Anthony et al., 2009; Green et al., 2008; Green et al., 2009; Lerret et al., 2017; Lerret et al., 2014; Lochridge et al., 2013; Mantulak, 2014; Mantulak & Cadell, 2018; Mantulak & Nicholas, 2016; Meaux et al., 2014; Stubblefield & Murray, 1998, 1999, 2000, 2001; Wright et al., 2016). This included the sub-themes ‘consumed by new demands’, ‘striking a balance: Adapting to a new normal’ and ‘preparing to forgo parent-dominated care’.

### *Consumed by new Demands*

Parenting a child with an organ transplant meant prioritizing new roles and responsibilities to meet the demands of their child’s new and ongoing health care needs, including being responsible for

accurate medical administration, managing additional medical care at home, coordinating follow-up care, continuously monitoring for signs of illness, record-keeping and advocacy roles. One mother likened this experience to, “becoming a health care professional” (Stubblefield & Murray, 2000, p.283). Assuming these new roles and responsibilities was experienced by some parents at times as overwhelming, insurmountable, relentless and all-consuming. For example, one parent stated “it’s just something that kind of controls you. Something that you have to revolve your life around” (Green, et al., 2009, p.124); and another stated, “your whole life revolves around the hospital and your child’s health” (Stubblefield & Murray, 2002, p.501). Parents therefore felt the pressure to successfully organize the routine to meet many competing demands (Lerret et al., 2017). This was particularly difficult when juggling other family members’ needs and keeping on top of general family life. As described by one parent: “we still feel so consumed with her care, we have to remember the other kids need some time with us too” (Lerret, et al., 2017, p.4).

*Striking a Balance: Adapting to a ‘New Normal’*

For parents, the difficulty therein lay in successfully adapting to life posttransplant in a way that accommodated new demands, roles and responsibilities whilst also achieving a semblance of normality and balance. As one parent summarized, “Our challenge is getting back to normal” (Lerret, et al., 2017, p.4). However, what came across strongly was the importance of establishing a ‘new normal’ to coordinate home-care requirements, family routines, follow-up appointments and the needs of all family members (Green, et al., 2008; Mantulak & Cadell, 2018; Lerret, et al., 2017; Lerret et al., 2014; Stubblefield & Murray, 1998). This involved “‘striking a balance’ between family members’ needs, personal needs, and the transplant recipient’s needs (Stubblefield & Murray, 2000, p.285). Parents described the importance of seamlessly weaving the new regime into existing parental responsibilities and routines. For example, as one parent said: “make it just a normal part of the daily routine” (Green, et al., 2008, p.53) and thus establish “the new normal” (Lerret et al., 2014, p.534).

Adjustment to new roles and responsibilities was also facilitated by the practical and emotional support from others (Green, et al., 2009; Lerret et al., 2014; Stubblefield & Murray, 2001). For some parents, obtaining emotional support from those who had “gone through it or someone who understands where you’re coming from” (Stubblefield & Murray, 2001, p.62) was invaluable. There



was a sense that for parents, normalizing their child's health regime acted to reduce feelings of being overwhelmed and controlled by the new demands and fostered accepting it as another parenting necessity (Green, et al., 2009). Even though difficult at times, parents perceived the new demands on parenting as embedded within their existing parental obligation. As one parent described, it was "what needs to be done as a parent" (Green, et al., 2009, p.125). Thus, parents could be described as occupying these roles intrinsically: "I didn't even think about it. I just did what I had to do for him" (Mantulak & Cadell, 2018, p.116).

#### *Preparing to Forgo Parent-Dominated Care*

Finally, parents acknowledged the need to step back from parent-dominated care to promote their child's personal responsibility and autonomy in the future. This was signaled during points in the child's transplant journey and life which required more self-reliance and entailed less opportunity for parental monitoring, such as returning to school (Stubblefield & Murray, 1998, 2000) and leaving pediatric services (Anthony et al., 2009; Lochridge, et al., 2013). This finding was particularly prevalent in studies involving parents of children who were currently adolescents or had passed into adulthood since their transplant (Adams et al, 2014; Anthony et al., 2009; Lochridge et al., 2013; Meaux et al., 2014; Subblefield & Murray, 1998; Stubblefield & Murray, 2000; Wright et al., 2017) signifying the complicating factor of organ transplantation to the typical dilemmas of parenting an adolescent. Letting go was important not only as a normative part of adolescent development but also to secure their child's ability to manage their own health-care needs in the future (Adams et al., 2014; Green, et al., 2008; Lochridge et al., 2013; Meaux et al., 2014 Stubblefield & Murray, 1998).

Forgoing their position of parent-dominated care to help their child thrive meant confronting the way in which parenting in the context of fear and uncertainty could be counterintuitive. For instance, as one parent stated, "if I restricted her from everything, 'You can't go over there because you might get sick or you can't do this because you might not feel well', I just felt she wouldn't have flourished as much as she has." (Green, et al., 2008, p.52). This overlapped with their desire to help their child live a normal life and not be limited by their condition: "I'm trying to let my son be as normal as possible" (Meaux et al., 2014, p.230). However, one parent discussed their simultaneous resistance:

After everything we've been through, probably the hardest thing for us is letting her go and be a kid. We'd like to keep her in our safe little bubble and keep her all to ourselves but she's going so well and she feels great; it's time to let her be a normal kid. (Lerret et al., 2017, p.5)

This revealed the dichotomy of parenting in pediatric organ transplant, between sheltering them from risk versus ensuring they experience normal childhood and future autonomy. For example, one parent summarized, "whilst in some ways I treat him as an adult and he should be treated as an adult in regard to his care and his future because he's going to be taking personal responsibility for it, as a parent I probably don't want him to be" (Wright, 2017, p.5). Subsequently, parents tried to achieve the right balance between medical management/ protecting from risk versus ensuring their child was not stifled by these measures and could benefit from the opportunity transplantation had given them to live a life of fulfilment (Stubblefield & Murray, 2000; Green, et al., 2009).

### **Theme 3: An Opportunity for Renewal and Growth**

The final theme resulting from the current meta-ethnography 'an opportunity for renewal and growth' represented findings within six articles (data from five studies; Adams, et al., 2014; Green, et al., 2008; Mantulak & Nicholas, 2016; Mantulak & Cadell, 2018; Stubblefield & Murray, 1998; Wright, et al., 2016). Included within the theme were the sub-themes, 'a renewed perspective on life', and 'strengths and personal growth'. Although this theme was the least represented by the articles in the current review, it was provided a valuable perspective of meaning that could potentially benefit parents who are struggling with their experiences of parenting a child with an organ transplant. The articles contributing to this theme covered heart, kidney, lung and liver transplantation.

#### *A Renewed Perspective on Life*

In contrast to experiences of worry and struggle were reports of parents who had a positively renewed perspective on life (Adams et al., 2014; Green, et al., 2000; Mantulak & Cadell, 2018; Mantulak & Nicholas, 2016; Stubblefield & Murray, 1998; Wright, et al., 2017). This theme overlapped with the previous themes 'parenting in the context of uncertainty' and 'assimilating to new roles and responsibilities' in that for parents, managing these challenges (i.e. the unknown and new demands) aided acceptance and helped foster appreciation. Parents valued breaking free from the

clutches of fear to, as parents stated, “deal with life as it is” (Stubblefield & Murray, 1998, p.123), “taking what comes” (Mantulak & Nicholas, 2016, p.588). As Mantulak and Nicholas (2016) interpreted, accepting the unknown for participants in their study “necessitated a philosophy of living in the moment” (p.587). For example, as one participant said, accepting that: “life’s not going to be the way it was before. It’s not ever going back there, it’s going someplace new” (Mantulak & Cadell, 2018, p.118). Instead one must learn, “how to live day-to-day and enjoy it” (Stubblefield & Murray, 1998, p. 382). For some parents, this meant making peace with the way life had unfolded and connecting with what makes their experience unique yet fulfilling. As one parent described her view using the metaphor of a foreign holiday:

It’s like instead of taking a trip to Italy, you envision this trip to Italy and you’re going to do this, this and this in Italy, but you then end up in Holland, so then you get a whole new experience. You’re still on a trip, but it’s a different place. And there’s still good things about going to Holland. You expected to go to Italy, but you’re now in Holland and there are still things you can enjoy in Holland. (Mantulak & Nicholas, 2016, p.588)

Despite the unavoidable difficulties involved in parenting a child through organ transplant, some parents found solace in viewing transplant as transformative to their child’s life and potential for happiness and fulfilment. For these parents, gratitude for their child’s current health in relation to what ‘could have been’ is focused on (Adams, et al., 2014; Green, et al., 2009;). For example, for parents in Adams, et al., (2014), transplant represented “liberation” for their child from the restrictions imposed by their chronic cardiac illness (p.643). A renewed perspective gave parents an appreciation for being with their child today and restored their focus on what they fundamentally valued. As one parent said, “you almost have to step back and appreciate all the things you have” (Mantulak & Cadell, 2018, p.118). This was encapsulated succinctly in Green, et al’s., (2009) thematic finding of parents’ experiences of pediatric heart transplant, feeling “constantly blessed” (p.125).

#### *Strengths and Personal Growth*

Finally, the way in which being a parent of a pediatric transplant recipient had led to personal growth and skill development was highlighted in three of the articles (Green, et al., 2009; Mantulak &

Nicholas, 2016; Mantulak & Cadell, 2018). This included becoming “stronger” (Mantulak & Cadell, 2018, p.115), growing in “confidence” (Mantulak & Nicholas, 2016, p.588), achieving a “renewed sense of empathy for others” (Mantulak & Nicholas, 2016, p.588), and in general as one parent described, making “you a better person” (Green, et al., 2009; p.125). Parents who reappraised they’re caregiving experience were able to reflect on positive change and personal growth. This was described by Mantulak and Nicholas (2016), as the ability of parents to “move from a place of stress and challenge to one that recognizes the opportunity for growth amid difficult experiences [through an] apparent process of reconciling meaning within caregiving” and as one parent in this study summed up: “we’re not going to say it’s suffering, we’re going to say it’s an experience” (p.588).

### **Discussion**

The current metasynthesis used the first order and second order constructs of selected studies to develop third-order interpretations that encapsulated parents’ experiences of pediatric organ transplant. The meaning of these experiences was constructed around three key themes across the articles: ‘parenting in the context of uncertainty’ ‘assimilating to new roles and responsibilities’, and ‘an opportunity for renewal and growth’. These themes highlighted the inherent challenges as well as positive change and personal growth parents experienced as they navigated through the transplant journey with their child which will be discussed in more detail below.

It is argued that “important commonalities exist in the experience of children and families affected with various kinds of conditions” (Perrin et al., 1993, p.23). Therefore, the findings in the current review have been considered in the context of the wider literature concerning the broader spectrum of transplantations and chronic physical illness.

#### **Parenting Amidst Uncertainty**

Uncertainty has been described as that which is “unknown and unknowable” (Cohen, 1993, p.77). Findings in the current review confirm that for parents, transplantation involves facing a tenuous future containing many unknowns. Although transplantation can be lifesaving, posttransplant prognosis is tentative and for that reason parents can feel like they’re “living on borrowed time” (Stubblefield & Murray, 1998). Coffey (2006) reported a similar theme from their metasynthesis, ‘Living Worried’, to describe the lived experiences of parenting a child with a chronic illness. Parents

who live through periods of sustained uncertainty with the ubiquitous prospect of impending loss might experience ongoing sorrow in relation to the drastic change in their projected outlook of life and the unpredictable nature of their child's illness (Wong & Chan, 2006).

Parents' experiences of uncertainty in the context of transplantation can be mapped onto the construct of uncertainty in chronic illness as developed by Mishel (1988; 1990). Mishel (1990) described uncertainty as the cognitive experience caused by an inability to understand the meaning of an illness-related event due to unpredictable health outcomes. The current review highlighted that parenting in the context of uncertainty can be difficult for parents of pediatric transplant recipients to bear and cause apprehension and worry. This finding is supported by Stewart and Mishel's (2000) and Szulczewski, Mullins, Bidwell, Eddington and Pai's (2017) respective syntheses showing parental anxiety and depression was commonly associated with uncertainty in the context of acute and chronic illness.

Lazarus and Folkman's (1984) stress and coping model postulates that if an individual appraises uncertainty as a threat, then they manage this fear by adopting behavioral and cognitive coping strategies that can reduce uncertainty and alleviate a perceived lack of control (Kerr, Harrington & Scott, 2017). It could be argued that for parents of pediatric transplant recipients, uncertainty perceived as a threat might lead to protective and vigilant parenting as a way of coping with the unknown. This holds parallels with findings from Hinton and Kirk's (2017) qualitative study exploring parents' experiences of living with childhood multiple sclerosis where participants reported engaging in continuous monitoring of their child as a strategy to reduce the uncertainty they experienced. Indeed, recent research has found overprotective parenting styles occur more frequently amongst parents of children with a chronic illness compared to parents of children without a chronic illness (Holmbeck et al., 2002).

In contrast, those who embrace uncertainty as an inevitability might experience an enhanced appreciation for life, reduced anxiety and instead live more consciously and gratefully (Parry, 2003). In the current review, parents of organ transplant recipients who had come to accept uncertainty as something that is inevitably an aspect of anyone's life, were able to live a life less governed by fear. This is consistent with previous research findings, for example, parents of children with childhood

cancer have emphasized the importance of becoming accustomed to the inescapable uncertainty of their child's illness (Woodgate & Degner, 2002). Hinton and Kirk (2017) also found that parents described their focus on the immediate present as opposed to worrying about the future as a strategy to manage uncertainty in the context of their child's multiple sclerosis.

### **Parenting Toward Autonomy**

The current synthesis of qualitative literature pertaining to parental experiences of pediatric transplant found that parents were challenged with the task of forgoing parent-dominated care. This finding encapsulates how parents were confronted with the task of releasing some of their control over health management to allow their child the freedom and self-reliance needed to live an independent and fulfilling adult life. Again, these experiences were imbued with uncertainty and fear of future threats and were particularly relevant to older children embarking on adolescence and adult care services.

The family play a crucial role in the development of adolescent autonomy, reducing parental dependency and allowing the child to acquire greater personal responsibility (Pardeck & Pardeck, 1990). Given that parents have been heavily involved and emotionally invested in the whole transplant journey, the prospect of letting go can be experienced as daunting, leaving parents feeling conflicted. The current review revealed that parents appeared to occupy two mutually exclusive values of being protective versus promoting autonomy. The tension between giving children opportunities to take responsibility for medical management whilst wanting to protect against potential life-threatening consequences has been found elsewhere in the qualitative literature. For example, in parents negotiating the responsibility for asthma self-care with pre-adolescent children (Meah, Callery, Milnes & Rogers, 2010). Similarly, Akre and Suris (2014) conducted focus groups with parents of children with a wide range of chronic illnesses and found parents expressed "difficulties striking a balance between controlling, letting go and everything else on the spectrum between the two such as trusting and guiding" (p.770).

Parents of pediatric transplant recipients appear to be making a conscious effort to slowly release control over medical management in preparation for adult-orientated care. Despite concerns and difficulties, they also discussed the long-term value of stepping back to ensure their child can be

personally responsible for their own health care. This finding is consistent with Heath et al., (2017) thematic synthesis of parents' experiencing of parenting a child with a chronic illness as they transition into adulthood: The systematic review of 32 articles revealed that parents regarded transition toward self-management positively and were motivated to achieve this. This was ultimately described by Heath et al., (2017) as "an incremental and negotiated process of gradually transferring responsibility for self-care" (p.82).

### **Parental Coping and Adaptation**

As was evident in the current review, parents of pediatric organ recipients become expert caregivers delivering care in the home, similar to parents of children with chronic illnesses (Balling & McCubbin, 2001; Freedman, Litchfield & Warfield, 1995; Ray & Ritchie, 1993). Parents expressed becoming overwhelmed in this role which replicates the experiences of psychological strain within parents caring for children living with chronic illnesses (Tong et al., 2008; Smith, Cheater & Bekker, 2015). Similar to the literature on caregiving children with chronic conditions, social support for parents of pediatric organ transplant recipients was perceived as essential in coping and adapting to new demands (Tak & McCubbin, 2002; Tong, Lowe, Sainsbury & Craig, 2010). In addition to this, the current review highlighted that parents want their plight to be fully comprehended by others: in that, transplantation creates hope when no alternative is left, whilst also causing fear in the context of uncertainty. Parents of transplanted children can be left feeling misunderstood when others adopt the stance of "transplant as cure", a social discourse that does not adequately reflect their experienced reality (Mantulak, 2014). Thus, parents of transplant recipients seek empathic individuals who can validly authenticate their experiences.

Findings from the current review demonstrated that some parents adapted to the demands of posttransplant life by re-framing illness management as the 'new normal'. Parents expressed a similar coping strategy in Tong, et al., (2010) qualitative study of parents' experiences on caring for a child with Chronic Kidney Disease (CKD). They found that although challenging, accepting their child's illness and perceiving their new circumstances as that which was now the 'norm', facilitated coping. It is theorized that normalization of illness management helps the family sustain usual patterns

of family and child functioning whilst meeting treatment regime demands (Knafl, Breitmayer, Gallo & Zoeller, 1996; Knafl & Deatrck, 2002).

### **Reconciliation and Post-Traumatic Growth (PTI )**

Findings in the current review suggest that parents who let go of fear and accepted the unknowable, experienced appreciation and a desire to view each day as a gift. This is consistent with qualitative exploration of parenting a child with chronic health conditions, where parents experience increased appreciation, personal growth and newfound inner strength (Kratz et al., 2009). Despite the challenges involved in the caregiver role, parents of children with an organ transplant experienced psychological benefits which could be understood within the framework of PTG. PTG is determined as the positive changes in self, interpersonal relationships and philosophy of life after dealing with a major life crisis or traumatic event (Tedeschi & Calhoun, 2012). This has been conceptualized as the following: (1) greater appreciation of life, (2) improved interpersonal relationships, (3) greater personal strength, (4) recognition of new possibilities in one's life course, and (5) spiritual or religious growth (Tedeschi & Calhoun, 1996; Tedeschi & Calhoun, 2004). The current finding is consistent with research elucidating PTG amongst parents of children with serious pediatric illness (Barakat, Alderfer & Kazak, 2005; Hungerbuehler, Vollrath & Landolt, 2011; Picoraro, Womer, Kazak & Feudtner, 2014; Wiedebusch et al, 2010).

### **Clinical Implications**

Understanding the perspective of parents is critical for tailoring support to help manage the practical and emotional demands associated with caring for a transplanted child. This is of added importance as parental coping is linked with the child's posttransplant health outcomes (Fredericks, Lopez, Magee, Sheck & Oipari-Arrigan, 2007). Parenting a child with an organ transplant can be experienced as demanding and might put parents at risk of suffering caregiver strain and burnout (Cousino, et al., 2017). The themes developed as a result of the current metasynthesis indicate that parents experience anxiety, strain, adjustment, acceptance and reconciliation in relation to parenting a child who has received an organ transplant. It is argued that a family's ability to draw on resources that promote resilience in times of crisis can increase the likelihood of adaptation (LoBiondo-Wood, 2003). Interventions aimed at supporting families who are struggling to adjust to posttransplant life



should help parents manage uncertainty and build resilience when confronted with concerns about the uncertain future.

Being a parent of a child with a transplant can be demanding on parents who are often already fulfilling multiple responsibilities. Family systems theory argues that factors, such as chronic illness, can directly and indirectly impact individual family members as well as the overall family environment (Moos & Moos, 1994). Parents who ensure their child's needs are met without sacrificing the individual needs of other family members might protect the integrity of the family system as a whole (Cohen, 1999). This has been referred to as a process of 'balanced coping' where parents are able to foster a sense of equilibrium between (1) fulfilling the needs of the child presenting with additional caregiver requirements, (2) attending to factors related to personal physical and mental health, and (3) meeting the demands of other roles (Major, 2003). Clinical services should encourage parents to readdress the balance when they feel dominated by their medical-caregiver responsibilities.

Parents value support from others who truly understand their situation. Speaking to 'experts by experience' is often valued amongst individuals who feel isolated by their experiences (Dennis, 2003). Parents taking part in peer mentoring schemes have discussed the benefits of receiving informational, affirmational and emotional support from parents with similar experiences (Sullivan-Bolyai & Lee, 2011). Giving parents the opportunity to seek peer support or mentorship might enable families to structure a supportive social network that can help them cope with the unique difficulties they face.

Finally, clinical services should be mindful of the impact transitioning between pediatric to adult services has on parents of pediatric transplant recipients. Preparing the family for the transition from parent-controlled management to autonomous care is recommended to begin as early as possible (Kieckhefer & Trahms, 2000). The process of achieving independence from parents is best accomplished in a gradual fashion ensuring the child has the capacity for self-sufficiency before the event (Baumrind, 1991).

### **Limitations and Future Research**

Most of the articles reviewed explored experiences of both male and female participants. However, every sample was made up of more mothers than fathers. None of the articles explored the

differences between experiences of mothers or fathers. It could be argued that the interpretations reached in the current synthesis relied heavily on the experiences given by mothers and caution should be drawn when generalizing these findings to fathers. Indeed, previous research has found convergent experiences when looking in more detail at mothers' and fathers' responses to parenting a child with chronic illness (e.g., Akre & Suris, 2014). However, in contrast, Knafl and Zoeller (2000) compared mothers' and fathers' experiences of childhood chronic illness in a qualitative study and found that parents developed a shared view of the illness, how it is managed and its impact on family life. Exploring more explicitly the differences in parenting experiences between mothers and fathers of children who have had an organ transplant is warranted.

The current review synthesized experiences of parents related to different types of solid organ transplant across a wide age range of children. There was evidence during the synthesis process that some experiences varied somewhat because of the type of organ transplant received and the current age of the transplant recipient. As the research base increases, a synthesis of qualitative findings related to specific types of organ transplant might be possible as well as research specifically addressing the differences in parenting adolescent transplant recipients compared to parenting younger transplant recipients.

### **Conclusion**

The current metasynthesis deepens current understanding of the challenges faced by parents of pediatric organ transplant recipients. Bringing together the qualitative literature available in this way allows a rich and thorough exploration of parents' thoughts, feelings and experiences in this domain. Being a parent of a child who has undergone organ transplant can be exhausting and emotionally challenging. However, many parents use strategies to cope and manage within their situation and have positive experiences of acceptance and gratitude. Ultimately, parents should be able to access support when struggling aimed at helping them navigate through the transplant journey to a place of adaptation and emotional stability.

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Table 1

*Search Terms*

<b>Search Term</b>	<b>AND</b>	<b>AND</b>
"organ transplant*" OR	"parent*" OR	"qualitative" OR
"heart transplant*" OR	"mother*" OR	"narrative" OR
"card* transplant*" OR	"father*" OR	"thematic" OR
"lung transplant*" OR	"caregiver*" OR	"interview*" OR
"pulmonary transplant*" OR	"maternal" OR	"grounded theory" OR
"heart-lung transplant*" OR	"paternal"	"phenomenolog*" OR
"kidney transplant*" OR	"guardian*" OR	"IPA" OR
"renal transplant*" OR	"family" OR	"focus group*" OR
"liver transplant*" OR	"grandparent*" OR	"experience*" OR
"hepatic transplant*" OR		"semi-structured"
"pancreas transplant*" OR		
"transplant recipient*" OR		

Table 2

*Examples of Studies Excluded from the Meta-ethnography*

<b>Author</b>	<b>Title</b>	<b>Reason for Exclusion</b>
Young, et al (2003)	Symptoms of posttraumatic stress disorder in parents of transplant recipients: Incidence, severity, and related factors	Quantitative methods of analysis used
Adelboyejo et al (2012)	Daily burdens of recipients and family caregivers after lung transplant	Caregivers and transplant recipients were spouses
Sque, Long, Payne & Alladyce (2008)	Why relatives do not donate organs for transplants: 'sacrifice' or 'gift of life'?	Study exploring the reasons why family members declined donation from a deceased relative
Gilmore & Newall (2011)	The experience of parents and children where children have been supported with a ventricular assist device as bridge to heart transplantation	Study specifically looking at the experiences of having a ventricular assist device and not exploring the experiences post-heart transplant
Burnell, Hulton & Draper (2015)	Coercion and choice in parent-child live kidney donation	Research related to parental live-donors
Medes-Castillo & Bousso (2009)	Not being able to live like before. The family dynamics during the experience of pediatric liver transplantation	The paper did not include any original quotes to illustrate their findings
Higgins, Kayser-Jones & Savedra (1996)	Parental understanding of the consequences of pediatric cardiac transplantation	The study did not explore parental experiences



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Author	Title	Reason for Exclusion
Nicholas (1999)	Meanings of maternal caregiving: Children with end stage renal disease	Participating parents included those of children with transplantation, hemodialysis or peritoneal dialysis but data presented in the study was not identified into these categories, therefore it was unclear how findings specifically may relate to parents of transplant recipient.
Sadala, Stolf, Bocchi & Bicudo (2013)	Caring for heart transplant recipients: The lived experience of primary caregivers	Parents of pediatric heart transplant recipients only formed a minority of the participant pool. Therefore, the interpretations of the data did not explicitly relate to the target population of the current review

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Table 3

*CASP Scores*

Study	Research Design	Strategy	Data Collection	Reflexivity	Ethical Considerations	Data Analysis	Findings	Value of the Research	Total Score
1. Adams et al., (2014)	3	2	3	2	3	3	3	3	22
2. Anthony et al., (2009)	3	3	3	2	2	3	2	3	21
3. Green et al., (2008)	3	2	2	1	1	3	2	3	17
4. Green et al., (2009)	3	3	2	1	3	2	2	3	19
5. Lerret et al., (2017)	2	3	2	1	2	2	3	3	18
6. Larret et al., (2014)	3	3	3	2	3	3	2	3	22
7. Lochridge et al., (2013)	3	3	3	1	1	2	2	3	18
8. Mantuak (2014)	3	1	2	2	2	1	2	3	16
9. Mantulak & Cadell (2018)	3	2	3	2	3	3	3	3	22
10. Mantulak & Nicholas (2016)	3	3	2	2	2	3	3	3	21
11. Meaux et al., (2014)	3	3	2	1	2	2	2	2	17
12. Stubblefield & Murray (1998)	3	2	1	1	1	3	3	2	16
13. Stubblefield & Murray (1999)	3	2	1	1	1	3	2	2	15
14. Stubblefield & Murray (2000)	3	3	3	1	3	3	3	3	22
15. Stubblefield & Murray (2001)	3	2	2	2	2	3	2	1	17
16. Stubblefield & Murray (2002)	3	2	1	1	1	3	3	2	16
17. Wright et al., (2016)	3	2	3	2	3	3	3	3	22

Table 4

*Characteristics of the Included Studies*

Author, Date/ Country	Title	Methodology	Number of Participants	Type of Organ Transplant	Reported demographics of child
1. Adams et al., (2014) UK	Restriction and dependence to autonomy and freedom: Transformation in adolescent heart transplant recipients	Semi-structured interviews which were analyzed according to the principles of IPA.	5 (4 mothers, 1 father)	Heart	Adolescent focus Average current age: 13 years (ranging between 14-18 years) Average age at transplant: 12 years (ranging between 13-17 years)
2. Anthony et al (2009) Canada	Perceptions of transitional care needs and experiences in pediatric heart transplant recipients	Semi-structured interviews analyzed using van Mahen's phenomenological approach.	17 (13 mothers, 4 fathers)	Heart	Adolescent focus Average current age: 15.7 (ranging between 11.7-17.8) Median time post-HT of 4.1 years (ranging from 0.3 to 9.2 years)
3. Green et al., (2008) USA	Comparing parents' and children's views of children's quality of life after heart transplant	Content analysis from semi structured interviews	11 (9 mothers, 2 fathers)	Heart	Average current age: 9 years (ranging between 6-11 years) Average age at transplant: 2.3 years (ranging from 0.007-9 years)

Author, Date/ Country	Title	Methodology	Number of Participants	Type of Organ Transplant	Reported demographics of child
4. Green et al., (2009) USA	Constantly responsible, constantly worried, constantly blessed: Parenting after pediatric heart transplant	In-depth qualitative interviews. Thematic analysis	*as above	*as above	*as above
5. Lerret et al., (2017) USA	Parents' perspectives on caring for children after solid organ transplant	Qualitative component of a mixed methods study design. Content analysis from semi structured interviews.	48 (41 mothers, 7 fathers)	Liver (20), Heart (15), Kidney (8), Multivisceral (5), Lung (1)	Average current age: 2.8 years (ranging from 3 weeks to 17.5 years)
6. Lerret et al. (2014) USA	Transition from hospital to home following pediatric solid organ transplant: Qualitative findings of parent experience	Qualitative component of a mixed methods study design. Content analysis from semi structured interviews.	37 (27 mothers, 10 fathers)	Heart (18) Kidney (10), Liver (9)	Average current age: 7.9 years (ranging from 3 months to 18 years)

Author, Date/ Country	Title	Methodology	Number of Participants	Type of Organ Transplant	Reported demographics of child
7. Lochridge, et al (2013) USA	Perceptions of solid organ transplant recipients regarding self-care management and transitioning	Semi-structured interviews analyzed using van Mahen's phenomenological approach	9 (6 mothers, 3 fathers)	Heart (6), Liver (3), Kidney (1)	Adolescent and young adult focus Average current age: 18.6 years (ranging between 17-22 years) Average age at transplant: 9.6 years
8. Mantulak (2014) Canada	The experience of mothering a child with a kidney transplant and the implications of illness-related uncertainty	Semi-structured interviews analyzed using van Mahen's phenomenological approach	7 (mothers = 7)	Kidney	Current age: ranging between 6 – 17 years Five children 3-5 years posttransplant, one 1-year posttransplant and one child 15 years posttransplant
9. Mantulak & Cadell (2018) Canada	Mothers' experience of post-traumatic growth in pediatric kidney transplantation	*as above	*as above	*as above	*as above
10. Mantulak & Nicholas (2016) Canada	"We're not going to say it's suffering; we're going to say it's an experience": The lived experience of maternal caregivers in pediatric kidney transplantation	*as above	*as above	*as above	*as above

Author, Date/ Country	Title	Methodology	Number of Participants	Type of Organ Transplant	Reported demographics of child
11. Meaux, et al (2014) USA	Transition to self-management after pediatric heart transplant	Online focus group. Electronic transcripts of online focus groups analyzed using Thematic Analysis.	6 (4 mothers, 2 fathers)	Heart	Adolescent focus Average current age 15.8 years 75% had received their heart transplant within the previous year and 25% had received a heart transplant more than 9 years before the study
12. Stubblefield & Murray (1998) USA	Parents' perceptions of their children's lung transplant experiences	Unstructured in- depth interviews using Colaizzi's (1978) phenomenological method of analysis.	15 (12 mothers, 3 fathers)	Lung	Current age ranging between 1 – 16 years 16% children were younger than 2 years of age at the time of transplantation; 24% children were between 6-9 years of age; the remaining 58% children were 12 years of age or older. All had undergone transplantation in the last 18 months
13. Stubblefield & Murray (1999) USA	Parents call for concerned and collaborative care	*as above	*as above	*as above	*as above
14. Stubblefield & Murray (2000) USA	Making the transition: Pediatric lung transplantation	*as above	*as above	*as above	*as above

Author, Date/ Country	Title	Methodology	Number of Participants	Type of Organ Transplant	Reported demographics of child
15.Stubblefield & Murray (2001) USA	Pediatric lung transplantation: Families' need for understanding.	*as above	*as above	*as above	*as above
16.Stubblefield & Murray (2002) USA	Waiting for lung transplantation: Family experiences of relocation	*as above	*as above	*as above	*as above
17. Wright et al., (2016) UK	Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services.	Semi-structured interviews which were analyzed according to the principles of IPA	9 (6 mothers, 3 fathers)	Liver	Adolescent and young adult focus Average current age: 19.6 years (ranging between 15.2 and 25.1 years Average age at transplantation 9.4 years (ranging between 0.9-15.9 years)

\*participants represent one sample

Table 5

*Summary of the Main Findings regarding Parents' Experiences of Pediatric Organ Transplant*

Reference	Main Findings
1. Adams et al., (2014)	<ul style="list-style-type: none"> <li>• Before transplant, parents feel that child is physically limited and not participating in normal teenage activities and are missing out as a result.</li> <li>• The experience the day-to-day responsibilities of care, such as providing high levels of supervision and monitoring, are demanding and relentless.</li> <li>• After transplant, parents feel that their child has become liberated by their improved physical health. They experience conflict with their child as their child strives for more independence and to catch up on what they have missed. Although they support autonomy, parents find it difficult to accept and adjust due to pre-transplant experiences (child is fragile). They find it difficult to negotiate the balance between autonomy and control, particularly around medication management. Ultimately, they fear the consequences of nonadherence.</li> </ul>
2. Anthony et al. (2009)	<ul style="list-style-type: none"> <li>• Parents experience worry and fear in relation to their child transitioning to adult services in the future.</li> <li>• Parents experience concern over whether they will lose their key roles, such as spokesperson and advocate, in their child's care once the child had transitioned to adult care.</li> <li>• Parent's anticipate adult care to be busy atmosphere and reduced individualized attention on child – causing concern.</li> <li>• Parents desire well managed transition with good collaboration and communication between adult and child services.</li> </ul>
3. Green et al., (2008)	<ul style="list-style-type: none"> <li>• Parent's view enjoyable activities, normalcy, staying healthy, sources of strength and support and struggles as important factors to their child's quality of life (QOL).</li> <li>• Parents try to limit the restrictions they place on their child accessing enjoyable activities to enhance their child's quality of life post heart-transplant. However, they must take into consideration transplant team advice, perceived risk of infectious disease and their child's physical ability.</li> <li>• Parents feel that they should treat their children as normal (normal discipline, chores, homework) to enhance their child's quality of life.</li> <li>• Parents felt that they had some control and responsibility to keep their children healthy post heart-transplant exerted through following the regime and being vigilant to their child's health.</li> </ul>



Reference	Main Findings
4. Green et al., (2009)	<ul style="list-style-type: none"> <li>• Parents find the overall experience of parenting a child after heart transplant challenging but worth it for child's life and when considering the alternative.</li> <li>• Parents feel constantly responsible for maintaining their child's health. Responsibilities are around-the-clock in nature. Parents feel responsible for keeping constant vigilance to prevent infection. Some parents integrate these responsibilities into life, others feel that life must revolve around them.</li> <li>• Parents feel constantly worried/ stressed about their child's health (infection, biopsy results, long-term prognosis, long-term morbidity risk) medical regime and child's participation in normal activities (whether their child is limited).</li> <li>• Parents' experiences of difficulties intertwined with feeling constantly blessed. Blessed that child is alive. Blessed because experiences have helped them focus on what's important in life.</li> <li>• Parents use coping strategies to deal with their experiences/ life. This includes (a) focusing on the positive, (b) recognizing lack of choice in what they are responsible for/ what their role is in child's health posttransplant, (c) the support received from faith and others (particularly those who fully understand), and (d) getting the right balance between the care the child needs vs. desire for their child to have a normal life.</li> </ul>
5. Lerret (2017)	<ul style="list-style-type: none"> <li>• At 3-weeks post-discharge parents' experiences are characterized by the process of 'getting back to normal'. This includes establishing a new routine, organizing competing demands and juggling multiple responsibilities. Some parents find this task challenging. Parents also find the need to strike a balance between self-care and care for transplanted child a challenge. Parents start to show fear for unknown future.</li> <li>• At 3-months post-discharge, parents' experiences are characterized by the process of "becoming routine". Here, parents are starting to feel more confident and adjust to the new routine. However, they face the challenge of helping their child regain health and function. At this stage parents have trouble accepting their child is ready to resume normal activities and their need to let them go. They worry about their child's vulnerability and risks to health posed by infection/ rejection.</li> <li>• At 6-months post-discharge parents' experiences are characterized by the process "facing the future". They start to reflect on the impact the experiences have had on personal change. They continue to be concerned about their child's future and engage in vigilant monitoring to prevent infection, injury and rejection which was challenging.</li> </ul>

Reference	Main Findings
6. Lerret et al., (2014)	<ul style="list-style-type: none"> <li>• On the day of discharge, parents experience several concerns including knowledge about the new medical regime/ medical care needed at home, restrictions placed on child due to medical-needs and who to access continued support from.</li> <li>• Parents' readiness for discharge depends upon their experiences of education methods and support.</li> <li>• Following discharge (3 weeks post) parents' experiences of coping are affected by developing a 'new normal', a routine that encompasses all family members, demands of clinic follow-up and adherence to medical regime. This task can be experienced as stressful/ challenging.</li> <li>• Following discharge, parents' experiences of coping are affected by dealing with uncertainty and worry regarding unknown complications, rejections and child's future health. Parents become vigilant to signs and symptoms.</li> <li>• Coping post-discharge can be enhanced by parents feeling supported and educated. It is also enhanced by seeing their child have fun and experiencing a sense of normalcy.</li> <li>• Coping post-discharge can be hindered by parents struggling to adjust lifestyle, struggling to find a suitable routine and by parents feeling overwhelmed by hospital systems.</li> </ul>
7. Lochridge et al., (2013)	<ul style="list-style-type: none"> <li>• Parents are fearful of transition to adult services. Fear centers around unfamiliarity, questioning competency of adult provider, losing control over child's medical care. Worry regarding losing relationship with pediatric provider. Acknowledging feelings of being overly involved in child's medical care and subsequent difficulty letting go of role 'primary medical caretaker'. Worry about how child will cope. Feelings of helplessness.</li> <li>• Important for parents to feel prepared for transition aided by aspects of child's care and actions of providers (e.g. asked to leave clinic room). Difficult to accept at first but realize importance of stepping back for child's autonomy/ independence. Recognizing what child needs developmentally helped feel more secure about transition.</li> <li>• Experiences of conflict with child regarding child's need to adopt more self-care skills and personal responsibility, e.g., medication schedule. Parents push towards this while feeling that their child resistant. Experiencing conflict with pediatric provider – feeling abandoned.</li> <li>• Holding negative perceptions of adult care facilities and providers. Feelings of uncertainty.</li> </ul>

Reference	Main Findings
8. Mantulak (2014)	<ul style="list-style-type: none"> <li>• Despite barriers, acknowledge transition as potential positive experience. Wanting to ease the transition through building relationships with staff early on, having discussions early on in child's care, having transition tailored to child's needs.</li> <li>• Parents experience uncertainty beginning at diagnosis and continuing through all stages of child's transplant.</li> <li>• Transplant signifies a tenuous and unpredictable future that is reliant on timelines and managed prevention of organ rejection.</li> <li>• Parents experience life filled with unknowns and uncertainty which they need to manage. Must learn to accept uncertainty in order to cope with the emotional and psychological impact of it.</li> <li>• Parents experience an acute sense of time (waiting, anxiety of its passing, future).</li> <li>• Awareness of time in the moment by parents waiting (e.g., on transplant day), in relation to monitoring and medical adherence, and in relation to being within hospital settings (feeling no control over time passing). Therefore, lapsing of time structured parental experiences. Uncertainty meant living in the moment.</li> <li>• Time passing embedded within parents fear of organ rejection. This being an ongoing unrelenting concern; source of stress and anxiety for parents. Therefore, time passing represents being closer to feared organ rejection and implications of this.</li> <li>• Frustrations with social misunderstanding of transplant as 'cure'</li> </ul>
9. Mantulak & Cadell (2018)	<ul style="list-style-type: none"> <li>• Post-traumatic growth emerged as an over-arching theme in mothers' lived experiences of being a mother of a child who has undergone kidney transplantation. Presence of growth found amidst the stressors of caregiving.</li> <li>• Mothers experience a stronger sense of self, tapping into unknown strengths such as patience and confidence and learning how to manage emotions. This benefitted other areas of life.</li> <li>• Transplant experience came with new possibilities. Mothers' experience skill development essential for their new roles, responsibilities and obligations as a caregiver. They develop a new role of advocating for their child.</li> </ul>

Reference	Main Findings
11.Meaux et al., (2014)	<ul style="list-style-type: none"> <li>• Transplant experience enhanced mothers' relationships with others. It helps to know they were not alone in their experience. They value the support (practical and emotional) from others. They feel connected to their child's experience in a sense of mutuality. They experience increased empathy for other caregiving parents.</li> <li>• Mothers' experience a reappraisal which leads to a greater appreciation of life despite inherent challenges.</li> <li>• Mothers' focus shifts from stress and challenge of their situation to recognizing positive meaning of caregiving experience.</li> <li>• Parents experience their responsibility to manage medication as all-consuming and overwhelming at times. They develop complex organizational systems and processes of coordination to manage. Parents will enlist help from the adolescent but continue to oversee.</li> <li>• Parents try to balance staying on top of things (parent-dominated management) with adolescent desire for independence and self-management of medication. Parents remain vigilant as their child transitions to self-management. They continue to experience constant worry and monitoring. They encourage their child to assume more responsibility acknowledging the importance in helping them become independent. However, sometimes they take control for these responsibilities back after complications/ rejection.</li> <li>• Parents perceive their child to be a normal teenager. However, they also experience anxiety in letting them participate in normal teen activities. They weigh up desire for normalcy with risks.</li> <li>• Parents continue to worry about consequence of non-adherence considering adolescent independence, a worry that reduces with time but never really goes away.</li> </ul>
12. Stubblefield & Murray (1998)	<ul style="list-style-type: none"> <li>• The prospect of transplantation gives hope for a new lease of life for their child.</li> <li>• Accepting child's need for transplantation represents an uncertain future: facing the threat of the unknown including surgery, long-term prognosis, outcomes.</li> <li>• Parents experience day-to-day uncertainty living with lung transplantation related to their child's health status in the moment "we live on a roller coaster" p.378.</li> </ul>

Reference	Main Findings
13. Stubblefield & Murray (1999)	<ul style="list-style-type: none"> <li>• An opportunity for normality provided by transplantation drives parents to adapt. Parents must learn to accept risk of infection and threat of rejection as well as protect against it.</li> <li>• In the context of living with transplantation, parents focus on normalizing the lives of all family members whilst balancing this with responsibilities to manage the transplant.</li> <li>• Transplant situation used as a basis for developing a new perspective on life: accepting the benefits outweigh the risks, focusing on positive outcomes, finding meaning, appreciating the value of life.</li> <li>• Parents perceive health care providers in terms of concerned care and collaborative care.</li> <li>• Concerned care is perceived when parents feel they are treated as an individual (meeting individual needs, being reassured, encouraged and supported), feel there is a continuity in care (trust), and feeling that their child is important to their health care provider.</li> <li>• Concerned care experienced allows parents to feel able to tend to their own needs.</li> <li>• Parents who don't experience concerned care feel a sense of being abandoned and needing more support</li> <li>• Parents feel they need a voice and role in their child's care. Experiences of collaborative care with health care provider valued, reflecting a shared alliance.</li> <li>• Parents who experience a lack of collaboration experience being caught in the middle of divergent opinions, feel uncertain, fearful and guilt.</li> </ul>
14. Stubblefield & Murray (2000)	<ul style="list-style-type: none"> <li>• Parents face challenges and a need for adaptations when transitioning their child back home from being cared for in hospital.</li> <li>• Reuniting the family when returning home is an eagerly anticipated but stressful transition causing unexpected emotional impact and difficulties with role change amongst family members.</li> <li>• Parents need to assume new roles of health care provider and care coordinator on returning home which can be experienced as stressful.</li> <li>• The child returning to school can be experienced as worrying and stressful particularly regarding concerns related to their social adjustment (lengthy absence and body image changes) and increased risk of infection in school environment. Sometimes parents experience conflict with health team re. risk of infection vs. benefits of resocialization.</li> </ul>

Reference	Main Findings
	<ul style="list-style-type: none"> <li>• Parents experience ongoing concern about risk of infection, guarding against it becomes a way of life.</li> <li>• Organ rejection is a serious threat, the stress of which is minimized by focusing on medical management.</li> <li>• It is difficult striking the balance between what everyone needs in a life complicated by transplantation.</li> <li>• Approaches to managing posttransplant situation either within the foreground (heightening fear and uncertainty) or in the background (uncertainty minimized by focusing on medical management).</li> </ul>
15. Stubblefield & Murray (2001)	<ul style="list-style-type: none"> <li>• Lung transplantation experience influence parents' relationship with others.</li> <li>• Others are perceived as a source of support – this includes family, friends, other transplant parents, professional counsellors, community and religion.</li> <li>• Other transplant parents felt to be understanding which can lead to close friendships being formed.</li> <li>• Parents who perceive others as supportive before and immediately after surgery, experience diminished support as they adapted posttransplant.</li> <li>• Parents feel misunderstood by others not understanding the ongoing demands of living with transplant.</li> <li>• Parents attribute diminished support to others' fear and uncertainty.</li> <li>• Parents feel labelled by others who only focus on the transplant situation – desired normal interactions.</li> </ul>
16. Stubblefield & Murray (2002)	<ul style="list-style-type: none"> <li>• The stress associated with waiting for transplantation complicated by need to relocate to be within certain proximity of transplant center.</li> <li>• The waiting period experienced as a time when life is on hold and other responsibilities are set aside to support transplant patient.</li> <li>• It is emotionally difficult and stressful to be separated from family members at home when relocated during waiting period.</li> <li>• Other transplant parents can become a source of support during this time. However, this can be experienced as instable, particularly when these parents return home. And it can have a negative impact, particularly when other parents share negative information regarding posttransplant complications and mortality.</li> <li>• Parents who remain at home can undergo role change during the waiting period as they take on additional roles normally fulfilled by the parent who has relocated.</li> </ul>

Reference	Main Findings
17. Wright et al., (2017)	<ul style="list-style-type: none"> <li>• The negative effects of relocation can be minimized when parents focus on the positive aspects of the situation.</li> <li>• Supporting their child through transplantation has an emotional impact on parents. The experience is unpredictable, anxiety inducing and upsetting.</li> <li>• Parents appreciate lifesaving measure; however, they are also aware of lifelong management needed for long-term health condition.</li> <li>• The experience is both positive and negative. Parents reflect on the difficult experience of witnessing other patients dying during their child's transplant journey, and the sense of perspective this gives to manage everyday issues. Being negative about experiences creates feelings of guilt.</li> <li>• Experience of waiting for transplant is a time of anxiety and feelings of not being able to live life as a family in a normal way.</li> <li>• As child emerges into adulthood parents are faced with conflicting feelings of wanting to protect child whilst also wanting them to be independent. Feeling out of control is experienced as distressing. Parents worry about whether child will be able to cope without them as they transition into adult services. They feel attached to their role of managing their child's health condition. Parents are concerned their roles will be taken away when child transfers to adult services.</li> <li>• Parents feel strong connection to pediatric team. They have found this relationship supportive and important for coping.</li> <li>• Child transitioning into adult services, feel side-lined and role redundant.</li> <li>• Parents find letting go difficult due to the emotional investment they have made. Delegating responsibilities outside of their role feels difficult. They feel concerned about being out of control and excluded from child's care.</li> </ul>

Table 6

*Contribution of the Studies to Meta-ethnographic Theme 1*

<b>Theme 1: Parenting in the Context of Uncertainty</b>		
<b>Reference</b>	<b>Inescapable fear and uncertainty</b>	<b>Managing the unknown</b>
3. Green et al., (2008)		<p><i>Theme: Parents' views. Enjoyable activities</i></p> <p>At times necessary to place restrictions due to medical advice/ infection risk; however not so much it hinders child's QOL.</p> <p><i>Theme: Parents' views. Staying Healthy</i></p> <p>Feel sense of control/ responsibility over child's health through following regime and being vigilant.</p>
4. Green et al., (2009)	<p><i>Theme: Constantly worried</i></p> <p>Worry never stops; worry about child's health, risk of complications, long-term prognosis, risk of long-term morbidity; intense worry when child sick or waiting for biopsy results.</p>	<p><i>Theme: Coping with life</i></p> <p>Focusing on positives, "better than alternative"; finding the right balance between providing care/ protecting against risks vs. allowing child to live a normal life.</p> <p><i>Theme: Constantly Responsible</i></p> <p>Constant vigilance and monitoring to prevent infection.</p>
5. Lerret et al., (2017)	<p><i>Theme: "Getting back to normal" 3 weeks after discharge</i></p> <p>Frightened about unknown future.</p> <p><i>Theme: "Becoming routine" 3 months post-discharge</i></p> <p>Child is vulnerable, worry about infection; concern about protecting/ maintaining transplant for future.</p> <p><i>Theme: "Facing the future" 6 months after discharge</i></p> <p>Worry about child's future, financial and ability to self-care.</p>	<p><i>Theme: "Facing the future" 6 months after discharge</i></p> <p>Vigilant monitoring; constant surveillance to protect child's transplanted organs; limiting exposures; vigilant monitoring.</p>



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**Theme 1: Parenting in the Context of Uncertainty**


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Reference	Inescapable fear and uncertainty	Managing the unknown
6. Lerret et al (2014)	<p><i>Theme: Coping at home after discharge</i></p> <p>Worry and stress about rejection; watchful vigilance; difficulty not knowing post-transplant potential complications/ hospital readmissions; uncertainty of child's future health; concern over child's reaction to diagnosis and treatment; concern for germs impacted on daily routine and family activities; unknown difficult for whole family.</p>	<p><i>Theme: Coping at home after discharge</i></p> <p>Creating a new normal that includes dealing with associated worry of possible unknown complications.</p>
8. Mantulak (2014)	<p><i>Theme: Time as Uncertain</i></p> <p>Life filled with unknowns; from diagnosis and throughout; acute awareness of time and worry about it passing; the unknown at forefront of thinking; uncertainty of waiting; transplantation represents a tenuous future; source of stress and anxiety; disruption of normal timeline; ongoing unpredictability of illness; existentially trapped in future.</p> <p><i>Theme: Time as Living in the Moment</i></p> <p>Being unsure whilst experiencing "suspended time", i.e., waited time; "waiting and wondering"; time passing imbued with uncertainty related to feared unknowns/ no control over what it may bring; unexpected could occur any day.</p> <p><i>Theme: Times as Fear of Rejection of the Transplanted Organ</i></p> <p>Uncertainty re. eventual rejection of transplanted kidney; impact on every aspect of life; unrelenting worry; anxiety and stress; dread of return to dialysis/ re-transplantation; difficult to cope with; cannot celebrate time passing as signifies closer step to rejection/ re-transplantation/ dialysis.</p>	<p><i>Theme: Time as Uncertain</i></p> <p>Must learn to accept uncertainty and what cannot be known; coping meant managing uncertainty; making meaning from unpredictable; striving to accept chronic uncertainty</p> <p><i>Theme: Time as Living in the Moment</i></p> <p>Uncertainty means living in the moment; coping with and making meaning of lapsed time.</p> <p><i>Theme: Time as Fear of Rejection of the Transplanted Organ</i></p> <p>Daily rituals embedded with fear of transplant rejection; uncertainty and organ rejection mean living on 'margins' of child's good health; ability to cope depends on attitude 'glass being half-full or half-empty'.</p>
10. Mantulak & Nicholas (2016)	<p><i>Theme: The experience of time in pediatric kidney transplant</i></p> <p>Anxiety at never knowing what the future might hold; experience of time. passing and transplant vulnerability leads to uncertainty and fear of rejection; dread of unyielding cycle</p>	

**Theme 1: Parenting in the Context of Uncertainty**

Reference	Inescapable fear and uncertainty	Managing the unknown
11. Meaux et al. (2014)	<p><i>Theme: Worries and Stressors</i></p> <p>Does ease over time but never completely goes away</p>	
12. Stubblefield & Murray (1998)	<p><i>Theme: Uncertainty</i></p> <p>Experience filled with day-to-day uncertainty maintained in the background of family life; threat of the unknown; concerns over long-term prognosis; difficulty maintaining hope.</p> <p><i>Theme: Opportunity for Normalcy</i></p> <p>Organ rejection a major threat.</p>	<p><i>Theme: Hopes for the Future</i></p> <p>Frightening but necessary for life; trying to maintain hope and find a new source of hope post-transplant; transplantation gives hope within uncertainty of fatal chronic illness.</p> <p><i>Theme: Uncertainty</i></p> <p>Difficulty accepting uncertain outcomes; accepting no turning back; ability to cope with uncertainty depends on child's health.</p> <p><i>Theme: Opportunity for Normalcy</i></p> <p>Adapting to transplant and accepting threats gives opportunity for normalcy; focus on roles that prevent rejection; aspects of medical management; making vigilance a normal part of life.</p>
14. Stubblefield & Murray (2000)	<p><i>Theme: Making the Transition</i></p> <p>Uncertainty present but impact varied.</p> <p><i>Theme: Facing the Risk of Infection</i></p> <p>Fear pervades all areas of socialization; ongoing concern</p>	<p><i>Theme: Making the Transition</i></p> <p>Need to let children 'go' to lead a normal life; transplant management in foreground heightens fear and uncertainty; transplant management in background; minimizing uncertainty through control.</p> <p><i>Theme: Facing the Risk of Infection</i></p> <p>Protecting becomes way of life</p>

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**Theme 1: Parenting in the Context of Uncertainty**

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<b>Reference</b>	<b>Inescapable fear and uncertainty</b>	<b>Managing the unknown</b>
16. Stubblefield & Murray (2002)	<p><i>Theme: Experiences of relocation. Establishing a support network</i></p> <p>Other transplant parents can heighten fears when negative information shared.</p>	<p><i>Theme: Experiences of relocation. Putting life on hold</i></p> <p>Experiences of waiting period “keeping one’s head above the water”.</p> <p><i>Theme: Experiences of relocation. Making the best out of the situation</i></p> <p>Importance of focusing on positive aspects to minimize impact of stress.</p>
17. Wright et al., (2017)	<p><i>Theme: Emotional impact of transplantation</i></p> <p>Transplant experience unpredictable, anxious and upsetting time; anxious on waiting list for transplant; waiting family can’t enjoy normal life; experience unpredictable.</p>	<p><i>Theme: Emotional impact of transplantation</i></p> <p>Excessive planning; restricting activities.</p>

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Table 7

*Contribution of the Studies to Meta-ethnographic Theme 2*

<b>Theme 2: Assimilating to new Roles and Responsibilities</b>			
<b>Reference</b>	<b>Consumed by new demands</b>	<b>Striking a balance: Adapting to a 'new normal'</b>	<b>Preparing to forgo parent-dominated care</b>
1. Adams et al., (2014)			<p><i>Theme: Autonomy and freedom (post-transplant)</i></p> <p>Difficulty to adjust to adolescent need for independence; transplant added to typical parent-adolescent conflict; difficulty letting go due to previous fragility; difficulty negotiating responsibility; monitoring child surreptitiously; difficulty trusting child – they're not ready; difficulty negotiating balance between autonomy and control; fearing consequence of non-adherence; importance of supporting emerging autonomy.</p>
2. Anthony et al. (2009)			<p><i>Theme: Perceptions of transition. Differences between adolescents and parents</i></p> <p>Transition feared; worried and anxious; will child receive same care in adult setting?; must remain vigilant.</p> <p><i>Theme; Perceptions of transition. Adult care expectations</i></p> <p>Adolescent independence a risk; not good enough; exclusive of parents; worried about losing role as advocate/ key player in child's care; will child cope?</p>

**Theme 2: Assimilating to new Roles and Responsibilities**

Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
3. Green et al., (2008)		<i>Theme: Parents' views. Normalcy</i> Normalizing medical regime to benefit child's QOL.	<i>Theme: Parents' views. Enjoyable activities</i> Not so much restriction it hinders child's QOL.  <i>Theme: Parents' views. Normalcy</i> Not easy to treat child as normal but important for child's QOL.
4. Green et al., (2009)	<i>Theme: Constantly Responsible</i> For maintaining child's health; round-the-clock care.  <i>Theme: Constantly worried</i> The regime and as a result, child's social limitation.	<i>Theme: Constantly Responsible</i> Managed by either integrating responsibilities into life or something that controlled their lives.  <i>Theme: Coping with life</i> Social support helps parents cope; Needing additional support from those who fully understand (medical team, transplant parents) helped cope.	<i>Theme: Coping with life</i> Finding the right balance between providing care/ protecting against risks vs. allowing child to live a normal life.
5. Lerret, et al., (2017)	<i>Theme: "Getting back to normal" 3 weeks after discharge</i> Challenge of medication management despite feeling adequately prepared; exhaustion at newness; stressful; siblings neglected; post-transplant care very time demanding; guilt at impact on siblings; providing physical care challenging.  <i>Theme: "Becoming routine" 3 months post-discharge</i>	<i>Theme: "Getting back to normal" 3 weeks after discharge</i> Challenge in establishing new routine amongst other responsibilities; juggling multiple responsibilities; coordinating multiple demands; striking a balance  <i>Theme: "Becoming routine" 3 months post-discharge</i> Gained confidence in medications and care; relief that child adjusted and routines.  <i>Theme: "Facing the future" 6 months after discharge</i> Established manageable routines; typical activities resumed.	

Theme 2: Assimilating to new Roles and Responsibilities			
Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
	<p>Challenge of helping children regain health and function once posttransplant health stabilized; managing challenging behaviors.</p> <p><i>Theme: "Facing the future" 6 months after discharge</i></p> <p>Continued challenge supporting child's health and function; facing more long-term needs of child; difficulty adjusting to post-transplant circumstance; difficulty adapting to change.</p>		
6. Lerret et al., (2014)	<p><i>Theme: Education content of discharge preparation</i></p> <p>Concern at hospital discharge about their role with medication; how restrictions would impact on child and ability to return to normal.</p> <p><i>Theme: Coping at home after discharge</i></p> <p>Responsibility of the regime.</p> <p><i>Theme: Adherence difficulty</i></p> <p>Difficulty adhering to medications whilst juggling other responsibilities.</p>	<p><i>Theme: Readiness for hospital discharge</i></p> <p>Difficulty feeling confident to deliver care at home; valued support from others; need help and encouragement from others.</p> <p><i>Theme: Positive influences on coping</i></p> <p>Support from others; having knowledge/ education; "being normal"; watching child improve; remaining optimistic.</p> <p><i>Theme: Coping at home after discharge</i></p> <p>Developing a 'new normal'; challenging to juggle other responsibilities, follow-up visits, home care; coordinating family routines and needs of other family members; "figure it all out"</p> <p>developing pattern to best serve child's care at home; challenge to</p>	<p><i>Theme: "Becoming routine" 3 months post-discharge</i></p> <p>Accepting child healthy and ready to take part in normal activities; begin to treat child as normal, less restrictions.</p>

Theme 2: Assimilating to new Roles and Responsibilities			
Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
7. Lochridge et al., (2013)	<p><i>Theme: Negative influences on coping</i></p> <p>Difficulty developing a new routine to encompass all responsibilities. Feeling overwhelmed by hospital systems.</p>	<p>find routine by desire to lead a normal life in context of post-transplant restrictions.</p>	<p><i>Theme: "He/ she needs me to care for him/ her!" Parent and provider barriers in patient self-care management and transition</i></p> <p>Feeling overinvolved in medical care; difficulty relinquishing caretaker role; worried how child will cope; feeling helpless; Awareness that overinvolvement is holding child back.</p> <p><i>Theme: "Don't tell me what to do!" Discrepancies</i></p> <p>Parent-child conflict related to increased responsibility; pushing resistant child.</p> <p><i>Theme: "It's time for you to fly." Parent and provider role in self-care and transition</i></p> <p>Understanding importance of child experiencing autonomy in clinic appointments; desire to promote self-care/ personal responsibility; acknowledging child's developmental needs.</p> <p><i>Theme: "I can do this, but I need your help." Facilitating a smooth transition to adult center</i></p> <p>Building relationships with adult provider early aided smooth transition; patient-driven approach.</p>

Theme 2: Assimilating to new Roles and Responsibilities			
Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
8. Mantulak (2014)		<p><i>Theme: Time as Fear of Rejection of the Transplanted Organ</i></p> <p>Frustration with social misunderstandings of transplant as 'cure'.</p>	
9. Mantulak & Cadell (2018)	<p><i>Theme: Stronger self</i></p> <p>Caregiving experience insurmountable; advocacy role important.</p>	<p><i>Theme: Appreciation of life</i></p> <p>Life as the 'new normal'.</p> <p><i>Theme: Enhanced Relationships</i></p> <p>Supported by knowing not alone.</p>	<p><i>Theme: "Becoming Routine" 3 months post-discharge</i></p> <p>Worry in response to child taking more responsibility for medications.</p> <p><i>Theme: "Facing the future" 6 months after discharge</i></p> <p>Worry about letting child go/ not being able to monitor as much.</p>
10. Mantulak & Nicholas (2016)		<p><i>Theme: The lived experience of self in relation to others</i></p> <p>Relationship with others key to perceived sense of self and feelings of isolation; quality of relationship meaningful; highly valued for practical and emotional support; support enabled coping; support from others appreciated; unsupported/ alienated by those who do not understand; connection with others sought out.</p>	
11. Meaux et al. (2014)			<p><i>Theme: Managing Medications</i></p> <p>Not ready to completely let go; wanting to remain in control; trying to balance parent-dominated management with adolescent needing independence</p> <p><i>Theme: Staying on top of things/ becoming independent</i></p> <p>Remaining vigilant; influenced by years of management and coordinating complex treatment regime; constant worrying and monitoring; transition to self-management not linear, parents move between letting go and taking back control; desire and necessity of adolescent independence acknowledged</p>



Theme 2: Assimilating to new Roles and Responsibilities			
Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
			<i>Theme: Letting them be normal</i>
			Difficulty allowing adolescent to be independent when worried about their limitations/ health; adolescent participating in normal life through taking care of themselves in many areas; let their child be as normal as possible; weighed up with associated risks.
			<i>Theme: Worries and Stressors</i>
			"Catastrophic consequences of nonadherence".
12. Stubblefield & Murray (1998)	<i>Theme: Opportunity for Normalcy</i> Means to preventing against rejection impacts on family functioning.	<i>Theme: Opportunity for Normalcy</i> Balancing normalcy with medical management; meeting everyone's needs; opportunity for new normal; normalizing within the context of living with a transplantation; family life different but differentness accepted.	<i>Theme: Opportunity for Normalcy</i> Conflicting thoughts re. risk of infections vs. benefits of resocialization.
13. Stubblefield & Murray (1999)		<i>Theme: Collaborative Care</i> Important to be part of the team; voice for child; shared alliance with health team; lack of collaboration feeling misinformed/ uncertain/ fearful.  <i>Theme: Concerned Care</i> Needing concerned care from health care team throughout transplant trajectory; to be treated as an individual; to be reassured, encouraged and supported; continuity valued/ feels safe; trust; can address own needs; lack of concerned care feeling misunderstood and abandoned.	

**Theme 2: Assimilating to new Roles and Responsibilities**

Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
14. Stubblefield & Murray (2000)	<p><i>Theme: Assuming a New Role</i></p> <p>Medical and nursing aspects of transitioning home stressful; new role of health care provider; new role of care coordinator.</p>	<p><i>Theme: Striking a Balance</i></p> <p>Accommodation to potentially overwhelming demands.</p>	<p><i>Theme: Facing the threat of rejection</i></p> <p>Child's own involvement in care lessens impact of schedule on parent.</p> <p><i>Theme: Returning to School (social adjustment and avoiding infection)</i></p> <p>Concern about social adjustment, risk of infection in school environment, and resocialization; stressful experience.</p>
15. Stubblefield & Murray (2001)		<p><i>Theme: Others as source of support</i></p> <p>Importance of supportive others (family, community professionals, counsellors, religion); other transplant parents reliable source of support and encouragement; feeling understood; forming friendships; mediate effects of emotional stress; helped accept need for transplant; perspective of wider context; helped mend strained family relationships; hesitancy in seeking professional support reflects desire to be perceived as ordinary.</p> <p><i>Theme: Experiencing diminished support</i></p> <p>Posttransplant period of adaptation feeling less supported; feeling long-term demands of situation misunderstood by friends and family; feeling labelled by others focusing only on transplantation; Desire for less problem-focused/ normalcy in interactions with others.</p>	

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**Theme 2: Assimilating to new Roles and Responsibilities**

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Reference	Consumed by new demands	Striking a balance: Adapting to a 'new normal'	Preparing to forgo parent-dominated care
17. Wright et al., (2017)	<i>Theme: Emotional impact of transplantation</i>  Negative impact on family members; life-long management of long-term condition.	<i>Theme: Ending relationships</i>  Pediatric team experienced like a family; closeness; support network helped cope; comforting; familiar	

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Table 8

*Contribution of the Studies to Meta-ethnographic Theme 3*

<b>Theme 3: Opportunity for Renewal and Growth</b>		
<b>Reference</b>	<b>A renewed perspective on life</b>	<b>Strengths and personal growth</b>
1. Adams et al., (2014)	<p><i>Theme: Restriction and dependence (prior to transplant)</i></p> <p>Experiencing transplant as transformative in relation to how restricted and dependent child was before transplant; child not able to partake in the norm; demanding day-to-day care; child helpless; different from peers.</p> <p><i>Theme: Autonomy and freedom (post-transplant)</i></p> <p>Child is liberated by transformed physical health; restrictions lifted; my child is normal teenager again</p>	
4. Green et al., (2009)	<p><i>Theme: Constantly Blessed</i></p> <p>A new perspective on life gained; being thankful for what you have; focus on what you value; although difficult experiences, feel blessed that child is alive.</p>	<p><i>Theme: Constantly Blessed</i></p> <p>Making you a better person.</p>
9. Mantulak & Cadell (2018)	<p><i>Theme: Enhanced Relationships</i></p> <p>Increased empathy for other caregiving parents despite own care stress.</p> <p><i>Theme: Appreciation of life</i></p> <p>Reappraisal leads to greater appreciation despite challenges.</p> <p><i>Theme: Spiritual change</i></p> <p>Renewed meaning recognizes that life is not what intended; changes in spirituality and faith.</p>	<p><i>Theme; Stronger self</i></p> <p>Positive altered sense of self; tapped into unknown strengths; learning to manage emotions; personal resolve applied to other areas of life; experience made better able to meet other challenges; I am strong; I am capable; growth amidst stressors.</p> <p><i>Theme: New possibilities</i></p> <p>Skill development for provision of care; ability to advocate; ability to fulfil multiple roles/ responsibilities.</p>

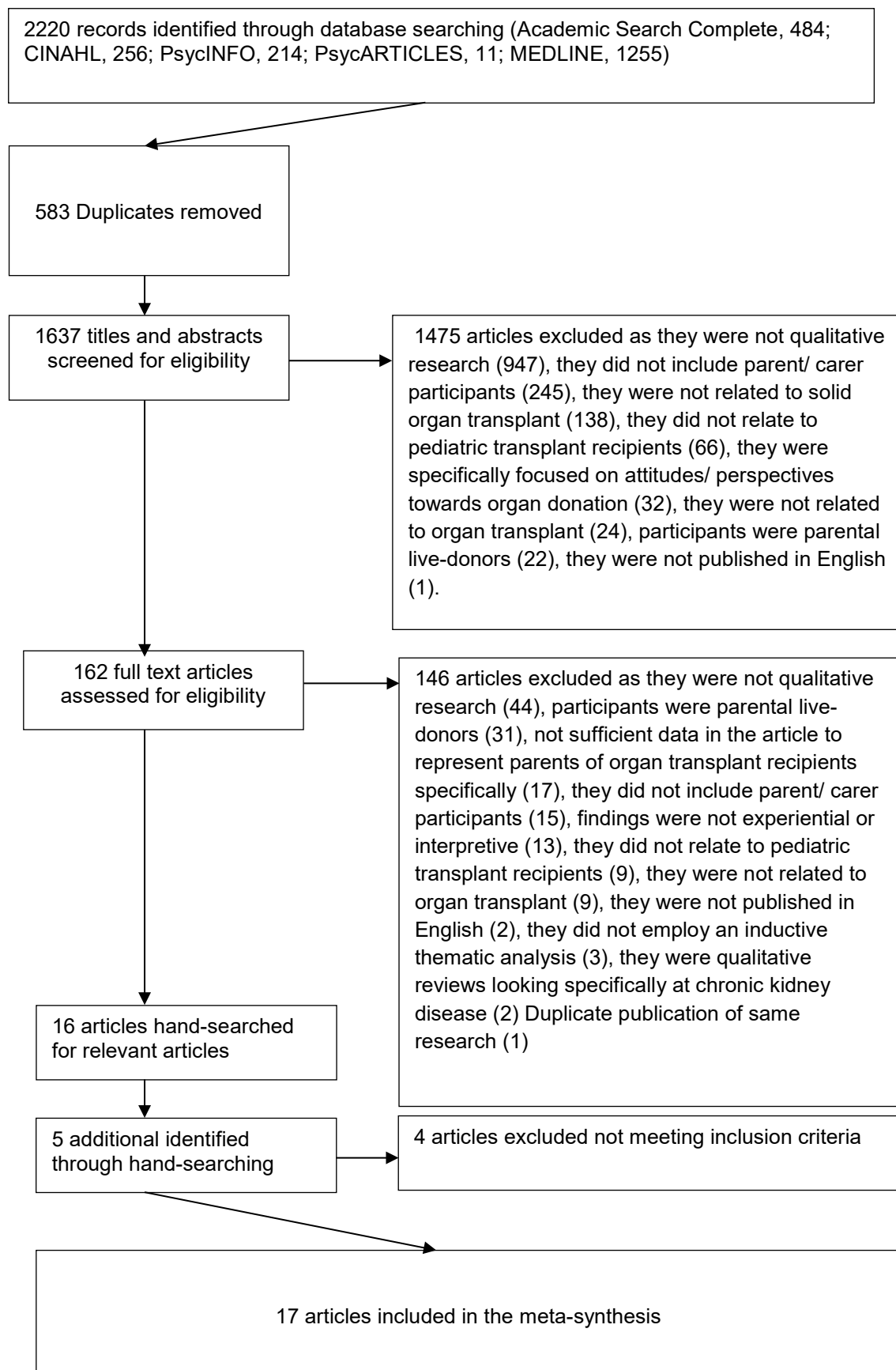
<b>Theme 3: Opportunity for Renewal and Growth</b>		
<b>Reference</b>	<b>A renewed perspective on life</b>	<b>Strengths and personal growth</b>
		<i>Theme: Enhanced Relationships</i>
		With others; with child (mutuality); child's health reflected function of mothers' role and what capable of accomplishing
10. Mantulak & Nicholas (2016)	<i>Theme: Development of strengths and personal growth</i> Challenges of parenting experience creates renewed sense of empathy for others; reconciled meaning of caregiving away from stress/ challenge; "taking what comes"; "It's not suffering it's an experience"; renewed appreciation for life and living.	<i>Theme: Development of strengths and personal growth</i> Emergence of strengths and personal growth; becoming stronger; developing meaningful skillset; gaining knowledge; gaining confidence; stronger sense of self; personal reinvention and adjustment to stress and emotional burden.
12. Stubblefield & Murray (1998)	<i>Theme: A New perspective on life</i> Using situation to develop new perspective on life; finding meaning in less than perfect; valuing what is important.	
17 Wright et al., (2017)	<i>Theme: Emotional impact of transplantation</i> Life changing (good and bad); experiencing highs and lows; transplant is lifesaving; can sometimes be difficult to focus on positives; death of other patients' difficult experience but gives perspective to manage every day; guilty at being negative about experiences considering others worse off.	

Table 9

*Contribution of Articles to Final Themes*

<b>Reference</b>	<b>Theme One: Parenting in the context of uncertainty</b>	<b>Theme Two: Assimilating to new roles and responsibilities</b>	<b>Theme Three: Opportunity for renewal and growth</b>
1. Adams et al., (2014)		X	X
2. Anthony et al (2009)		X	
3. Green et al., (2008)	X	X	X
4. Green et al., (2009)	X	X	
5. Lerret et al., (2017)	X	X	
6. Lerret et al. (2014)	X	X	
7. Lochridge et al., (2013)		X	
8. Mantulak (2014)	X	X	
9. Mantulak & Cadell (2018)		X	X
10. Mantulak & Nicholas (2016)	X	X	X
11. Meaux, et al (2014)	X	X	
12. Stubblefield & Murray (1998)	X	X	X
13. Stubblefield & Murray (1999)		X	
14. Stubblefield & Murray (2000)	X	X	
15. Stubblefield & Murray (2001)		X	
16. Stubblefield & Murray (2002)	X		
17. Wright et al., (2016)	X	X	X

Figure 1

*A Flow Diagram of Inclusion of Articles for Meta-synthesis*

**Appendix 1 – A: Manuscript Guidelines for Qualitative Health Research**



*Qualitative Health Research*  
An International, Interdisciplinary Journal

**QHR**  
**MANUSCRIPT**  
**GUIDELINES**

# Qualitative Health Research

*An International, Interdisciplinary Journal*

## **ABOUT QUALITATIVE HEALTH RESEARCH (QHR)**

Editor: **JANICE M. MORSE, RN, PHD (ANTHRO), PHD (NURS), FAAN**  
University of Utah College of Nursing, Salt Lake City, Utah, USA

**QUALITATIVE HEALTH RESEARCH**, widely referred to as **QHR**, is an international, interdisciplinary, refereed journal for the enhancement of health care. Published monthly, it is designed to further the development and understanding of qualitative research methods in health care settings. The journal is an invaluable resource for researchers, practitioners, academics, administrators, and others in the health and social service professions, and graduate students who seek examples of qualitative methods.

### **COMPREHENSIVE, TIMELY COVERAGE FROM A VARIETY OF PERSPECTIVES**

Issues of *QHR* provide readers with a wealth of information, including articles covering research, theory, and methods in the following areas:

- Description and analysis of the illness experience
- Health and health-seeking behaviors
- The experiences of caregivers
- The sociocultural organization of health care
- Health care policy
- Related topics

Articles in *QHR* examine an array of timely topics such as chronic illness; risky behaviors; patient–health professional interactions; pregnancy and parenting; substance abuse; food, feeding, and nutrition; living with disabilities; milestones and maturation; monitoring health; children's perspectives on health and illness, and much more. In addition, the journal addresses a variety of perspectives, including cross-cultural health, family medicine, health psychology, health social work, medical anthropology, sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

### **PUBLISHER**

*QHR* is published by Sage Publications, Inc., 2455 Teller Road, Thousand Oaks, CA 91320, USA; [www.sagepub.com](http://www.sagepub.com); telephone 1-800-818-7243.

[REV 1: 04 Nov 2008]

## WRITING TO PUBLISH IN *QHR*

Proper formatting will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication. Refer to the guidelines below, and to the *Publication Manual of the American Psychological Association*, [APA] 5th edition.

Improper formatting could result in burdensome revisions, lengthy delays in the review and production processes, and *the possible rejection of your manuscript*.

### AVOID

- Writing in the third person, passive voice
- Inclusion of irrelevant data
- Anthropomorphisms
- Very long or "wordy" sentences
- Inconsistent writing style (especially with two or more authors)
- Tables listing participants and their demographic characteristics
- Back-to-back parentheses [incorrect: (xxx)(yyy) / correct: (xxx; yyy)]

### WORD CHOICES

It is always best to use the most precise language possible to convey important data, concepts, and findings. Because *QHR* is an international journal published in U.S. English, there is the added need to avoid commonly-used English terms that might be misinterpreted by or confusing to readers whose first language is not English.

Word	Considerations
feel	It is appropriate to use this word when referring to a physical sense or state of mind; do not use it when your intent is "think" or "believe."
further	This word is appropriately used when referring to distance. When writing of something in addition to that already stated—particularly at the beginning of a sentence—it is more appropriate to use "furthermore," "moreover," "in addition," or "additionally."
may	It is a common mistake to use this word in place of "might." "May" implies permission, "might" implies possibility, and "can" implies ability.
over	Be careful not to use this word when the intended meaning is "more than."
since	"Since" is the appropriate word to use when referring to the passage of time; avoid using it when the intended meaning is "because."
U.S.	Use "U.S." only as an adjective; for all other purposes, spell out "United States."
while	Use "while" when referring to concurrent events. Do not use it when your intent is "whereas," "although," or "even though."

Instead of this . . .

Use this . . .

as regards	<i>with regard to; regarding</i>
due to	<i>because of</i>
firstly; secondly	<i>first; second</i>
in order to	<i>to</i>
paper	<i>article</i>
towards	<i>toward</i>
upon	<i>on</i>

### PUNCTUATION AND CAPITALIZATION

- If you use an acronym, the full spelling of the words must precede the first usage (even if you think everyone knows what it stands for), followed by the acronym in parentheses; e.g., *World Health Organization (WHO)*. Thereafter you may use the acronym alone: *WHO*. Avoid the overuse of multiple acronyms.
- Capitalize proper names; do not capitalize words unnecessarily, such as titles and ranks; e.g., director, professor, doctor, chairperson.

- *Title case* is properly created by capitalizing (a) the first letter of the first word, (b) the first letter of the first word following a colon or "em" dash, (c) all important words, and (d) *all words containing four or more letters*
- Use *no spaces* before, and only a *single space after* periods (.), commas (,), colons (:), semicolons (;), question marks (?), and quotation marks ("). Use no spaces after opening quotation marks.
- Check your manuscript for double periods (..) and extra spaces between words.
- Refer to the *APA Publication Manual* for an excellent explanation of the proper use of hyphens and dashes; *do not* depend on Word's "Spell Checker" function for decisions on hyphenation.

#### **"REVIEW" YOUR MANUSCRIPT**

One common reason for "revise" decisions is that authors are sometimes so immersed in their data and findings that they lose track of (a) whether the information presented contributes new knowledge, (b) whether the appropriate method and design have been used, (c) whether ethical standards have been met, (d) whether the information is presented in a complete, concise, and logical manner, with attention to writing style, and (e) what the reader needs/wants to know (remember that our readers have expertise in diverse areas, and therefore many will not be familiar with concepts and terminology common to your research area).

Before submission, we recommend an informal peer review of your article using these criteria:

##### Review Criteria

- Importance of submission: What are the manuscript's strengths? Is it significant? Does it contain new and unique information?
- Theoretical evaluation: Is the manuscript logical? Is the theory parsimonious? Complete? Useful?
- Methodological assessment: Inductive approach? Appropriate method and design? Is the sample appropriate and adequate? Are data saturated? Theoretical analysis? Linked with theory and/or praxis?
- Adherence to ethical standards?
- Manuscript style and format: Evaluate writing style, organization, clarity, grammar, appropriate citations, and so forth. Is the manuscript unnecessarily long?

#### **PRIOR TO SUBMISSION**

- Proofread your manuscript aloud; doing so will help you identify awkward phrasing, run-on sentences, incomplete sentences, improper punctuation, missing text, and much more. (We recommend proofreading from a paper copy rather than a computer screen.)
- Have your manuscript *professionally* edited. This is especially important if English is not your first language. Remember to inform your editor of the need to use U.S. English spelling, and provide him or her with a copy of these Guidelines.

## **PREPARING YOUR MANUSCRIPT**

#### **GENERAL STYLE**

In general, *QHR* adheres to the guidelines contained in the ***Publication Manual of the American Psychological Association ["APA"], 5th edition*** (ISBN 1-55798-791-2), with regard to manuscript preparation and formatting. [Elsewhere in these guidelines this book is referred to as the *APA Publication Manual*, or just *APA*.] Additional help may be found online at <http://www.apa.org/>, or search the Internet for "APA format."

Many universities and private organizations have Web sites devoted to *APA* style. Be aware, however, that whenever guidelines found on those sites, or in the *APA Publication Manual*, conflict with the guidelines included here, **you must follow the *QHR* guidelines**.

**KEEP IN MIND . . .**

- *Qualitative Health Research* is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration; do not send query letters or e-mail messages.
- It is preferred that you write both the abstract and the text of your manuscript in the *first person, active voice*; however, this is not a requirement. If you choose to write otherwise, ensure that the abstract and manuscript "match" in voice.
- We do not publish stand-alone abstracts, *quantitative* studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles *must be pertinent to health*.

**CONFIDENTIALITY AND PROTECTION OF PARTICIPANT IDENTITY**

*QHR* is committed to protecting the identity and confidentiality of research study participants. With the exception of participant action research (PAR), no information that could potentially allow identification of a participant—or even a specific study site—should be included in a submitted manuscript or, subsequently, included in a published article.

Each study participant referred to in the manuscript should be assigned a pseudonym. Study sites, such as hospitals, clinics, or other organizations, should not be named, but instead should be described; for example: "Study participants were recruited from the coronary care unit of a large metropolitan hospital on the eastern seaboard of the United States." Authors who include participant names and/or photos must submit written permission from the participants to do so.

Manuscripts submitted to *Qualitative Health Research* are "blind" reviewed. *Do not include author information, author references, or acknowledgements in the main manuscript document.*

**ELEMENTS OF A MANUSCRIPT**

The following elements are **required** for each manuscript, and should be compiled in the following order:

1. Title page [submitted as a separate document]
2. Abstract [p. 1]
3. Keywords [p. 1]
4. Main body of the manuscript ([main document"; beginning on p. 2]
5. References

The following elements **may** be included in your submission (they are *optional*):

- A. Notes/footnotes/endnotes [place after the main body of the text, before the reference list]
- B. Tables [place at the very end of the document]
- C. Figures [submit in a separate document]
- D. Appendices are published *only in certain circumstances*, at the editor's discretion [place after the reference list and before any tables]

**ORDER OF ELEMENTS**

Compile the elements of your main manuscript document in the following order. Each element (except notes) should begin on a new page:

- A. Abstract and keywords - required
- B. Main manuscript text - required
- C. Notes/footnotes (if any)
- D. References - required
- E. Appendices (if any)
- F. Tables (if any)

**DOCUMENT SETUP** (See also Sample Manuscript)

- **Document file type:** Submit only documents created in Microsoft Word, and only with the regular file extension of ".doc"; Word documents with ".docx" extensions, PDF files, or other types of documents cannot be accepted for consideration.

*Do not add any special coding or formatting to your documents that is not described within these guidelines.*

- **Paper size:** Letter, 8.5" x 11"
- **Margins:** 1" on all sides

\* \* \* \* \*

- **Ellipses/Ellipsis Points:** Almost every manuscript contains ellipses. They are used to indicate missing words in quotations, and are to be created in a very specific manner. *Do not* use the "Insert Symbol" function in Word to enter ellipses. The proper way to create ellipsis points is as follows: space/dot/space/dot/space/dot/space (. . .); that is, 3 dots, preceded, divided, and followed by spaces, like . . . this. If it is necessary to indicate missing words between sentences (instead of in mid-sentence), place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space. Do not place ellipses within parentheses or brackets (. . .); the exception to this is in conversation analysis, when appropriate.
- **Font Size:** 11 point font, including font used for titles, regular text, section headings, and quotations; however, fonts between 8 and 10 points in size should be used in tables and figures
- **Font Style, Main Manuscript:** Use Times New Roman font. *Italics* should be used *only* (a) as appropriate in the reference list (see *APA*), or (b) to introduce new or non-English words, or new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font. *QHR* does *not* use italics for emphasis, and does not use underlining for any purpose other than conversation analysis (conversation analysis does not refer to regular participant quotations). Bolded font may be used for section headings, as appropriate according to these guidelines, and (sparingly) in tables and figures.
- **Font Style and Formatting of Conversation Analysis:** [Note that this instruction **does not pertain** to normal quotations or block quotations.] *Courier* font should be used for sections containing conversation analysis (if any). Retain the conversation analysis sections in the desired location among the regular manuscript text, and *do not set them as figures, in a box, or as excerpts*. Use the following steps to apply (required) special formatting to the conversation text only:
  - Set your font at 10 points, *Courier* style.
  - Set your margins (*only for the sections with this special text*) at 1" on the left, and 4.55" on the right, so the available print area is 2.95" wide, flush left. (*Do not* attempt to achieve this with tabs and hard returns; use Word's formatting features in Page Setup.)
  - The line number, participant pseudonym (or other speaker identification), and transcribed text will need to fit across the 2.95" of printable line space. This is to ensure that the text will fit within the column format of the printed journal.
  - Manipulate your text within this space until you have achieved the desired alignment for all lines.
  - If your article is accepted, be sure to examine the publication proofs of the conversation analysis sections very carefully to confirm that the text is set and aligned correctly.
- **Font Style, Figures:** For printing clarity and ease of reading, "sans serif" fonts are strongly recommended for figures; some common examples include Arial (this is the preferred style), Calibri, Franklin Gothic Book, **Tahoma**, and **Verdana**.

It is recommended that only one font style be used in each figure, with possible variations introduced through bolding, italicizing, capitalizing, or underlining—all of which should be used

*sparingly*. It is further recommended that all figures within a single manuscript be prepared with the same font style.

- **Line Spacing:** **Everything**, in all elements of the manuscript, from the title page through the references, must be (exactly) double-spaced. The only exception is text within a figure. To set double spacing, go to Format > Paragraph > Line spacing > Double. *Do not create double spacing with hard returns* (by striking the "enter" key twice).
- **Text Justification:** All text should be left-justified; *do not use full justification* for any portion of your manuscript. The text at the right margin *should be uneven*.
- **Paragraphs:** Indent the first line of every new paragraph by .5" (½ inch; do not use two, .25" indentations). Do not insert additional line spaces between paragraphs, or between paragraphs and headings; *the exceptions are (a) an extra line space (hard return) between the abstract and the keywords, and (b) after (not before) each excerpt/block quotation, numbered or bulleted list, or section of conversation analysis*. Use a blank line between block quotes/excerpts if you have placed two or more in a row. *Do not add any special formatting*, such as increased line space before and after paragraphs, or before and after headings.
- **Headings:** *Do not follow APA guidelines for headings*. QHR uses 4 distinct levels of headings (H = level), including:

**H1: Centered, Bold, Uppercase and Lowercase Text in Title Case**

**H2: Flush Left, Bold, Uppercase and Lowercase Text in Title Case**

*H3: Indented (.5"), Italicized, Uppercase and Lowercase Text in Title Case*

*H4: Indented (.5"), italicized, lowercase text in sentence case and ending with a period. At this level, the paragraph text begins immediately after the heading, instead of on the next line.*

Use at least two heading levels:

For manuscripts with 2 heading levels, use H1 and H2

For manuscripts with 3 heading levels, use H1, H2, and **H4**

For manuscripts with 4 heading levels, use H1, H2, H3, and H4

- **Quotations:** Quotations of 40 or more words should be set as separate paragraphs, with the entire quotation indented .5" from the left margin (this is also referred to as a "block quote"). Do not change the right-hand margin. Some quotations of fewer than 40 words may also be set separately for uniformity of appearance. All other quotations should be contained within regular paragraphs, along with regular text.
- **Quotation Marks:** In general, use double quotation marks (e.g., "Xxxx.") to set off quotations appearing within regular paragraphs, and to set off words being used with "special" meaning (or unusual spelling to convey special meanings within the text; e.g., "busy-ness"). In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., "Xxx, 'Yyy,' xxxx. ").  
  
Do not use any quotation marks for block quotes *unless* there is a separate quote contained within the larger quote. In such a case, use double quotation marks (e.g., "Xxxxxx, 'Yyyy,' xxxxx.") only for the separate quote within the larger quote.
- **Spelling:** The spelling of English words varies among the many English-speaking countries of the world. QHR is published in *U.S. English*. Use Word's spell check feature to ensure that you have used U.S. English spellings throughout your manuscript. Exceptions to this include (a) direct quotes from *written*, published material, and (b) as appropriate for titles in the reference list.
- **Manuscript Length:** There is no predetermined page or word limit. Provided they are "tight" and concise, without unnecessary repetition and/or irrelevant data, manuscripts should be as long as they need to be. The editor may require a reduction in length if the manuscript contains superfluous material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.

### PREPARATION OF REQUIRED MANUSCRIPT ELEMENTS

- A maximum of three (3) *types* of documents should be submitted: (1) title page; (2) main manuscript; and (3) figures (if any). Despite what the online system (Manuscript Central) programming might allow, *do not submit such elements as abstracts, references, and tables as separate documents.*
  - Refer to the Sample Manuscript for additional information.
1. Title Page [submitted as a separate document]

The title page should include the following, *in this order*:

- a. Text for a running header (abbreviated title of your article) of no more than 40 characters + spaces in length. Place the running head on the title page only, and do not include it in the main manuscript document [set flush left]. *Do not actually format the text as a header.*
- b. Any author's/authors' notes or acknowledgements (optional), limited to two or three sentences, maximum. [set flush left]
- c. The article title. Capitalize all important words, and all words with four or more letters. [set centered; see the heading on this page for an example of title case]
- d. The name (not just initials) of each author, *without* credentials, in order, together with the affiliation of each author, including the institution/agency/organization (but *not* including department or division information); city where the institution/agency/organization is located; the state or province (if any); and country. *Example*: Janice M. Morse, University of Utah, Salt Lake City, Utah, USA [set centered; all state, province, and country names (except USA) must be spelled out]
- e. Complete contact information for *all* authors, including the proper form of address (i.e., Dr., Professor, Mr., Ms., Miss, Mrs., etc.), name, credentials, affiliation, mailing address (including the country name), primary e-mail address, secondary e-mail address (if any), telephone number, and fax number (if any) [set flush left]
- f. A 1-sentence biographical statement about each author. Use the following example for formatting your statement(s), and be sure to include name, credentials, university or other institution (you may include department or division information here), city, state/province (if any), and country:

**Janice M. Morse**, PhD, FAAN, is a professor and presidential endowed chair at the University of Utah College of Nursing in Salt Lake City, Utah, USA.

The title page may actually be longer than one page. To retain author anonymity during peer review, it is submitted as a *separate document*. Title page information *should not be included* in the main manuscript document.

Manuscript title: A title should convey, as clearly and succinctly as possible, the main idea of a manuscript. It should be clear in meaning even when standing alone. Avoid unnecessary words, such as "A Qualitative Study of," "A Doctoral Student's Investigation of," or "An Ethnographic Study." A good title is generally 10 to 12 words (or fewer) in length. *Avoid* titles with a colon or a quotation unless it/they is *necessary* to convey an important concept or a particular meaning about the article.

*Do not* (a) type your title in ALL CAPITAL letters, or (b) place a period (.) at the end of your title.

2. Abstract

The abstract should be placed on page 1 of the main manuscript document. It should be a single paragraph, no more than 150 words in length, and briefly describe your article. Briefly state the purpose of your research, the main findings, and your primary conclusions. Whether written in the first person, active voice, or otherwise, the abstract should "match" the voice in the manuscript. *Do not* (a) indent the first line of the abstract, (b) include in-text citations, (c) show the word count, or (d) include the manuscript title.



3. Keywords (See *QHR* Keyword List)

This is a brief list of words related to the topic(s) of your article that readers could search on to find the article (if published). Include all desired keywords *selected only from the QHR keyword list*. You may request that new keywords be added to the list, but the words should be *general* in nature, and not specific to a narrow topic. New keywords will be added at the editor's discretion. Keywords should follow on the same page as the abstract; leave a blank, double-spaced line between the abstract and the keywords.

4. Main Manuscript Text

The main text of the manuscript begins on page 2, the page following the abstract and keywords. We prefer articles written in the first person, active voice, but will consider articles written in the third person provided the voice of the abstract and manuscript match (see Abstract, above). Use U.S. English translations of non-English quotations. *Do not include the manuscript title in the main document*. Authors are required to attend to copyright regulations.

The main text of the manuscript should be broken into appropriate sections by the use of section headings. Sections should flow in a logical sequence, and include, *at a minimum*, Method(s), Results, and Discussion (these are level-1 headings); other level-1 headings and subheadings may be used at the author's discretion. The author may choose to use different names for the three main sections, but the basic content should be that which would appropriately fall under the headings of Methods, Results, and Discussion. *QHR* does not use *any* headings (such as "Introduction" or "Background") at the beginning of articles.

There are very specific guidelines for the use and formatting of in-text citations; refer to the *APA Publication Manual*, 5th edition, for details (the specific edition is very important). Every in-text citation should have a corresponding reference in the reference list, and vice versa.

5. References

The reference list (also known as a bibliography) should include complete references for the sources used in the preparation of your manuscript and cited in the text. Every citation should have a corresponding reference, and every reference should be cited in the text. *You must cite and reference pertinent articles published in QHR in the 12 to 14 months immediately preceding submission of your manuscript*.

The list should begin on a separate page following the last page of manuscript text (or the notes, if applicable). Each type of reference (journal article, book, chapter in edited book, newspaper, online reference, and so forth) must be formatted in accordance with the precise guidelines contained in *APA*. Elements such as spelling, punctuation, spacing, capitalization, and the use of italics or Roman (regular) font are as important as the content of the reference. (Note that if an author has two or more initials, there should be a space between the initials; incorrect = X.Y.Z.; correct = X. Y. Z.)

References should be listed in hanging paragraph format, in alphabetical order by the last name of the first author. The hanging paragraphs should be created by using Word's Format > Paragraph feature, and *not by using tabs*. Be sure to use italics, rather than underlining, for titles. Non-English titles should be translated into U.S. English, with the English translation following immediately after the original title, in [brackets]. *Proper formatting of the reference list is the responsibility of the author*.

*Avoid the use of unnecessary references and over-long reference lists*. Extensive bibliographies will not be published; articles will include only the "essential" or key references. If the author wishes to offer a secondary reference list (for example, references used in meta-analysis), it should be so stated in the Author's Note, and made available to readers by contacting the author directly; do not include it in the manuscript document, but it may be submitted separately for purposes of review.

## PREPARATION OF OPTIONAL MANUSCRIPT ELEMENTS

### A. Appendix / Appendices

Appendices are discouraged. If essential, refer to *APA* for the proper formatting of your appendix. If included, it should be placed in the main manuscript document following the reference list and before any tables. Appendices must be referred to in the text.

### B. Tables

Tables organize *relevant, essential data* that would be too awkward or too lengthy to include in the text, and should be used only to provide data not already included in the text. For example, participant demographics take less space presented in a descriptive paragraph than they do as a table. Do not list participants one by one; instead, present group characteristics. *QHR* neither creates nor revises tables; this is the responsibility of the author.

Tables are to be accompanied by both their number (Table 1, Table 2, and so forth) and their title (required). Avoid shading, the use of color, and the use of multiple font styles. Table placement is mentioned in the text, but the tables themselves are placed at the very end of the document. The author should designate placement of each table within the manuscript by entering (on a separate line between paragraphs), INSERT TABLE 1 ABOUT HERE. (When published, tables are generally placed following the paragraph in which they are first mentioned.) Detailed formatting guidelines are contained in the *APA Publication Manual*. Table titles should be short and concise.

### C. Tips on Tables

#### HOW TO CREATE YOUR TABLE

- Include only necessary data
- *Neatness counts*. Text alignment, spacing, and consistency of style are all important.
- *Keep it simple*, without unnecessary lines and text.
- Keep the table as small as possible, both in width and length; use only the amount of space necessary to contain your data. To fit within a single column of the journal it should be no wider than 2.95," to fit across both columns it should be no wider than 6". Narrow the table columns to eliminate unused "white" space. Only under special circumstances (as determined by the editor) may a table be placed with a vertical orientation on the page.
- Multiple tables within the same manuscript should be similar in appearance and design.
- Create the table the way you wish it to appear when published, then double space all text, including column headers. *Set double-spacing with formatting specifications*, rather than manually inserting line breaks with the "enter" key.
- Use font no smaller than 8 points and no larger than 10 points. Use no more than two different font sizes in one table (one is preferred).
- "Hide" all vertical lines and all horizontal lines except the following: top line of table, bottom line of table, and line below the main column headers.
- Place explanations, clarifications, symbol identification, identification of unusual abbreviations, and other "nondata" information in a note below the table.
- Avoid the overuse of bolded and/or italic font, which can make a table look "busy" without enhancing it in any way.

### D. Figures

Like tables, figures should be used sparingly, and only when it is necessary to clarify complex relationships in the text. Avoid shading, the use of color, and the use of multiple fonts. Hand-drawn

figures (such as participant artwork) must be dark enough to reproduce clearly when published. Figure placement should be mentioned in the manuscript text, but the figures themselves are to be placed in a *separate document*, with all figure numbers (Figure 1, Figure 2, etc.) and figure titles together, in order, on the first page, followed by the figures—each on a separate page. You may choose to submit each figure separately, but each one should be prepared in the same manner (see the Sample Manuscript). The author should designate placement of each figure within the manuscript by entering (on a separate line between paragraphs) INSERT FIGURE 1 ABOUT HERE. (When published, figures are generally placed following the paragraph in which they are first mentioned.) Detailed formatting guidelines for figures are contained in the *APA Publication Manual*, but note that *regular Word documents are preferred over .jpg or other document types. The figure number and title should be included on the previous page, and not saved as part of the figure itself.* Figure titles should be short and concise.

**Appendix 1 – B: Example of Data Extraction Table**

Paper	Research question/ aim	Methodology and data collection	Participants
Green et al., (2009)	To describe parents' experiences parenting a school-aged child after heart transplant.	Content analysis from semi structured interviews.	Parents of school-aged (6-12 years) heart transplant recipients  N=11 (9 mothers, 2 fathers)
<b>Results</b>			
<b>Summary</b>			<b>Participant Illustrative Quote</b>
<ul style="list-style-type: none"> <li>Overall experience of parenting child after heart transplant hard but worthwhile.</li> </ul>			<p><i>"considering the alternative, it is more than worth it" (p.124).</i></p>
<ul style="list-style-type: none"> <li><b>Theme 1: Constantly Responsible:</b> Everyday feeling continually responsible for maintaining child's health. This includes (a) constant around-the-clock care: This contrasted significantly to responsibilities for other children. How much the regime dominated parents' lives varied between being integrated into daily life vs. something that their lives revolved around/ they felt controlled by. (b) constant vigilance: close monitoring of signs and the environment to prevent infection.</li> </ul>			<p><i>"The work is on us. The maintaining his health...Your work never stops. It's continual" (p.124).</i></p>
<ul style="list-style-type: none"> <li><b>Theme 2: Constantly Worried:</b> Transplant, particularly at beginning, causes stress and worry to parents. Worries never completely stop. Worried about child's health, medical regime and child's participation in normal activities. Worried about infection. Intense worry awaiting biopsy results. Worrying about child's prognosis and risk of long-term morbidity. Worried about effects of the limitations on their children. Worries centered around uncertainty.</li> </ul>			<p><i>"You have those moments few and far between that make you still feel like you can just not have to deal with something just for a little while. But it never completely goes away. You know, it's in the back of your head the whole time" (p.124); "Once you get the transplant, you have to worry about infection, inside and outside" (p.124)</i></p>
<ul style="list-style-type: none"> <li><b>Theme 3: Constantly Blessed:</b> The difficulties and blessings of the transplant experience intertwined for parents. Blessing of the child's life. Blessing because of what they have experienced. Helped to focus on important things in life.</li> </ul>			<p><i>"At first, you're wondering, what did I do to deserve this? And then it turns into- what did I do to deserve to get all this good stuff happening? I get to bring my child home" (p.125)</i></p>
<ul style="list-style-type: none"> <li><b>Theme 4: Coping with Life:</b> Using coping strategies. <b>Subtheme 1: Focusing on the positive:</b> Recognizing there were others worse off. Mindful of alternatives. <b>Subtheme 2: Recognizing lack of choices:</b> Even though difficult, it's their responsibility and their role to adhere medical regime, <b>Subtheme 3: Faith and support from others:</b> For emotional support. Practical assistance. Helpful to have respite. Needing support from health care team and parents of other children transplanted. Faith in God helped parents feel less helpless and gave them hope. <b>Subtheme 4: balancing:</b> The care the child needed balanced with desire for child to have a normal life. Important in parental decision making re. activities for the child/ family.</li> </ul>			<p><i>"You want to shelter him from things like that [infectious disease risk] but sometimes you want to let him be a 6-year old little boy" (p.126)</i></p>

<b>Data Extraction</b>	
<b>Authors interpretations (verbatim)</b>	<b>Key Concepts</b>
"Parents described their overall experience parenting a child after heart transplant in positive terms, yet they acknowledged hardships" (p.123-124).	Overall experience parenting positive but hard
"They made it very clear that despite any hardships, 'considering the alternative, it is more than worth it'" (p.124).	Hardships worth it considering alternative
"One of the key issues parents identified was the constancy of the responsibilities and worries, even though the children in the study had received their transplants at least 2 years earlier and were going well medically" (p.125).	Being constantly responsible and worried
"All parents acknowledged the around-the-clock nature of their responsibility for their child's health and medical regime." (p.124).	Responsibility for child's health around-the-clock in nature
"The degree to which this responsibility dominated parents' lives varied along a continuum from something they incorporated into their lives like 'brushing your teeth' to something that controlled their lives" (p.124); "In this study, parents described a range of ways of managing the responsibilities for the child's care, from those who integrated the responsibilities into their life to those whose lives revolved around the responsibilities" (p.125).	Responsibility for child's health managed by either it integrating into life or revolving life around it (continuum)
"In addition to being constantly responsible, parents described around the clock vigilance required to 'keep my child healthy'" (p.124).	Constant vigilance needed to keep child healthy
"The parents also described "a lot of worry". Although they all described that they experienced more stress and worry 'in the beginning' (meaning immediately after transplant) they reported that the worries never stopped completely" (p.124).	Being constantly worried – never stop completely
"Parent's worries focused on their child's health and medical regimen and their child's participation (or nonparticipation in some cases) in normal childhood activities" (p.124); "The parents in this study described themselves as chronically worried about their child's health, the medical regimen, and the child's ability to participate in developmentally appropriate activities. Much of the worry centred around uncertainty related to risk of complications and long-term prognosis" (p.125).	Constant worry re. child's health, regime and child's participation in norm centred around uncertainty (risk of complications and long-term prognosis)
"They also described intense worrying when their child is sick and worrying after biopsy as they awaited results" (p.124).	Worrying intense awaiting biopsy results
"Although they primarily described worries about their child's state of health, parents also described worrying about their child's prognosis" (p.124).	Worrying about child's prognosis/ risk of long-term morbidity
"Parents were well aware of the risk of serious long-term morbidity" (p.124); "Parents also described worries about the child's participation in normal childhood activities. Although these worries were less constant in nature, they were difficult for the parents" (p.124); "Parents also described worries about their child's participation (or the lack thereof) in activities related to the child's physical or social limitations" (p.125)	Parent's worried about child's physical or social limitations and impact of these

<b>Data Extraction</b>	
<b>Authors interpretations (verbatim)</b>	<b>Key Concepts</b>
(from discussion); “Most parents described decreased endurance, strength, and/ or skill that limited their child’s ability to participate in activities. Parents worried about the effect of the limitations on their children and also experienced distress themselves” (p.124); “For some of the parents, the worries were related to developmental or social delays that either restricted children’s ability to participate in activities or resulted in participation with an age appropriate, but not developmentally appropriate group.” (p.125).	
“Although parents described difficulties, they also described the blessings of ‘having my child with me’” (p.125); “Although difficulties and blessings are being described separately here, they were intertwined for the parents” (p.125).	Feeling constantly blessed that child alive intertwined with experienced difficulties
“In addition to the blessing of the child’s life, parents also described blessings because of what they had experienced. In the words of the mother of a 6 year-old “It’ll make you a better person and make you family a better family. You’ll just have a new perspective on life and just be more thankful that you have what you have” (p.125).	Experience of transplant make parent and family better – new perspective on life, being thankful
“Other parents described that their experiences helped them focus on what is really important” (p.12).5	Experience of transplant – focus on what’s important in life
“Focusing on the positive included several dimensions: ‘better than the alternative’ and the recognition that there were others who were worse off” (p.125); “Parents were ever mindful, even many years after the transplant, that the alternatives were or had been ‘deal with life as it is’ or the child’s death” (p.125).	Focusing on positive as way of coping with life – could have been worse
“In addition, as they described some of the difficulties associated with the medical regimen, such as restraining a toddler to administer medication, the parents identified that they had “no choice”. Even though difficult at times, the parents recognised their responsibility for the medical regime as “what needs to be done as a parent” recognising this as their role and that they had no choice other than to do it seemed to help parents carry out parts of the regimen that were difficult” (p.125).	No choice but to be responsible for medical regime – way of coping with difficult aspects
“Parents also described key sources of support that helped them cope. These key sources of support included faith, family, friends, and the health care team” (p.125).	Social support helped parents cope
“Family and friends were the most important sources of emotional support” (p.125).	Family and friends valuable emotional support
“Family members, most often grandmothers, also provided assistance with the care of the child after transplant and his or her siblings. This respite was very helpful to parents”. (p.125)	Family practical support/ respite helpful
“However, because family and friends did not always understand the implications of transplant, other sources of support were especially important. The parents described needing the support from the health care team and parents of other children who had received a transplant.” (p.125)	Needing additional support from those who fully understand (medical team, other transplant parents) – helped cope

<b>Data Extraction</b>	
<b>Authors interpretations (verbatim)</b>	<b>Key Concepts</b>
"Finally, parents described learning to balance the care the child needed with the desire for the child to have a normal life. This balance was very important in parental decision making about activities for the child and family and helped them cope" (p.125); "Most often, the care the child needed revolved around protection from infectious diseases. As one mother stated, "It's little things like that. You want to shelter him from things like that [infectious disease risk] but sometimes you want to let him be a 6 year-old little boy" (p.126).	Balance providing care needed/ protecting against infection vs. desire for child to experience normal life – helped cope



Running head: SUPPORTING SPOUSE THROUGH HEART TRANSPLANT

**Section Two: Research Paper**  
**Experiences of Supporting a Spouse Through Heart Transplant.**

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Word Count: 8,000

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Prepared for submission to Qualitative Health Research<sup>1</sup>

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<sup>1</sup> The manuscript was prepared in line with author guidelines for Qualitative Health Research (see Appendix 1-A). Where these guidelines have not been followed, Lancaster University thesis guidelines have been followed. Of note, the word count is in line with University guidance.

### **Abstract**

The support spouses offer to Heart Transplant (HT) recipients is significantly valuable to the patient's adaption and recovery. However, spouses are vulnerable to psychological strain and burnout in the context of HT. The limited prior research exploring spouses' specific experiences of HT gives cause for further exploratory investigation. The aim of this study was to understand the experiences of supporting a spouse through HT using interpretative phenomenological analysis (IPA). The experiences of seven wives and two husbands of HT recipients were analyzed, resulting in three themes 'driven by a sense of responsibility', 'striving for togetherness', and 'wrestling with the prospect of them dying'. Each is discussed in relation to the previous literature as well as discussing clinical implications, strengths, limitations and future research.

**Keywords:** *interpretative methods; family, caregivers; phenomenology; support; transplantation*

Heart transplant (HT) is a treatment of choice for patients with irreversible heart failure where alternative treatments are not able to improve or control symptoms (Banner et al., 2011; Jessup et al., 2009; Metra et al., 2007). Most recent reports indicate that a total of 5,149 HTs were performed internationally between 2016/2017 (ISHLT, 2018); and a total of 198 were performed in the United Kingdom (UK) between 2017/2018 (NHS Blood and Transplant, 2018). In 2018, the average wait time in the UK for patients who received a HT from the non-urgent list was 1.4 years; after 3 years of waiting, 14% of patients had died before transplantation (NHS Blood & Transplant, 2018). This report also stated that in March 2018, the national waiting list for HT was particularly high, with 284 patients waiting for HT, a 14% increase from the previous year and containing the highest ever number of patients on the urgent list ( $n = 28$ ). As the demand for HT increases, understanding and supporting the wellbeing of patients and their families is paramount.

Although HT can offer patients a chance of improved functioning and a prolonged life, the process can present multiple stressors (Dew et al., 1997; Dew et al., 2001). HT candidates reported that having a terminal disease, needing a HT, worrying family members, and undergoing prolonged hospitalization as their greatest stressors (Cupples, Nolan, Augustine & Kynock, 1998). On average, patients remain in hospital for 24.4 days after HT (Grady, Hiller, Grusk & Corliss, 1990). Following surgery, the patient must engage in a long period of recovery and adjust to the demands of life-long follow-up care, committing to a rigorous medical regime to prevent graft rejection and infection (Kittleson & Kobashigawa, 2014; Olbrisch, Benedict, Ashe & Levenson, 2002). The median survival rate of adults with HT is 10.7 years (Lund et al., 2017). Along with this, the likelihood of 10-year survival after HT will depend on multiple factors meaning that patients and families must live with chronic ambiguity regarding the HT recipient's future health (Kilic et al., 2012).

For most recipients, HT is not experienced in isolation from those who offer the patient social support. Social support is a multidimensional construct that has been operationalized as emotional (e.g., demonstration of love, care, compassionate presence, encouragement and sympathy), informational (e.g., problem-solving) and instrumental assistance (e.g., practical tasks; House and Kahn, 1985). The receipt of social support is argued to help sustain an individual's sense of mattering, self-esteem and belonging which act to lessen the burden of and buffer against the impact of stress

(Cohen & Willis, 1985; Thoits, 2011). Given the scarcity of suitable donor organs, potential transplant candidates are selected based on their clinical need and on their capacity to benefit, which includes assessing their social support network (Banner et al., 2011; Dobbles, Verleden, Dunpont, Vanhaeae & De Geest, 2006). Social support has been associated with superior posttransplant physical and psychological outcomes and improved long-term survival rates in HT patients (Coglianese, Samsi, Leibo & Herox, 2015; Tam et al., 2011; Young, Molzahn, Starzomski & Budz., 2010). Although Ladin, Daniels, Osani and Bannuru's (2018) recent meta-analysis has cast aspersions on the strength of this association, Conway et al's (2013) qualitative meta-summary revealed that HT recipients considered adequate social support an essential coping resource through their transplant experience.

Social support originates from multiple sources including family, friends, intimate partners, community and co-workers (Taylor, 2011). Spouses are typically ranked the most important supportive source by married persons (Berterö, 2000; Ptacek, Pierce, Dodge & Ptacek, 1997). Although friends and relatives are significantly valued, they cannot necessarily match what a supportive spouse is able to provide (Coyne & DeLongis, 1986; Holt-Lunstad, Birmingham & Jones, 2008). For instance, there is some evidence to suggest that married transplant recipients demonstrate better posttransplant survival outcomes than unmarried ones (Dobbles et al., 2009; Tam et al., 2011). Given this, spouses are a key supportive resource to transplant recipients, frequently taking on the task of supporting their partner through the process.

Partners of organ transplant recipients, by nature of their involvement in the transplantation process, must cope with significant life changes such as altered roles, making sense of the medical experience, coping with financial difficulties, and changes to identity (Ullrich, Jänsch, Schmidt, Strüber & Niedermeyer, 2004; Young, et al., 2010). There is evidence of disruption to partner relationship from the onset of diagnosis and deterioration of the relationship in the posttransplant phase (Bunzel, Laederach-Hofmann & Schubert, 1999; Dalteg, Benzein, Fridlund & Malm, 2011). As a result, partners of HT recipients might find the HT experiences physically and mentally demanding and be vulnerable to high levels of burn-out, stress and depression (Collins, White-Williams & Jalowiec, 1996; Dew et al., 2004; Ivarsson, Ekmeahag & Sjöberg, 2014; Miyazaki et al., 2010).

Despite quantitative evidence indicating psychosocial cost to partners of HT recipients, there are relatively few qualitative studies that have elucidated their firsthand experiences. Mishel and Murdaugh (1987) conducted a grounded theory study using a sample consisting mostly of wives of HT recipients. The basic social psychological process emerging from the data to explain family adjustment in HT was the process of 'redesigning the dream': During the waiting period, participants pledged themselves to the patient's welfare, prioritizing the patient above their own needs. During hospitalization, participants began to appreciate the patient's health vulnerability and unpredictable lifespan, beginning to grieve the loss of their previous "normal" life. During recovery, participants' dream that their life will return to normal was reformulated to consider how transplantation had altered this possibility; couples negotiated life together with this knowledge.

Subsequent to Mishel and Murdaugh's (1987) study, a handful of qualitative studies have been published exploring family members' experiences of HT, some of which sample partners alongside other family members (Ivarsson et al., 2014; Salada, Stofl, Bocch and Bicudo, 2013); and others which have directly elicited questionnaire responses to measure variables such as quality of life (QOL; McSweeney, Richards, Innerarity, Clark & Mitchell, 1995).

Casida (2005) conducted a phenomenological study specifically with wives of partners with a left-ventricular assist device (LVAD) during the period before HT to ascertain their caregiving experiences. Participants experienced emotional distress regarding uncertainty and felt overwhelmed but determined to fulfill their role of designated caregiver. Casida (2005) posited that once participants had accepted uncertainty and started 'living with hope', they were able to adapt to the reality of life having a husband with a LVAD and experience 'optimism: A new lease on life'. McCurry and Thomas (2002) conducted a phenomenological study of seven wives of HT recipients to explore their experiences across the transplant trajectory (transplant recipients were 2.4 to 8.9 posttransplant at the time of study). The predominant experience of participants related to 'death and life': a profound awareness of the nearness of death resulting in (1) 'vigilance': becoming increasingly watchful and protective over their partner's physical condition; (2) 'change': adjusting to differences to their husband (mood and behavior), their roles and their relationship brought on in the context of HT; and (3) 'gift': concern as well as appreciation toward the donor and their family and feeling responsible to optimize this 'gift'.

As prior research shows, spouses are frequently implicated in supporting HT recipients and have an important role in patient adaptation and recovery. There is evidence to suggest that spouses of HT recipients are vulnerable to psychological strain and burden. At present, there is limited research pertaining to an in-depth exploration of how spouses cope and adapt to their partners HT. Therefore, the primary research question of this study is to explore the experiences of people who have supported their partner/ spouse through HT. As this is a subject area where there is relatively little research, qualitative findings will help develop an understanding of the psychological needs of partners supporting HT recipients. Findings from this could be helpful in highlighting the importance of working systemically with transplant recipients and their partners and provide guidance on how partners could be best supported through this process to promote long-term adjustment. This insight might also have implications for psychological service protocol and service delivery within cardiothoracic transplant units and in wider health and social care domains.

## **Method**

### **Design**

Based on the limited knowledge and paucity of research currently available in this area, a qualitative method of inquiry was deemed the most appropriate (Smith, 2008; Willig, 2001). This decision also corresponded with a social constructivist epistemology adopted within this study. This is the belief that reality is socially constructed and that humans seek understanding of the world they occupy developing their own subjective meanings that are consequently varied and multiple (Creswell, 2003). Therefore, the goal of research is to explore how people create meaning and make sense of their lives, selves, relationships and the world. This epistemological stance lends itself to a phenomenological approach concerned with an in-depth analysis of lived experiences and created meaning contained within rich personal accounts (van Manen, 1990). Therefore, semi-structured interviews were used to gather detailed first-person descriptions of participants' lived experiences in a way that allowed flexibility and feasibility of data collection (Clarke & Jack, 1998; Rubin & Rubin, 2011).

Considering the aims and epistemological position of the current research, data gathered from the interviews were analyzed using Interpretative Phenomenological Analysis (IPA; Smith, 1996; Smith, Flowers & Larkin, 2009). IPA is a phenomenological qualitative methodology that prioritizes individual experiences and endeavors to capture the subjective meaning of a phenomenon under investigation (Smith & Osborn, 2008). IPA is also idiographic in nature involving detailed examinations of personal accounts produced by a relatively small number of participants (Willig, 2001). These individual case examinations are later integrated to gain an understanding of collective experience (Larkin, Watts & Clifton, 2006). Finally, IPA is interpretative: it recognizes the impact of the individual and the researcher on the construction of knowledge and considers the influence each one's standpoint will have on shaping the research and data interpretation (Smith et al., 2009). This is related to the process of 'double hermeneutics' whereby the researcher is trying to make sense of the participant who is themselves trying to make sense of their own personal and social world (Giddens, 1996; Smith, 2004).

### **Participants and Sampling**

Participants were recruited from two NHS cardiothoracic transplant centers in England and through an online community forum for HT patients and their families based in the UK. HT recipients had all been transplanted in adult services.

Smith and Osborn (2008) argue that a small homogenous sample of participants who share experiences of the phenomenon being investigated is ideal for the in-depth analysis of individual interview data required for IPA. It was appreciated several demographics of participants in the current study might produce divergent experiences (such as participant age, length of relationship, time since transplant). However, Smith et al., (2009) argue that "how homogeneity is defined depends on the study" and when the potential population is small "one can be more selective about which factors to consider for homogeneity and which are likely to be more important" (p.50). Therefore, the focus of the current research was to more broadly investigate experience and meaning of HT from partners' perspectives. As is such, the current study does not claim generalizability to the experiences of all partners in this context.

Nevertheless, it was important to use inclusion and exclusion criteria to define the sample that will illuminate the specific experiences and meaning being investigated (Smith, et al., 2009). Based on this, the current research recruited a sample who met criteria determined in collaboration with a clinical supervisor (a clinical psychologist working at a cardiothoracic transplant center) and a research supervisor (with expertise in IPA and qualitative research). This stipulated that: (a) participants would be partners or spouses of HT recipients; (b) to ensure that HT patients were currently discharged from hospital and that enough time had passed for participants to be ready to discuss their experiences, a lower threshold of 6-months post-HT was applied<sup>2</sup>; (c) given that the average survival rate following HT is 10 years, it is likely that experiences of partners beyond this threshold would have differences based on this, therefore an upper threshold of 10 years post-HT was applied; (d) to allow comparison between supporting the HT recipient at different stages of the HT trajectory, participants would identify as having been within an intimate relationship (married or cohabiting) with the HT recipient at least one year inclusive of transplantation; and finally, (e) the HT recipient would not have died as a result of their health condition or HT. Furthermore, because of funding restrictions, individuals would not be eligible if they required an interpreter for the interview.

A total of fourteen eligible participants expressed an interest in taking part. Participants were recruited on a first come basis until reaching the target recruitment<sup>3</sup>. A total of nine participants were recruited: four from transplant unit A, three from transplant unit B and two in response to the online advertisement. The final participant sample consisted of seven wives and two husbands of HT recipients. On average, HT recipients were 18.7 months (mean) posttransplant (ranging between 1-42 months). On average participants were aged 50.8 years old (mean; ranging between 33-75 years) and had been in a relationship with their partner for 25.8 years (mean; ranging between 8-48 years). Participants resided in nine different towns/ cities located in England. One participant identified as

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<sup>2</sup> This was widened retrospectively with ethical approval to include a participant of a partner who had received a heart transplant more recently (1 month prior) the information about which was established after they had already completed the research interview.

<sup>3</sup> Although the original target was eight, one additional participant was recruited as it was not known whether the interview data from the participant who fell outside of the original inclusion criteria would be viable. Approval was gained in retrospect to allow for all participants who had completed the research interview to be included in the analysis of data



Asian British and eight as White British. Although there is some variation between sample, given that the participants share characteristics of chief concern (all were spouses of HT recipients in a relationship for at least eight years inclusive of transplant) it was decided that the sample had the necessary homogeneity to honor the research aims.

### **Recruitment and Data Collection**

In the first phase of recruitment, information packs were handed out by the field supervisors (clinical psychologists), containing a study information sheet (see Appendix 4 - A). To protect confidentiality at this stage, participants were asked to express interest by contacting the researcher directly or return a 'consent to contact' sheet (see Appendix 4 – B). An additional phase of recruitment was initiated to increase the sample pool using an advertisement shared by an online community forum for HT patients and their families based in the UK (see Appendix 4 – C). For those participants who contacted the researcher through this recruitment stream, participant information was sent to them.

An interview schedule was developed in respect of the research aims and in line with recommendations for semi-structured interviews within IPA research (Smith & Osborn, 2008; See Appendix 4 - D). Questions were centered around perceptions, thoughts, feelings and interpretations related to experiences of supporting a spouse through HT (Pietkiewicz & Smith, 2014). Additional prompts were included to expand in areas the researcher thought were important for achieving the research aims. The schedule was used flexibly to guide the interview accommodating interview flow and pace along with giving space for arising original or unanticipated issues. Moreover, to ensure the questions were consistent with an IPA framework and remained sensitive to the population under study, the supervisors involved in the study were consulted along with a member of a service-user group who identified as a partner of someone with heart failure.

Participants were given the choice to engage in the research interview at home, in a room at the transplant center, or over the phone. Three participants were interviewed at home and six over the phone. At the research appointment, participants gave informed consent and signed a consent form which included a full explanation of voluntary participation and confidentiality (see Appendix 4 - E). For telephone interviews, participants were sent a consent form to complete and return before the

appointment. Following consent, participants were asked to complete a brief demographics questionnaire (see Appendix 4 – F). The research interviews lasted a mean average of 78 minutes and were all digitally recorded. At the end of the interview, participants were given a debrief sheet containing information on who to contact if they required additional support (see Appendix 4 - G). The interviews were then transcribed, anonymized and assigned pseudonyms for data analysis.

### **Analysis**

Using IPA (Smith, Flower & Larkin, 2009), a series of steps were followed to explore idiographic content and thematic patterns within each individual case study initially before identifying cross-case themes. Beginning with the first participant, the researcher repeatedly listened to and read the transcript to familiarize themselves with the data. The transcript was then coded, highlighting extracts of the interview that specifically related to the research question. Each highlighted extract was then summarized as a succinct notation aimed at interpreting personal experience and sense-making (Chamberlain, 2000). An example of a coded extract from Paul can be found in Appendix 2 – A. For example, Paul described his feelings when he was told his partner needed a HT: “I haven’t got time to deal with what I’m going through. What I need to do is be head strong, and mentally and physically strong for my wife”. This was summarized into the notation ‘No time to address own emotion, need to be strong for my wife’. These codes were then actively and iteratively grouped into discrete clusters based on what they appeared to share in meaning. Once these groupings had been finalized, an interpretative theme summary was written followed by a final thematic label. For example, the above notation coded from Paul’s transcript was grouped with similar coded notations such as, ‘putting on a fake front, carrying on regardless’ and ‘partner takes priority – want to make her life easier’ to produce the narrative theme ‘Suppressing emotions/ hiding emotions from others’ (see Appendix 2 – B for example of this narrative theme). This process was repeated with each individual transcript resulting in nine participant analyses each containing idiographic themes and interpretative thematic summaries. Individual findings were then integrated resulting in three master themes which encapsulated the experiences of supporting a partner through HT. All three themes were represented by at least six participants; six participants’ accounts contained all three themes (see Table 1). Table 2

shows how each participants' individual narrative themes contributed to the final superordinate themes.

INSERT TABLE 1 ABOUT HERE

INSERT TABLE 2 ABOUT HERE

### **Credibility of Analysis**

To ensure that the research process and interpretation of findings authentically represented the lived experiences of participants, several steps were taken to uphold the trustworthiness and credibility of findings (Fossey, Harvey, McDermott & Davidson, 2002). First, to minimize researcher bias on the selection of themes within the analysis, a thorough audit trail was compiled to allow cross referencing between emergent qualitative findings with the original raw data (as described by Wolf, 2003=Smith, Jarman & Osborn, 1999). This allowed the researcher and consulting supervisors to check that the interpretations made were significantly grounded in the participants' first-person accounts. Second, transcripts were re-read following each stage of analysis to confirm the findings were representative of the participants original responses. Third, a research supervisor gave feedback before overarching themes were finalized. Lastly, a clinical supervisor was consulted to ensure the researcher could appreciate the nuances in the transplant journey important in making interpretative assumptions.

### **Reflexivity**

IPA recognizes that the role of the researcher in qualitative research is both interactive and dynamic (Smith & Osborn, 2004). It argues that it is impossible to infer with absolute certainty that participants' lived experiences have been directly accessed: what is offered instead is the researcher's interpretations of participant sense-making (Finlay, 2002). Therefore, the researcher must adopt a position of reflexivity whereby they strive to be aware of their own feelings and expectations and the impact this might have on data collection and interpretation of the results (Alvesson & Sköldbberg, 2009). To increase research rigor, IPA requires that the researcher's preconceptions are reflected on in attempt to suspend judgments and privilege participants' personal meaning: also known as 'bracketing' (Tufford & Newman, 2012). This was achieved by keeping a reflective diary that

captured thoughts, feelings and responses to interviews and data to discuss in supervision and consider during data analysis (Ahern, 1999).

### **Ethical Approval**

Final ethical approval was received from a Research Ethics Committee and the two Research and Development departments associated with the recruiting cardiothoracic transplant centers (see Appendix 4 – H; 4 – I; 4 – J). Interviews explored experiences of potentially upsetting events, such as recalling their partner’s life-threatening illness. Participants were reminded that they were not obliged to answer any questions and were free to discontinue the interview at any point. In addition to this, the researcher adhered to a series of steps to respond to and debrief participants if they displayed distress during the research study (Draucker, Martsof & Poole, 2009).

There was one ethical issue that arose during the data collection process that was acted on: Because of a miscommunication, the first recruited participant fell outside of the recommended time since partner’s transplant (< 2 months). It was advised by the Chair of the research committee that the data could still be used following receipt of the participant’s consent which was duly sought and confirmed (see Appendix 4 - K).

### **Results**

The analysis yielded three themes explicating experiences of supporting a spouse through HT: ‘driven by a sense of responsibility’; ‘striving for togetherness’ and ‘wrestling with the prospect of them dying’. These will be illustrated below with anonymized excerpts from the interview data. Data extracts were selected from at least half of the participants contributing to the theme, to give an indication of the convergence, divergence, representativeness and variability as recommended by Smith (2011).

#### **Theme 1: ‘Driven by a Sense of Responsibility: Establishing a Supportive Role’**

Hospitalization and critical health represented a crucial period for participants in establishing a supportive role in the context of their partner’s medical care. This included engaging in tasks which provided their partner with comfort and care, such as offering practical assistance and keeping their partner occupied and content. Partaking in these supportive actions appeared to be motivated by a sense of responsibility to fulfil the expectations of their spousal role. For example, for Lianne,

supporting her husband whilst waiting for transplantation was effortless as this aligned with her perceived duty to be there for him as his wife:

To support Phil was easy. Because that's what we do. So that was no trouble because what else would I have done? I wouldn't have been anywhere else. I wouldn't have done anything differently. The only thing I would have done maybe is spend more time with him, but you can only do so much. In an ideal world, I would have been there every day to the end of everything. (Lianne)

Although partners reflected that they perceived an element of choice in their supportive actions, for instance they would do the same again, this choice was conflicted by being duty bound:

It was the hardest thing I've ever done in my life. I couldn't have not done it. It was something that I didn't have a choice in doing and I would do the same again. It was what I did, and it was my job to do it. (Sammy)

A feeling of accountability and responsibility was conveyed by participants who established their supportive role through juxtaposition with medical professionals. For instance, Faye, expressed: "Yes, they [hospital staff] were responsible at least for his physical state, but I was perhaps still responsible for his emotional state" (Faye). This was in turn associated with combatting feelings of powerlessness experienced during their partners critical care. Thus, delivering supportive roles enhanced participants' psychological wellbeing through experiencing purpose and control. For example, after her husband's transplant, Sammy felt suddenly stripped of her supportive roles and displaced by hospital staff, evoking feelings of being role redundant:

I washed him every day when he was in there, and moisturized him, and I couldn't do that once he'd had the transplant. I couldn't do that because I had to do visiting times then, so I felt a bit bereft because I couldn't look after him then and do those things. So, I felt like I wanted to do those things, but I couldn't do those things and I had to hand those things over then to somebody else. I did find that quite hard. (Sammy)

Finally, showing true feelings was thought by participants to be burdensome to their partner, undermining the quality of their support: “I was trying to be mindful that if Fiona sees me at my weakest and me breaking down, I’m not going to be any use to her as support” (Paul). For most participants, this meant sacrificing the self to focus on their partner’s needs. Several participants achieved this by masking authentic feelings. For Lorna, the make-up that she wore to visits symbolically hid her inner turmoil:

I used to put make-up to go and see him so he could see me all nice, and not worried and all crying and upset, because I know that would have upset him more knowing I was upset. So, I had to...not put a front on but...but I did, because I knew he was going through such a lot and I wanted to stay there for him and stay strong. (Lorna)

In summary, experiences of supporting a partner with HT was driven by the perceived responsibility to align with spousal duties and by drawing comparisons with the roles of medical professionals in the context of their partner’s medical care. For participants in this study, being responsible necessitated hiding true feelings to protect their partner from additional worry.

## **Theme 2: ‘Striving for Togetherness: The Impact on Couple Identity’**

Participants interpreted their relationship with their partner as being part of a unit, with the two of them functioning together as an undivided whole: “we don’t work without each other” (Sammy); “he’s my other half. Literally my other half. The other half of me” (Lucy). Reflecting on their identity as a unified couple meant that HT was consistently viewed as something that had to be navigated together: “He’s had days when he’s felt down and I’ve just gone, ‘come on, we’re going to do this, we’re going to get through this. Me and you together’” (Lorna). There was evidence to suggest that the process of HT, particularly during the hospitalization period, disrupted this joint identity. For example, Lianne reflected on how the process of HT had created an unfamiliarity between her and her husband she became aware of when he returned home: “It was almost like being married again to be honest. We had to get used to each other again. We’d been separated for so long and we’d been through so much during that time.” (Lianne).

Participants demonstrated the need to uphold their couple identity, exemplified by the way they tried to 'strive for togetherness' and maintain attachment to their partners, particularly during the pretransplant and perioperative period. For Paul, the importance of experiencing relationship normality during his wife's hospital stay was crucial:

I'd have a normal conversation with Fiona [wife], try not to talk about what was going on, and for once in a long time we were getting back to a normal husband and wife relationship. We'd have normal conversations about the kids. Things like the weather, what I've had to eat for my lunch, what Fiona's had, what we're going to have for tea (Paul)

Other participants 'stroved for togetherness' during their partner's hospital stays by replicating their homelife context representative of their joint identity. For instance, Faye decorated her partner's room with pictures she had painted and sent him excerpts from a book she was writing. The objects Faye described were self-created, providing Faye's husband not only with representations of their shared life together, but also an extension of herself he could connect to when they were apart. What appeared most pertinent was the importance of sharing a connection with their partner during a time where they felt detached from them:

We would exercise up and down the corridor, go for a walk, go in the day room. We'd spend time in there reading, doing jigsaw puzzles. We managed to fill the day. We talked and just spent time together. It didn't matter if we were reading all day or doing a jigsaw. We were spending quality time together. (Lucy)

As time went on, experiencing unity was believed to be possible again. For instance, Lorna felt hopeful that as her partner regained strength, normality in their relationship, togetherness and their pre-established identity as a couple would ensue:

In time, when he does get stronger, we will be able to do things we have always done, and we look forward to that and that's my positive. Things are going to get better, and we are going to get back to normal and do the things we used to do. It's going to take some time, but we will get there. (Lorna)

In summary, as their partner's illness and hospitalization threatened the normality of their relationship, participants' ability to support their partners during this time acted to reaffirm spousal connection, protecting the integrity of the couple dyad and helping them achieve a sense of togetherness.

### **Theme Three: 'Wrestling with the Prospect of them Dying: The Impact of Anticipating loss'**

Although participants felt driven to support their partner through HT as a way of fulfilling spousal responsibility and strengthening relationship connection, they were simultaneously challenged by "wrestling with the prospect of them dying" (Faye). Anticipating loss of their partner impacted on participants' experiences of uncertainty and imagined futures. The transitory experience of time passing without transplantation during the waiting period heightened fear of loss. During this time, some participants felt temporally stuck: "The whole time you can't plan anything because your future is so uncertain, even more so when you're on the list" (Faye). For Faye in particular, her partner being listed took away the certainty of his death that had provided her with something tangible to prepare for and deal with, contributing to her feeling trapped by not knowing:

Before he went on the list, actually I felt quite a bit of a weight lifting up really. Because the whole thought of transplant was so worrying and such a big deal that now I thought he couldn't have one, it felt...it felt a bit freeing really. I thought, that's it then, we actually know what's going to happen. He will decline and his organs will pack up and my job will be to help him through that. There was a bit of certainty, even though it was horrible certainty.  
(Faye)

In contrast to this, other participants responded to anticipated loss during this time by maintaining planning:

Yea, we decided it was something we weren't going to let rule our lives. It was quite a conscious decision, that we thought, okay it [the HT] might happen, because it was a 'might' then. And you can't live in fear of 'might' can you. You know, there's things to do, we've got



grandchildren to play with, and holidays to go on. So, it didn't color our lives in a big way.

(Lucy)

For Judy, facing the prospect of losing her partner created a sense of pressure to accomplish planned goals more quickly than intended:

We moved out together, we got married and then we got pregnant. So, we still did normal relationship goals so to speak but we had to just...prior to his heart attack we always knew what we wanted with our relationship and where we wanted it to go very early on and we still maintained that [. . .] we wanted children...[it happened] a little bit earlier than we had anticipated. (Judy)

In addition to this, for Judy, the prospect of losing her partner added to the reasons for planning to have a baby, she recalled saying to her partner: "if there's a chance I'm going to lose you as well I want to be left with a part of you" (see Appendix 2 – C for an extended extract). The lived experience of anticipating being without her husband, for Judy meant planning to produce a shared expression of this unity, overlapping with her efforts of 'striving for togetherness'.

The HT recipient's illness and transplantation gave participants a poignant insight into the meaning of loss. For some, 'wrestling with the prospect of their partner dying' engendered renewed appreciation for life as precious and finite:

But when the doctor said, "well at best you've got two years", you think, oh Gosh! And you suddenly focus on what's important in your life and you suddenly stop and think about how much you take for granted in life. That's a big thing. Because you do. You sail through life, you take it all for granted, breathing for granted, and it makes you stop and realize, and take stock. (Tony)

Ultimately, happiness and fulfilment were now more consciously prioritized within their personal life and their relationship: “If the sun is shining one day well let’s go out because everything else can wait” (Lianne).

In summary, fearing loss of their spouse implicated participants’ projected timeline and future goals, particularly in the pretransplant phase. For some this meant putting life on hold to focus on their partner’s imminent vulnerability. For others, fearing loss engendered a need to maintain planning, to honor life goals, sometimes more quickly than anticipated. The meaning of near loss enabled participants to recontextualize living with this uncertainty to appreciate life’s value and its precarious finite quality.

### **Discussion**

The aim of the current study was to understand experiences of supporting spouses through HT. The significant issues raised in the analysis explicating partners’ experiences are discussed in more detail below.

#### **Role and Responsibility**

Participants in the current study dedicated themselves to the welfare of the HT recipient, assisting them physically, psychologically and socially. What came across strongly in participants’ accounts in relation to establishing a supportive role was being ‘driven by a sense of responsibility’, similar to participants in Mishel and Murdaugh (1987) study, “pledging self to the welfare of the patient” (p.334). This findings is consistent with the findings from other qualitative studies of family caregivers (Brown and Stetz, 1999; Marcuccilli, Bakas, Casida & Pagani, 2014). This was partly imbued with a perceived responsibility to fulfill spousal roles. Role theories provide a useful framework to conceptualize these findings (Biddle, 1979). A ‘role’ refers to an expected pattern of behaviors performed by a person within a particular position within a particular social context (Shaw & Costanzo, 1982). In relation to the current study, it could be argued that the action of supporting (role expression) confirmed participants’ identity as being a loving and committed spouse.

In addition to this, participants constructed their role through juxtaposition with medical professionals to distinguish differences whilst also emphasizing comparable importance and responsibility. For Sam, stricter visits imposed following her partner’s HT meant having to let

hospital staff take over the caring duties she had already integrated into her supportive role. It is thought that roles “bring regularity to complex social situations” (Nichols & Schwartz, 2006, p.13) which might explain why Sam experienced a sense of displacement when the hospital situation stipulated that her supportive roles were redundant. These findings deepen our understanding of establishing supportive roles in the backdrop of hospital settings and critical care for HT recipients.

From ‘being driven by a sense of responsibility’ participants benefitted from experiencing purpose and control through their supportive actions. However, although supporting their partner potentially ameliorated participants’ distress to feeling powerless, for many it also meant side-lining one’s own emotional needs. This finding could be conceptualised as ‘protective buffering’ (Coyne and Smith, 1991), a style of relational-coping which involves hiding concern and concealing worries in an effort to protect one’s partner from additional upset and worry, demonstrated by partners of heart-attack survivors (Suls, Green, Rose, Loundsbury & Gordon, 1997), cancer patients (Langer, Brown & Syrjala, 2009) and those with chronic illness (Johnson et al., 2014).

### **Reaffirming Couple Connection**

The study revealed the importance of couplehood in partners’ experiences of supporting HT recipients, a finding that has been documented amongst spousal caregivers elsewhere in the literature (Bielsten, Lasrado, Keady, Kullberg & Hellström, 2018). Participants in the current study referred to themselves as being part of unified couple and viewed transplantation as a joint venture, consistent with participants in McCurry and Thomas’s (2002) study who asserted they should be recognized as “coparticipants in the transplant experience” (p.192). Couple identity refers to partners’ sense of who they are as a unit, defined by Badr, Acitelli and Carmack-Taylor (2007) as “seeing the relationship itself as an entity (rather than seeing only two individuals)” (p.213). Fergus and Reid (2001, 2002, 2006) defined couple identity within a systemic-constructivist viewpoint as ‘we-ness’, that is the “collective reality that is both shaped by, and integral to, the personal identity of each member of the couple” (Fergus & Reid, 2001; p. 387-388). As participants in the current study constructed their relationship as mutual and cohesive, it could be argued that ‘we-ness’ is something they used to scaffold their experiences whilst supporting their partner through HT.

The current findings expand on McCurry and Thomas' (2002) findings to suggest that the way in which critical illness and hospitalization disorganizes couple identity, makes it necessary to reaffirm unity and 'strive for togetherness'. Participants in the current study endeavored to maintain closeness and unity with their partner by incorporating elements of their shared life together into hospital stays. Milligan (2003) argues that "a major source of identity continuity is the locations or types of locations within which given identities are enacted" (p. 382). Although the meaning of home is something that remains keenly contested (particularly in its research focus on western, white, middle-class, heterosexual, nuclear family), it is viewed as symbolic of family relationships (Mallet, 2004). The meaning of homelife as the space of shared spousal identity might explain why participants in this study used that which symbolized 'home' and 'normal relationship' to maintain connection to their partner in the hospitalization phase of transplant.

### **The Impact of Fearing Loss**

The most salient challenge depicted in participants' experience was supporting their partner whilst 'wrestling with the prospect of them dying', a finding consistent with previous qualitative research in this field (McCurry & Thomas, 2002; Mishel & Murdaugh, 1987; Salada et al., 2013). Similarly, empirical evidence has found that spouses of HT candidates awaiting transplant reported high levels of psychological distress related to fear that their partner might die (Collins, et al., 1996; Bohachick, Reeder, Taylor & Anton, 2001), and in relation to the inability to make future plans (Buse and Peiper, 1990). Participants in the current study might have been experiencing 'anticipatory grief', the premature mourning experience some people have before the loss of a significant loved one (Costello & Hargreaves, 1998; Lindemann, 1944), impacting on their ability to maintain plans/ goals.

The phenomenology of time in scaffolding psychological responses was evident when 'wrestling with the prospect of them dying'. Participants configured their experiences narratively when anticipating the way in which uncertainty and prospective loss in the present impacted on their imagined futures. Construction of narrative is argued to be one way a person makes meaning and can therefore be considered within phenomenological approaches to understanding experience (Smith, et al., 2009). The current finding fits well within Heidegger's (1924/2011) ontological focus of 'being

and time' within interpretive phenomenology: here it is argued that the experiences of 'time' (past, present and future) is important in the interpretation of lived experience, or 'being'.

The results of the current study yielded conflicting responses to participants' phenomenological experiences of prospective loss: (1) becoming temporarily stuck, and (2) maintaining (and for Judy accelerated) planning. First, putting life on hold when uncertain about a partner's health and future has been described elsewhere in qualitative literature of spouses' experiences of HT (Casida, 2005; McCurry & Thomas, 2002). Uncertainty in Illness theory (acute and chronic; Mishel, 1997) could be used to understand this finding, describing the inability to determine the meaning of illness-related events, stemming from, for example, an unknown future. The findings also suggest that participants were managing the stress of unknown loss using different coping strategies: passive (e.g., behavioral disengagement including the abandonment of efforts to achieve goals) versus active (e.g., planning; Folkman & Lazarus, 1985). Burker, Evon, Loisel, Finkel and Mill (2005) found spouses of HT candidates similarly used both these types of coping strategies during the pretransplant wait; adaptive coping strategies such as planning were associated with decreased levels of depression and linked to giving spouses perceived control.

Mishel and Murdaugh (1987) found that during recovery after HT discharge, some well-spouses focused on obtaining security for themselves whilst imagining life without the HT recipient. This is reminiscent of Judy's response of accelerating life goals such as marriage, cohabitation and having children in the context of prospective loss. However, the current findings suggest that this might occur earlier in the transplant trajectory (i.e. pretransplant phase) than Mishel and Murdaugh (1987) suggested. Additionally, for Judy, a baby represented security as well as a 'part of' her partner that would remain if she lost him, a finding where 'striving for togetherness' and 'wrestling with the prospect of them dying' overlap. Smith, Flowers and Osborn (1997) discuss the symbolic union of sexual intercourse and embodied selves in their IPA of the lived experiences of gay men. In this study, the semen was understood to be representative of the lover himself; that sexual intercourse represented "unity, sharing, giving, receiving and becoming one" (p.84) and the coming together of

two selves. For Judy, having a baby might have represented her and her partner's shared union, to ultimately produce a continuation of it beyond her partner's anticipated death.

Finally, participants described appreciating life as precious and fragile in the posttransplant phase, reminiscent of adaptive coping strategies such as positive reinterpretation and acceptance coping (Folkman & Lazarus, 1985). Having 'wrestled' with the prospect of loss, they experienced acceptance and existential clarity into the insecurity of life and a pursuit for living true to values and fulfilment. This experience is consistent with evidence showing post-traumatic growth (PTG) whilst supporting a loved one through life-threatening critical illness (Cadell, 2007; Li, Mak & Loke, 2013).

### **Clinical Implications**

The findings from this research illustrate the impact HT has on supportive spouses and highlights the need for systemic understanding and practice in clinical services targeted at these client groups. One aim of a psychological intervention might be to promote dyadic coping. Bodenmann's (1995, 1997, 2005) model of dyadic coping explains that perceived stress and coping is an interactional and social concept rooted in close relationships and interdependence between partners (a conceptual step forward from more individual-level theories of stress and coping such as Lazarus and Folkman, 1984; discussed in Papp & Witt, 2010). Given that well-spouses articulate feelings of interconnectedness and co-participation in their partner's HT, psychological services need to consider enlisting the couple in partnership to help minimize the risk of psychological strain on both and increase their ability to cope dyadically.

The importance of couple identity should be considered when preparing families for hospitalization necessary for HT. Fergus and Reid (2001) theorized that partners who feel estranged from one another and compromised in their mutual identity can experience personal suffering, the distress to which can be ameliorated by strengthening the experience of 'we-ness'. In relation to the current study, bringing something of relational meaning into the context of hospital stays helped participants experience a reaffirmed connection and a stronger sense of 'togetherness' during a time when couple identity was threatened. Partners and HT patients might benefit from being supported in engaging in ways to affirm and protect 'togetherness' during this phase of HT.

Finally, although challenging, supporting a loved one through HT can also foster positive experiences. Acceptance and Commitment Therapy (ACT) can help clients differentiate between unchangeable and changeable events and behave in a way that is consistent with their personal values (Hayes & Strosahl, 2004; Hayes, Strosahl & Wilson, 2009), the use of which has improved psychological wellbeing of those supporting a family member with chronic disease (Kuba & Weissflog, 2017). Therefore, using ACT my benefit partners of HT patients, for example when feeling temporally stuck.

### **Strengths and Limitations**

The current research addresses the gap in the literature giving attention to the lived experiences of spouses in HT generating novel findings that add to the knowledge base within this field. However, several limitations need to be considered. First, the findings only elucidate the experiences of partners who have sustained their relationship with the HT patient. It is likely that couples who have not been able to withstand the pressures and strains brought on by HT might have very different experiences not explored here. Indeed, research has established the disruption and deterioration of relationship following transplantation (Dalteg et al., 2011; Bunzel, et al., 1999). The current study might have been biased in recruiting participants within particularly resilient relationships.

To recruit enough participants, inclusion criteria in some areas was broad. Therefore, the resultant sample consisted of participants whose partners were relatively newly transplanted (<3 months) as well as those whose partners had been posttransplant for several years (3 ½ years). Additionally, the length in which participants had been in a relationship with the transplant patient also varied considerably (8 years to 48 years). The impact this variation has on the findings needs to be considered when using them to explain partners' experiences of supporting HT recipients. Given the uptake for this study was good, future research might want to select participants after expression of interest has been saturated to choose a sample that is the most homogeneous. However, this would need careful consideration in study protocol. Given that interested participants might not necessarily be asked to take part might present as an ethical issue.

### **Future Research**

Given that the findings referred to partnership and togetherness, a direction of future research might be to interview and analyze the responses of both the partner and HT recipient. In addition to this, to get a better representation of experiences across the transplant trajectory and improve the quality of retrospective accounts, future research might conduct a longitudinal study collecting interview data at specific time frames pre and posttransplant. Although the current sample included both wives and husbands, it was beyond its scope to ascertain gender differences in participant responses. Therefore, future research might want to specifically focus on the differential experiences of wives versus husbands of HT recipients.

### **Conclusion**

This research aimed to capture the experiences of supporting a partner through HT. Findings demonstrated how partners established supportive roles in the context of their partner's medical care; how hospitalization threatened couple identity leading to participants acting in ways to reaffirm spousal connection; and varying responses to anticipating loss including pausing life's goals versus actively pursuing them. The findings provide novel insight into this area and suggest that services need to support partners as individuals and within the couple dyad before, during and after HT.



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Table 1

*Participant Contribution to Final Themes*

<b>Participant</b>	<b>Theme 1:</b>	<b>Theme 2:</b>	<b>Theme 3:</b>
<b>Pseudonym</b>	<b>Driven by a Sense of Responsibility</b>	<b>Striving for Togetherness</b>	<b>Wrestling with the Prospect of them Dying</b>
Sammy	x	x	x
Georgia		x	x
Lorna	x	x	x
Lianne	x	x	x
Judy		x	x
Paul	x	x	x
Lucy	x	x	x
Tony			x
Faye	x	x	x
<b>Total</b>	<b>6</b>	<b>8</b>	<b>9</b>
<b>participants</b>			
<b>represented in</b>			
<b>theme</b>			

Table 2

*Contribution of Participants' Theme Narratives to Final Themes*

	<b>Theme 1: 'Driven by a sense of responsibility'</b>	<b>Theme 2: 'Striving for togetherness'</b>	<b>Theme 3: 'Wrestling with the prospect of them dying'</b>
Participant Pseudonym	Names of Participant Narrative Themes		
Sammy	<ul style="list-style-type: none"> <li>• Fulfilling a natural obligation of dutiful spouse</li> <li>• Feelings of powerlessness</li> <li>• Be their 'rock': Responsibility to stay strong and stable for partner despite own emotional turmoil</li> <li>• Now is a time for self: Reflections of impact to self at posttransplant</li> </ul>	<ul style="list-style-type: none"> <li>• Needing to feel connected and close to partner</li> <li>• Feelings of powerlessness</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty maintaining hope amidst uncertainty</li> <li>• Processing worst fears: Experiences of concluding heart transplant necessary</li> </ul>
Georgia	<ul style="list-style-type: none"> <li>• Living in autopilot: Experiences of coping with partner's hospitalization</li> <li>• Being supportive dual purpose: Fulfilling role whilst facilitating coping</li> <li>• Prioritizing others needs and hiding genuine feelings</li> </ul>		<ul style="list-style-type: none"> <li>• Dealing with uncertain prognosis: enduring worry and concern</li> <li>• Growth and gratitude arising from traumatic experiences of near loss</li> </ul>

	<b>Theme 1: ‘Driven by a sense of responsibility’</b>	<b>Theme 2: ‘Striving for togetherness’</b>	<b>Theme 3: ‘Wrestling with the prospect of them dying’</b>
Lorna	<ul style="list-style-type: none"> <li>Responsibility and loyalty: To be strong, to be supportive</li> </ul>	<ul style="list-style-type: none"> <li>Commitment to cope in unity</li> <li>The importance of maintaining a semblance of normality in face of extremes/ uncommon circumstances</li> <li>Yearning for togetherness: looking back and looking forward</li> </ul>	<ul style="list-style-type: none"> <li>Fearing partner’s death and impact on hope</li> <li>Renewed focus to be bold and positive in the face of a future unknown</li> </ul>
Lianne	<ul style="list-style-type: none"> <li>Duty as a partner to be there: That’s my purpose</li> <li>The process of acknowledging personal emotional impact</li> <li>Presenting as emotionally stable to addressing need to recuperate:</li> </ul>	<ul style="list-style-type: none"> <li>Importance of feeling connected to Phil when fearing loss</li> <li>A new beginning: Readjusting and appreciation after separation (hospitalization)</li> </ul>	<ul style="list-style-type: none"> <li>Being faced with partner’s fragility and mortality: Fear of loss</li> <li>Experiences of wavering hope: Lost, false and restored</li> <li>Impact of heart transplant on current outlook: Prioritizing happiness and fulfilment</li> </ul>
Judy	<ul style="list-style-type: none"> <li>Commitment and loyalty despite difficult times</li> <li>Being responsible: Enabling purpose and feeling in control</li> <li>Going on ‘autopilot’: Minimizing emotional processing in order to fulfil role</li> </ul>		<ul style="list-style-type: none"> <li>Experiencing partner close to death: fear, worry, retaliation and relief</li> <li>The challenge of maintaining hope</li> </ul>

	Theme 1: 'Driven by a sense of responsibility'	Theme 2: 'Striving for togetherness'	Theme 3: 'Wrestling with the prospect of them dying'
Paul	<ul style="list-style-type: none"> <li>• Suppressing emotions/ hiding emotions from others</li> <li>• Becoming emotionally overwhelmed: pent up emotions surfacing</li> <li>• The demands of taking on partner's family roles</li> </ul>	<ul style="list-style-type: none"> <li>• Losing sense of partnership: Feeling alone</li> <li>• Striving towards experiencing relationship normality</li> </ul>	<ul style="list-style-type: none"> <li>• Facing the unsolvable: Feeling useless and out of control</li> <li>• Experiences of hope and fear of loss in the context of uncertainty</li> <li>• Facing partner's mortality: Shock, processing meaning, relief and joy in transplantation success</li> <li>• The lasting impact of nearly losing Fiona: Current enduring worry and current day appreciation</li> </ul>
Lucy	<ul style="list-style-type: none"> <li>• Adopting supportive roles: Finding meaningful ways of supporting partner</li> <li>• Feeling pressured and responsible in supporting partner</li> <li>• Hiding own feelings to protect and prioritize partner</li> </ul>	<ul style="list-style-type: none"> <li>• Adopting supportive roles: Finding meaningful ways of supporting partner</li> <li>• Life with partner intertwined</li> </ul>	<ul style="list-style-type: none"> <li>• A journey of hope when fearing loss</li> <li>• Facing prospect of partner dying: Wanting to live normally amidst the fear</li> </ul>
Tony			<ul style="list-style-type: none"> <li>• Unknown loss: The worry of endless hoping and waiting</li> <li>• Facing the many unknowns surrounding potential loss: Anxiety, helplessness, acceptance, relief and joy</li> <li>• Valuing hope when fearing loss</li> </ul>

	<b>Theme 1: ‘Driven by a sense of responsibility’</b>	<b>Theme 2: ‘Striving for togetherness’</b>	<b>Theme 3: ‘Wrestling with the prospect of them dying’</b>
Faye	<ul style="list-style-type: none"> <li>• Needing to be stable: self-preservation</li> <li>• Performing roles that supported partner emotionally</li> </ul> <p>Being responsible: Sense of duty and feeling burdened</p>	<ul style="list-style-type: none"> <li>• Performing roles that strengthened relationship normality and connection.</li> <li>• Loss of connection: temporary loss of partner, unrewarding contact and regaining connection</li> </ul>	<ul style="list-style-type: none"> <li>• Living through the absolute extremes of experiences: prospective loss and fragile state of shock</li> <li>• Wrestling with the prospect of him dying; concern, worry, feeling helpless, processing meaning</li> <li>• Uncertainty of prospective loss unbearable: the ‘horrible’ certainty of death</li> </ul>



**Appendix 2 – A: Extract from Paul’s Transcript with Initial Summary Notes (lines 45- 153)**

<p>35 Having time to self to absorb/ process situation and seriousness of it alone, unbearable experience 36 time passing slowly, as trying to process what the situation would mean</p>	<p>And what was it like to be her husband through that</p>	<p>Author</p>	<p>35</p>
<p>37 no time to address own emotions, need to be strong for my wife</p>	<p>I think if I was to be honest with you, from that point up until the point when the transplant happened I think...that night was the worst night because I'd spent the night in hospital with Fiona, when I went home the next morning, I think it was only literally a 10 minute drive, but it seemed like forever, because I think at that point when I was away from her I was absorbing what was going on and what had happened, I was trying to put everything in</p>	<p>Author</p>	<p>36</p>
<p>38 duty to her to be there, like she has been for me</p>	<p>perspective, and I was thinking, I haven't got time to be emotional. I haven't got time to deal with what I'm going through. What I</p>	<p>Author</p>	<p>37</p>
<p>39 becoming robotic – not showing true feelings in order to be functional/ useful/ supportive</p>	<p>need to do is be head strong, and mentally and physically strong for me wife. Because she's always been there for us and now is my</p>	<p>Author</p>	<p>38</p>
<p>40 Becoming regimented, planning the day and keeping schedule to keep functioning, suppressing emotions</p>	<p>time to be there for her. I think...I don't know whether it was a face shield or what it was, I just fitted onto something else. It was like I was a robot from the point she went to [site hospital]...from</p>	<p>Author</p>	<p>39</p>
<p>41 Preying for the best</p>	<p>that point onwards I seemed like a robot, where I had a schedule, I</p>	<p>Author</p>	<p>40</p>
<p>42 getting through each day at a time, not emotionally investing in what could happen</p>	<p>know everybody writes a schedule, you know daily routine part of life, but for me it was, wake up, check my phone in case I missed</p>	<p>Author</p>	<p>41</p>
<p>43 ignoring negative feelings, being stoic</p>	<p>any phone calls from the hospital, ring the hospital in the middle of the night, and you just pray for the best. Get in the car, get to the</p>	<p>Author</p>	<p>42</p>
<p>44 experiences of being emotionless, in order to be strong for partner</p>	<p>hospital and see Fiona talking to me and everything, and get through one day...each day, as and when we were faced with whatever dilemmas in the way, we just get passed it. I didn't</p>	<p>Author</p>	<p>43</p>
	<p>really want to be negative. So, I think I just sucked everything up, and I was pretty much at that point, emotional...not emotional, I'd say...what's the word. I just had no emotions. I basically had</p>	<p>Author</p>	<p>44</p>

<p>45 going into overdrive, being functional when emotionally struggling</p> <p>46 not dwelling on what they faced, becoming a blur</p> <p>47 keeping busy and occupied, not alone with feelings as way of coping with emotional distress – didn't want to address it</p> <p>48 Feeling supported by close knit family</p> <p>49 <u>subject</u> of seriousness/ concept of what was happening and potential loss too sensitive to discuss</p> <p>50 driving, escaping coming to terms with situation</p>	<p>no...because I had to be strong for Fiona. I just went into overdrive and everything from that point to now is a blur, I mean I can remember it if I dissect it in my head, but you don't want to dwell on what was going on, because I know that at any point, from the point we got told she would need a transplant to having it, in all honesty I kept myself occupied as much as I could because even a second in the day where I was on my own, I'd get emotional. I'd just sit there and start crying. I'd get upset. You know, I had to move back to my parents' house because they were so worried about me. They would never leave me alone, we're a close knit family, you know, my sister would talk to me, my mother would talk to me, and the minute they would talk to me on a particular subject, even though I had massive support from the rest of my family, and they were very supportive, but as soon as they mentioned the subject I'd just break down. So, I'd get out the situation and just get in the car and drive. It was just a way to escape so then I don't have to come to terms with what was going on.</p>	<p>A Author 45</p> <p>A Author 46</p> <p>A Author 47</p> <p>A Author 48</p> <p>A Author 49</p> <p>A Author 50</p>
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### Appendix 2 – B: Paul’s Theme Narrative: ‘Suppressing Emotions/ Hiding Emotions from others’: Initial Comments and Theme Narrative

Initial summary notes (codes)	Description of cluster theme
<p>43 ignoring negative feelings, being stoic  45 going into overdrive, being functional when emotionally struggling  46 not dwelling on what they faced, becoming a blur  47 keeping busy and occupied, not alone with feelings as way of coping with emotional distress – didn’t want to address it  37 no time to address own emotions, need to be strong for my wife  40 Becoming regimented, planning the day and keeping schedule to keep functioning, suppressing emotions  55 putting on fake front, carrying on regardless  82 fake me, not my time to deal opening with emotions, couldn’t be ‘me’  54 no time to address own emotions, it’s not about me, I need to be strong  187 partner takes priority – want to make her life easier  42 getting through each day at a time, not emotionally investing in what could happen  39 becoming robotic – not showing true feelings in order to be functional/ useful/ supportive  27 hiding emotions to present to partner as strong and useful/ supportive (not weak and not coping) presenting coping  10 Partner dynamics/ identity – partner emotionally strong, Paul hides emotions, less strong mentally  76 must just grin and bear it  81 hiding emotional experiences  198 work – not able to open up about feelings  117 difficulty expressing feelings of extreme happiness and joy as still wanted to present as being stable, concerned about perception of others  112 Happiness however needing to be reserved  28 although oneself is suffering, partner is the person going through it physically – it’s a different experience  44 experiences of being emotionless, in order to be strong for partner  78 partner worrying, brushing it off – must prioritize you  77 putting on a mask, hiding feelings (and exhaustion through caffeine) as partner needed me  154 acting like unaffected, benefits partner  175 not wanting to show children distress, needing to be positive  174 being emotionally strong for sake of children  177 being strong, not showing distress to children, as I’m their role model, it would be unsettling to them  156 partner recovery, not showing emotions, being normal for sake of partner – positive for them  183 currently feeling less fake – more myself – however remaining strong – not breaking down – accepting emotions but not being overwhelmed by them  150 partner recovery – returning to how I used to be  199 switch on robot mode and cruise control/ autopilot – not address emotions and function as normal  56 currently still not easy to discuss own emotions about experience to others  197 currently still not sharing impact of experiences of emotions – not gone into depth with anyone over these  80 not opening up about feelings to partner, too sensitive, scared to break down – not supportive and not respectful of her support in the past  71 shutting self off from others as didn’t know how to cope with emotional experiences  72 like a storm – avoiding everything and anyone  66 didn’t want to see anyone, wanting to cope alone, hide and hope that it disappears</p>	<p>This theme represents Paul’s experienced related to suppressing his true feelings, the reasons he did so and the strategies he used.</p> <p>Paul described how he felt that addressing his emotional experience to Fiona’s transplant and the uncertainty they faced was not only overwhelming and unbearable, but he also felt it interfered with his ability to support his wife and be useful through the difficult time. He felt that addressing his emotions, sharing them with others was too time consuming, selfish and challenging for him to deal with. He was also concerned that expressing his emotions particularly regarding presenting as distressed, would have a negative impact on others including his wife and children. Therefore, Paul felt it important to ignore/ give minimal attention to his own emotional experience in order to be strong, stoic and functional. In order to do this, he kept himself busy, became regimented in his daily routine and presented himself as coping (when underneath he felt differently). Some analogies he used included ‘fake me’ and ‘becoming robot’ to describe the way he masked his true feelings.</p> <p>This way of being appeared again when Paul described his response to his partner stabilizing after transplant surgery – that although he was ecstatic, he presented as reserved to some extent as he was concerned how others would evaluate him being over-emotional.</p> <p>Paul discussed this way of being in relation to current day. He described a slight shift in being authentic – feeling less fake. However, he still felt it important to present himself as coping, strong, contained – going on to autopilot – in order to function as normal.</p>

**Appendix 2 – C: Extended Extract from Judy’s Transcript (lines 285-296)**

We had the wedding and then we kind of gave ourselves a few months and these transplant talks were starting to get more serious. We knew we were waiting for the call so then we started discussing really...I was like, in a way I probably pushed him into it, but I was like, “I’m not being funny And not to be too morbid about it but if you go I’m left with no one”. That’s how I was feeling. And he knew...we always knew we wanted children and I said to him, “Look if we do this, we need to do this before the transplant” because we knew that transplant came with its own complications for conceiving children because of the medication, so I said to him, “I don’t want to rush you. We’ve just lost Dad obviously. I know you probably think it’s the grief talking but I’m being deadly serious, if there’s a chance I’m going to lose you as well I want to be left with a part of you”. Which to some people might sound ridiculous but when you’re in that position that’s where you’re at.

Running head: CRITICAL APPRAISAL

### **Section Three: Critical Appraisal**

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The following section of this thesis is a reflective, critical discussion and appraisal of the empirical research not afforded to in the format of an article written for publication for a peer reviewed journal. An overview of the findings from the empirical study will be summarized. I will discuss the strengths and challenges experienced in this research, as well reflective insights that need consideration for the purposes of reflexivity. Finally, I will outline possible directions of future research along with my final conclusions.

### **Overview of the Research Findings**

The current empirical research investigated the experiences of supporting a partner through heart transplant (HT) from the qualitative first-person accounts of seven wives and two husbands of HT recipients. An interpretative phenomenological analysis (IPA) resulted in the themes, 'driven by a sense of responsibility: The experiences of establishing a supportive role', 'striving for togetherness: The impact on couple identity', and 'wrestling with the prospect of them dying: The impact of anticipating loss'.

First, the findings illustrated how feeling responsible contributed to participants' establishment and expression of supportive roles in the context of their partner's medical care. This was partly rooted in perceived spousal obligation as well as through drawing comparisons with the roles of medical professionals. Supportive actions enabled participants to experience purpose which in turn alleviated the psychological repercussions of feeling out of control. Although occupying supportive roles benefited partners in this way, it was also associated with sacrificing personal needs.

Second, the findings highlighted that participants felt interconnected with their partner's journey through HT, experiencing discomfort at aspects of their partner's illness and hospitalization that create distance in their relationship. In these cases, the transplantation process threatened their identity as a unified couple, resulting in partners seeking connection to reaffirm their attachment and bond.

Finally, participants were continually challenged with the prospect of their partners death which altered their imagined futures and infringed on their capacity to maintain planning. During the pretransplant phase, participants responded to anticipatory loss by either becoming temporally stuck

or maintaining/ accelerating planning. In the posttransplant phase, participants who accepted uncertain loss were able to experience a renewed appreciation for life.

Giving voice to spouses vicariously experiencing HT highlights how heavily implicated they are in the transplant process. The findings indicate there is a need for systemic understanding and practice in clinical services targeted at these client groups. Spouses are at risk of becoming overwhelmed whilst also not actively seeking support. Clinical services need to help spouses find ways of being supportive and connecting to the transplant recipient particularly during hospitalization. They should also highlight the importance of accessing personal support and offer psychological intervention as appropriate.

### **Strengths and Challenges of the Research Paper**

#### **Recruitment**

The aim of recruitment in clinical research is to obtain a sample of participants that adequately represent the target population and is sufficient in size for meaningful analysis (Patel, Tennakoon and Doku, 2003). However, recruitment can be challenging for many reasons including identifying and accessing potential participants and attracting them to take part. The challenges of recruiting those who support family members with medical-health needs has been identified in previous research studies, with common barriers including lack of interest, lack of time and participation being too burdensome (Heckel, Gunn & Livingston, 2018). My initial strategy to recruit partners of HT recipients was to collaborate with a clinical psychologist at a UK-based organ transplant center who had frequent contact with this client group. With only seven cardiothoracic transplant centers in the UK, the potential sample pool was already relatively limited. To address this issue, I approached an additional clinical psychologist from another UK-based transplant unit to secure two sites willing to facilitate recruitment.

Nonetheless, as this strategy was rolled out it became apparent that uptake was problematic. In a couple of months of active recruitment only three participants had expressed an interest to take part. I believed that there were three reasons for this: (1) awareness of the research project at recruitment sites had diminished; (2) clinical staff already managing busy workloads were struggling to cope with the task of identifying potential participants and disseminating research packs; and (3)



the target population (partners/ spouses) were not the primary clinical population these services directly catered for.

First, to resolve these issues, I endeavored to increase my presence in the supporting teams and actively worked on sustaining good supervisory relationships with the field supervisors, important when conducting post-graduate research studies (Abiddin, Ismail & Ismail, 2011). I reflected in supervision that widening recruitment channels at this stage was also necessary. Although the transplant centers were well-positioned to access partners/ spouses, potentially large numbers of the target population were being missed. For instance, those partners not involved in visiting the centers and indeed those of HT recipients who were no longer attending outpatient appointments. Therefore, a second phase of recruitment was rolled out where relevant community groups on social media were asked to advertise the study. Researchers have found promoting their study through trustworthy online organizations known to participants is effective in recruitment (Morgan, Jorm & Mackinnon, 2013). Therefore, online transplant communities were specifically approached. Although a far-reaching platform, solely relying on online channels for recruitment has its potential pitfalls and questions have been raised about the representativeness of internet samples (Koo & Skinner, 2005). However, I believe that as a contingency measure this strategy was complimentary to the existing modes of recruitment.

The result of these recruitment boosting strategies was fruitful and the number of participants expressing an interest surpassed the target for enrolment. Having multiple and well-balanced recruitment streams from the onset would be beneficial to future researchers. In addition to this, issues of communication and distant working relationships with field supervisors might have contributed to mistakenly recruiting a participant who was outside of the inclusion criteria. Future researchers would benefit on devising a screening questionnaire that can be completed by clinical staff as a basic preliminary check which can be thoroughly corroborated by the researcher before recruitment.

### **Sampling**

There were two issues related to the participant sample that might limit the conclusions drawn from the findings. First, the inclusion criteria deemed participants eligible if their partner was up to 10 years posttransplant. This resulted in a wide range of months since HT (1, 9, 9, 12, 18, 23, 29, 36, and

42 months), meaning that participants were at varying stages in their partners posttransplant status. Smith (1994) studied identity development in women transitioning into motherhood. It was found that women actively reconstructed their self-concept as they went through the transition into motherhood revealing a discrepancy between their contemporaneous and retrospective accounts. The way in which participants in the current study structured and made sense of their experiences could have been influenced by their partners' current stage of posttransplant care.

In addition to this, the inclusion criteria stated that participants were eligible to take part if they had been in a relationship with their partner for at least one year inclusive of HT. This resulted in a varying range of relationship length (8, 9, 20, 25, 27, 30, 32, 34, and 48 years). This should be considered, particularly in relation to experiences of couple identity in the hospital setting and the impact of prospective loss on maintaining goals. For example, Judy had been with her partner for 6½ years when he was transplanted: the relative infancy of their relationship at diagnosis compared with other participants might have contributed to wanting to accelerate life's goals.

Given that uptake was ultimately good, future researchers might want to recruit based on homogeneity of the sample following participant interest (rather than on a 'first-come first-served' basis necessary for the time constraints of the current research); for example making the time since transplant, or relationship length more homogeneous.

### **The Unexpected Third Party**

To increase uptake in the study and to reduce participation burden, I offered participants the option of completing the research interview at home, over the phone, or at the transplant center. Following my first research interview at the participant's home, I reflected on the value of face-to-face interviews in the home setting related to this topic area:

Completing the research interview in Sammy<sup>1</sup>'s home helped make the experience more personable and Sammy seemed comfortable in her own setting. I sensed a good rapport between us which I wonder whether this could have been achieved over the phone. Given that Sammy offered accounts describing the difficulties related to visiting her partner in hospital,

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<sup>1</sup> All names of participants included are pseudonyms

perhaps interviews at the transplant center (clinical and hospital setting) would have evoked distress. (Reflective diary extract, July 2017)

Nevertheless, I also appreciated that participants might want to remain anonymous when talking about sensitive topics. Offering telephone interviews was aimed at improving access to respondent groups who might have been reluctant or unable to meet in person (Sturges & Hanrahan, 2004).

Despite valuing the home-visit for research interviews, controlling the presence of a third person can be problematic (Rubin & Rubin, 2011). This occurred when interviewing Lorna. On arrival Lorna's husband was home and, although he said he was happy to sit in an adjacent room, Lorna said that she wanted him to stay for emotional support. I was aware that showing respect toward research participants is key in increasing the depth and quality of the interview and responses shared (Grafanak, 1996). I was also aware that taking part in qualitative research interviews can benefit participants who appreciate being able to speak to an objective person (the researcher) about their experiences (Birch & Miller, 2000). I concluded that it was important to honor the appointment and continue with the research interview. Afterwards, I reflected on the potential impact this had on the research findings:

It was hard and probably unnatural for Lorna's husband not to join in on some occasions when she was asked questions. At times it was challenging to steer the direction back to Lorna. I feel that the presence of her husband might have influenced what she was willing to share. (Reflective Journal entry, July 2017)

Some research has indicated that spouses give more cautious answers to questions that relate to relationship and marriage when their partners are present (Zipp & Toth, 2002). However, contrary to this, participants in Boeije's (2004) study, investigating chronic illness and caregiving in the marital relationship, found that the partner being present did not result in the participant being more cautious or 'rosy' in their answers. Nevertheless, the presence of Lorna's husband created an ethical dilemma and challenges to data validity that future researchers investigating how individuals are experiencing phenomena should avoid. Following this, where home-visits were requested, I confirmed with

participants in advance whether individual interviews could be ensured given that they shared the living space with their partner.

Despite the challenges this posed, I also reflected on how seeing the participant with their partner provided an interesting contextualization of their relationship and their joint experience:

The physical image of them both crammed together at the very end of the sofa was striking to me. He looked frail and small – they said he had lost a lot of weight due to his illness and transplantation. And she was a relatively small woman – together they seemed to occupy the space of one person. (Reflective Journal entry, July 2017)

In this moment, I really appreciated the non-verbal cues and couple dynamics missed from conducting individual and telephone interviews.

### **Single Interview Design Using an Interview Schedule**

The aim of the empirical research was to understand partners' experiences supporting HT recipients across the HT trajectory. However, as I started to analyze the interviews, I reflected how difficult it had been to capture experiences across such a wide-ranging timescale:

I feel that as the interview nears to 1-1½ hours respondents become jaded, just when we are covering the experiences of supporting in the posttransplant phase. (Reflective Journal entry, September 2018)

The time lived before, during and after HT has been used by transplant recipients to construct their lifeworld experiences (Salada & Stofl, 2008). Qualitative research regarding people's experiences of organ transplant have often focused on one particular aspect of the journey such as waiting for transplantation (Bjørk, & Nåden, 2008), experiences of mechanical circulatory support as a bridge to transplant (Casida, 2005) and life after transplantation (Peyrovi, Reiesdana & Mehrdad, 2014; Graarup, Mogensen, Missel & Berg (2017). In McCurry and Thomas's (2002) investigation of spouses' experience of HT, the authors concluded that, "as participants described their experiences, all aspects of time seemed to be woven seamlessly from the past through to the present. Participants seemed unable to look at the present without also seeing both past and future simultaneously" (p.191).

To ensure that the interview covered the breadth of experiences across time points, an interview schedule was developed which prompted responses across the entire trajectory of HT (see Appendix 4 - D). Constructing a schedule for semi-structured interviews is recommended for IPA research, particularly for the novice interviewer (Smith, Flowers and Larkin, 2009). The schedule provides the interviewer with “virtual maps” which can help guide the interview (p.59).

In one sense the interview schedule might have prescribed a format to sharing experiences (before, during, after) that could have left less room for in-depth exploration of posttransplant experiences. However, I also believe that this was implemented in a flexible manner as recommended by Smith and Osborn, (2008). I would argue that adopting a naïve but curious role of active listener and establishing a good rapport with participants led them to be forthcoming, open and reflective in their responses. Therefore, the findings derived from the research interview might represent the most salient experiences to the participant: that is, the experiences related to the more acute phase of HT.

### **Reflections of the Research Process**

Reflexivity in qualitative research requires the critical self-reflection of how the researchers' social background, assumptions, positioning and behavior impact on the research process, and gives attention to how the researcher is involved in the co-construction of findings (Finlay & Gough, 2003). This is an important component of doing IPA which recognizes that “the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2008, p. 53). Therefore, IPA requires us to bracket our presuppositions that might impact on the interpretations of another's lived experience (Shaw, 2010). In contrast to retrospective reflection, reflexivity involves a more “immediate, dynamic and continuing self-awareness” (Finlay & Gough, 20003, p. ix). In the current study, this was achieved by keeping a reflective journal that captured thoughts, feelings and responses to interviews and data occurring at the time (Ahern, 1999). I will present some of these, along with retrospective reflection to offer a reflexive position of myself within the current research process and findings.

### **Formulating a Research Idea**

Initially embarking on clinical psychology training, I was asked by a fellow trainee what I wanted to achieve on the course: my response was to broaden my experiences, working with clients

and in contexts that I hadn't done before. The course was the ideal space to discover and try out new and emerging interests. Health-related clinical psychology was a novel area to me and one that I wanted to explore. I therefore sought out academic and clinical experiences in this field prior to thesis, conducting a service-related project in pediatric burns and undergoing a health placement in a chronic fatigue syndrome (CFS) service.

During my health placement I became familiar with delivering psychological therapies for individuals with CFS but reflected on the lack of service for the wider family context. Anecdotal accounts regarding clients' partners in this service, led to an interest in researching the vicarious experiences of health-related conditions. Discussing this idea with a very experienced and passionate clinical supervisor in the field of organ transplant inspired me and shaped the initial empirical research concept. At this point in the research, I was positioned as a clinical psychologist-in training with limited prior knowledge but a budding interest in clinical health psychology and HT.

### **Becoming a Mother and Spouse**

I had two pregnancies during the research process. During my first pregnancy my son was diagnosed with ectopic heartbeats which really highlighted the timeless and unpredictable nature of health and illness from a parental perspective. This shaped my interest in conducting a literature review focusing on the parental experiences of pediatric organ transplant. During my first year of maternity leave I also married my long-term partner. As I returned to the research process and embarked on data collection, my position in relation to the research now included being someone who had recently transitioned into motherhood and married life: identifying as a new-mother and a newlywed wife.

Following research interviews, I began to reflect on my reaction to participants accounts in relation to my position in the research:

Georgia talked about her two younger boys; how she compartmentalized her life in order to cope with demanding roles. I felt parallels with my own life, such as feeling emotionally drained and occupying competing roles; mothering whilst training. (Reflective Journal entry, July 2017)

There was a point in the interview with Judy when I felt teary. She was describing deciding to have children in light of her father passing away and her husband's fragile health, that if she was going to lose him, she'd want a part of him passed on in a child. I felt a connection with that. It transpired that my son was the same age as hers. I thought about life without my husband or my husband bringing up my son without me. (Reflective Journal entry, August 2017)

During the time of data-collection I was also pregnant with my second son. I reflected on the impact this on the data generated in Sammy's face to face interview:

Being 5 ½ months pregnant: It was strange having an aspect of my personal life so obviously on show. There was a point in the interview when Sammy referred to not being able to have children/ not having children, and all her and her partner really having was each other. She spoke about fear of losing her husband and I wondered if me being obviously pregnant had influenced these musings in any way. (Reflective Journal extract, July 2017)

As I approached the analysis, I re-engaged with these reflections to try and bracket them from the lived experiences participants were offering. However, this was a challenge as my personal meaning of being a mother and a spouse was a new experience for me – I was in the process of negotiating new identities. It is possible that my position in the research might have privileged accounts resulting in the theme 'wrestling with the prospect of them dying', which held new personal meaning considering my recent life changes. However, I believe that my stance was empathic, and my clinical training had given me skills of being objective whilst also being compassionately understanding. It is also possible that being pregnant might have been a visual reminder of birth/ death; new life/ end of life, impacting participants who were interviewed at home. However, only three interviews were conducted face-to-face and the finding was prevalent throughout. Along with the research evidence corroborating this thematic finding, I believe that the claims of the empirical research were sufficiently grounded in the participants' lifeworld.

### **Potential Areas for Future Research**

As the empirical research highlighted, participants felt interwoven in their partner's experiences of HT. Mavhandu-Mudzusi (2018) argues that understanding the real experiences of partners in the context of their relationship is vital for services providing support to couples: In a study investigating the experience of living in a Human Immunodeficiency Virus (HIV)-serodiscordant relationship (where one partner is infected with HIV and the other is not), Mavhandu-Mudzusi (2018) modified IPA design to incorporate couple interview data. Hermeneutics is defined as the theory of interpretation (Smith, et al., 2009). Mavhandu-Mudzusi (2018) coined the term "triple hermeneutic" in their study, defined as "a third interpretation where the researcher tried to make sense of how each partner makes sense or interpret the interpretation of the other partner to understand the couple experience of the relationship" (p.3). Mavhandu-Mudzusi (2018) was able to gain in-depth information and observation of the couple interaction to answer the primary research aim. I would suggest that future research could adopt a similar methodology using couple interviews to explore how partners, where one is living with a HT, make sense of their experiences together.

Furthermore, future research into the topic area, particularly conducted by a more experienced qualitative researcher, might also consider unstructured interview techniques. In these types of interviews, the way in which the participant responds to a core question at the beginning of the interview will determine the direction of the interview (Smith et al., 2009). For example: "Now that you have been the spouse of a heart transplant recipient for some time, what in that experience stands out for you?" (McCurry & Thomas, p.185). Reducing the prescriptive nature of discussing the HT experience in respect of a timeline would support credibility of the findings.

In addition to this, the empirical research might have been limited by covering such a wide-ranging timeline in a short space of time. Subjective understanding of lived phenomenon might need to be considered at several temporal points (Snelgove, 2014). Smith et al., (2009) suggest the use of "bolder designs" in IPA research, such as interviewing participants more than once. They suggest this has value for the investigation of certain longitudinal and 'before and after' phenomenon (p. 52). McCoy (2017) explored using IPA in conjunction with a longitudinal approach. Here the author argued that both approaches hold the same ontological understanding of reality as a subjective construct; and both consider the "experiences of the past, what is known in the present and what is in



the moment to enrich understandings of experiences across time” (p.445). This has been exemplified in Speirs, Smith and Drage (2016) study: a longitudinal IPA of the process of kidney recipients’ resolution of complex ambiguities within their relationships with their living donor. Here the participants took part in three semi-structured interviews: (1) shortly before transplant; (2) two months posttransplant; and (3) nine months posttransplant: data was analyzed according to the principles of IPA. Adopting a similar methodology in exploring partners’ experiences of HT using contemporaneous accounts would be an interesting direction for future research.

### **Conclusion**

The current thesis explored the experiences of supporting organ transplant recipients from the perspective of family members: a qualitative meta-synthesis of parents’ experiences of organ transplant and an IPA of the experiences of supporting a partner through HT. Both papers highlight the challenges family members face when their loved one goes through organ transplantation and the importance of fully incorporating the whole family system in their psychosocial care.

I have faced many personal challenges throughout my research journey that have necessitated resilience and focus. This has both shaped my research interest as well allowing me to value to findings from a personal perspective of a mother and a spouse. The research process has developed and changed me in several ways. I have become more passionate about giving voice to those indirectly impacted by health-related experiences and I will strive to incorporate systemic methods of offering psychological support in my ongoing practice as a clinical psychologist.

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Running Head: ETHICS SECTION

**Section Four: Ethics Section**

Jessica Sheffield  
Doctorate in Clinical Psychology  
Lancaster University

Word Count: 4,704

Correspondence should be addressed to:

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## NHS Research Ethics Committee Application Form

IRAS Form

Reference:  
17/LO/0343

IRAS Version 5.4.0

Welcome to the Integrated Research Application System

### IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)

Experiences of Supporting a Partner through Heart Transplant

#### 1. Is your project research?

Yes  No

#### 2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

#### 2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation?  Yes  No
- b) Will you be taking new human tissue samples (or other human biological samples)?  Yes  No
- c) Will you be using existing human tissue samples (or other human biological samples)?  Yes  No

#### 3. In which countries of the UK will the research sites be located?(Tick all that apply)

- England
- Scotland

Date: 06/02/2017

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Reference:  
17/LO/0343

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- Wales  
 Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

- England  
 Scotland  
 Wales  
 Northern Ireland  
 This study does not involve the NHS

**4. Which applications do you require?**

*IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.*

- IRAS Form  
 Confidentiality Advisory Group (CAG)  
 National Offender Management Service (NOMS) (Prisons & Probation)

*For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.*

*For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.*

**Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?**

- Yes  No

**5. Will any research sites in this study be NHS organisations?**

- Yes  No

**5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?**

Please see information button for further details.

- Yes  No

*Please see information button for further details.*

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?**

Please see information button for further details.

- Yes  No

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The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

Yes  No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

Yes  No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes  No

9. Is the study or any part of it being undertaken as an educational project?

Yes  No

Please describe briefly the involvement of the student(s):  
 Doctoral Research (Thesis)  
 Doctorate of Clinical Psychology  
 Trainee Clinical Psychologist

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes  No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes  No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes  No



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**Integrated Research Application System**  
**Application Form for Research involving qualitative methods only**


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**IRAS Form (project information)**

Please refer to the *E-Submission* and *Checklist* tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
Experiences of Supporting a Partner through Heart Transplant

Please complete these details after you have booked the REC application for review.

**REC Name:**  
LONDON WESTMINSTER

**REC Reference Number:**  
17/LO/0343

**Submission date:**  
08/02/2017

**PART A: Core study information**
**1. ADMINISTRATIVE DETAILS**
**A1. Full title of the research:**

Experiences of Supporting a Partner through Heart Transplant

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

Title	Forename/Initials	Surname
Miss	Jessica	Morley

Address

Post Code

E-mail

Telephone

Fax

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:  
Doctorate in Clinical Psychology

IRAS Form

Reference:  
17/LO/0343

IRAS Version 5.4.0

Name of educational establishment:  
Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title	Forename/Initials	Surname
	Dr	Craig	Murray
Address	Furness College Lancaster University Lancaster		
Post Code	LA1 4YG		
E-mail	c.murray@lancaster.ac.uk		
Telephone	(0)1524 592730		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Jessica Morley	<input checked="" type="checkbox"/> Dr Craig Murray

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

**A2-2. Who will act as Chief Investigator for this study?**

- Student  
 Academic supervisor  
 Other

**A3-1. Chief Investigator:**

	Title	Forename/Initials	Surname
	Miss	Jessica	Morley
Post	Trainee Clinical Psychologist		
Qualifications	BSc Psychology PGCert Autistic Spectrum Disorders		
ORCID ID			
Employer			
Work Address			
Post Code			
Work E-mail			
* Personal E-mail			

Date: 06/02/2017

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Reference:  
17/LO/0343

IRAS Version 5.4.0

Work Telephone  
 \* Personal Telephone/Mobile  
 Fax



\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**  
 This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Dr Diane Hopkins
Address	Research Services, B14 Furness College, Lancaster University, B58 Bowland Main Lancaster
Post Code	LA1 4YW
E-mail	ethics@lancaster.ac.uk
Telephone	01524592838
Fax	

**A5-1. Research reference numbers.** Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):	Lancaster University
Sponsor's/protocol number:	NA
Protocol Version:	
Protocol Date:	
Funder's reference number:	NA
Project website:	NA

**Additional reference number(s):**

Ref.Number	Description	Reference Number
N/A		N/A

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

**A5-2. Is this application linked to a previous study or another current application?**

Yes  No

Please give brief details and reference numbers.

## 2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

IRAS Form

Reference:  
17/LO/0343

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**A6-1. Summary of the study.** *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

This study will be researching partners' experiences of supporting someone through heart transplant. For most transplant recipients, the journey through transplant involves the support of their close relatives. The social support given by partners/ family members has been related to the subsequent health and well-being of the transplant recipient and to the overall success of the transplantation. Although the support given by partners is invaluable, studies show that a lot of partners feel unprepared to fulfil this role and often experience high levels of burn-out, stress and depression. There is some emerging evidence to suggest that those supporting a person through a life-threatening illness can be positively transformed by the event in the long term, however the relatively small number of studies in this area gives rise to the need for further exploratory research. The current study will recruit partners of heart transplant recipients. Participants will be asked to complete a semi-structured interview lasting approximately one hour which will take place in a room at the Transplant Unit, at their home or via telephone/ skype. The results of this research will be useful in increasing understanding of how partners specifically describe their experiences of supporting their loved one through heart transplant and could also potentially be helpful in understanding how they could be best supported through this process. The study will be funded by Lancaster University.

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

The purpose of this study is to gather research findings about partners' experiences of supporting someone through heart transplant. As this is an area where there is relatively little research, the opportunity to gather a rich description of these experiences is presented. A qualitative design is seen as the most appropriate way to gather this data, whereby participants can describe these experiences in their own words. The interview schedule consists of a series of open-ended questions that are aimed at covering the main topic areas pertinent to eliciting participant's descriptions of their experiences supporting a partner through heart transplant. The aim of the interview schedule is to introduce discussion within specified topic areas whilst allowing for the researcher to be guided by the participants' responses and issues raised by them as the interview proceeds. The interview has been developed in respect of the research aims and the related research literature.

In developing the proposal, both an academic supervisor and a field supervisor (a Clinical Psychologist working at the Transplant Unit) have been consulted in this process. Both have given advice from their clinical perspectives in regards to the appropriateness of the research, design, ethical issues and proposed methodology.

During recruitment, potential participants who meet inclusion criteria will be identified by the field supervisor through the services outpatient clinics. To maximise the number of potential participants reached, advertisement will be placed in the clinic areas and within the hospital newsletter which will include the researchers contact details.

Once potential participants are identified they will be given information about the research by the field supervisor. In addition to this, nursing staff will be asked to hand out information about the research to people who meet the inclusion criteria when attending any nurse-lead appointments. To maintain the confidentiality of the potential participants who are identified at this stage, the researcher will not have sight of the potential participant's information until an expressed interest of the potential participant has been received. The pack will contain a covering letter, a participant information sheet and a consent to contact sheet. At this stage only the full name and contact details of the potential participant will be requested. The option will also be made available for the potential participant to contact the field supervisor directly if they would prefer to talk to them in the first instance about taking part in the research project.

To keep the sample of participants homogenous, the study will only be recruiting partners of heart transplant recipients. The study will also only recruit participants whose partner is still currently alive. Due to the time and financial constraints of the study, an interpreter will not be available. Therefore only participants who can speak English for the interview will be eligible for recruitment.

Participants will be given a participation information sheet to read before agreeing to take part in the study. This will be posted to participants in advance if the interview is being conducted via telephone or skype. This will give

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information about the study and who is conducting it. They will be told that if they decide to take part they will not have to answer any questions they do not feel comfortable in doing so. They will be free to discontinue the interview at any time if they wish. They will be told that they will be free to withdraw at any time up to 2 weeks after the interview at which point it is likely that the responses will have been anonymised, transcribed and incorporated into the analysis. They will be told that if they do not wish to take part, or decide to withdraw, that this will not affect their future involvement with services. They will be given details about who they can contact to access support following their involvement. They will be told about the potential risks involved in taking part, how their privacy will be protected and how their data will be stored. They will also be given the contact details for those who will be able to deal with any complaints they have during their involvement in the study.

Following this the researcher will gain informed consent from the participant before they are recruited to take part. The consent form will be posted out to participants to complete and return in a pre-paid envelope in advance of a research interview via telephone or skype. The participant will be asked to confirm that they have read and understood the participant information sheet and confirm that they would like to continue to take part in the study. The consent form will ask participants to confirm that they understand their participation in the study is voluntary and they are free to withdraw as above. They will agree to the interviews being audio recorded and responses being typed up into anonymous transcripts. They will agree to their transcripts and consent forms being stored electronically on the Lancaster University secure network for up to 10 years after the study has been submitted. They will agree to anonymous transcripts and recordings being accessed by a supervisor to assist in the project and that extracts from their anonymous transcripts may be included in the final written report. They will agree to understanding issues of confidentiality and times when the researcher may need to share their information if they are concerned about the health and well-being of the participant or anyone else involved. They will agree to their details being accessed where there is concern for the researcher safety during a home visit. The researcher will use their knowledge and skills gained during their training and previous experience to ascertain that they have understood all of the above.

The potential risks and benefits will be included in the participant information sheet. This will include the possibility that talking about their experiences may be upsetting. Participants will be reminded that they are free to take breaks or stop if they need to and will be given information for further support where needed. They will be told that there are no direct benefits in taking part but that other people sometimes like the opportunity to talk about their experiences and that it is hoped that the information gathered will help improve the services in the future. Before the interview starts, the researcher will ask the participant to refer to people where necessary by their occupation and avoid using names of professionals and the service where possible. They will be given the option to provide a pseudonym for themselves and their partner to be used in the write-up. Any identifiable information that is given will be anonymised in the transcripts. It is appreciated that participants may be resistant to provide certain demographic data. They will be reminded that they do not have to answer any questions they do not wish to. If, during the interview, the participant appears to become stressed or upset during the interview the researcher will employ the skills and knowledge they have developed through their training to date to contain and reduce the distress occurring. The researcher will offer breaks and check how the participant is during the interview where appropriate. Where participant's become distressed to the point where it seems that participating further will be detrimental to their well-being, the researcher will terminate the interview. Participants will be given a debrief sheet after the interview which will contain a list of contacts for sources of further support. This will be posted to participants in advance if the interview is being conducted via telephone or skype.

In order to manage any risk or safeguarding issues that arise during the interview it may be necessary for the researcher to act immediately on information received. Discussion of this will be made with the field supervisor and information shared with appropriate agencies where necessary. The details of this are included in the participant information sheet and will be discussed during the consent process.

Risks to the researcher will be minimised. This includes using a research mobile phone and not giving out any personal details to the participant. The researcher will encourage research interviews to take place in a room at the Transplant Unit in the first instance. Where home visits are conducted, adherence to the relevant lone working policies will be conducted. The participant will indicate during the consent process whether they would like to receive a summary of the project findings in the future. If this is the case, a 2-4 page summary document will be sent to the participant after the researcher has submitted.

After the submission of the research report, in line with the Lancaster University Doctorate in Clinical Psychology guidelines, electronic copies of the transcripts will be made and stored, along with scanned copies of the consent forms and any coded data produced in the analysis, on the university's secure network for up to 10 years. After this time the all this data will be deleted

### 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply:**

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- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

What are participants' experiences of supporting their partner through heart transplant?

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

Heart transplant involves the transplantation of a heart organ due to end of stage heart failure in the recipient. Internationally, an estimated 4055 heart and 53 heart/ lung transplants take place per year (ISHLT International Registry for Heart and Lung Transplantation, 2015). The 2015/ 2016 annual report for cardiothoracic transplantation within the United Kingdom (UK) revealed that in March 2016, 248 patients were on the active heart transplant list. The report also found that over a ten year period between 2006 and 2016, 3218 cardiothoracic transplants were made (NHS blood and transplant, 2016).

A transplant recipient can experience a vast array of emotions and challenges when undergoing the critical, acute and rehabilitation stages of the transplant journey. Coming to terms with their illness, waiting for a potential match and the acceptance of carrying someone else's organs can be a time of significant stress and difficulty (Sadala & Stolf, 2008). Heart transplant recipients have reported a number of negative feelings after transplant including fear, low-mood, guilt and grief (Sadala & Stolf, 2008; Kaba, Thompson, Burnard, Edwards & Theodosopoulou, 2005). The experience and diagnosis of psychological distress in the recipient post-heart transplant is therefore not uncommon (Dew & Di Martini, 2006).

For most recipients, this journey is not experienced in isolation from the partners and family members who are there to support and assist them on the way. In fact, the care from others, including family and friends, has been considered by heart transplant recipients as an essential supportive resource in the face of psychological distress (Conway, 2013). The capacity to thrive through adverse life events has been linked with the presence and quality of social support (Feeney & Collins, 2014). Indeed, the social support given by partners/ family members has been associated with superior post-transplant outcomes in recipients, including rates of survival (Coglianese, Samsi, Leibo & Herox, 2015).

Partners play a major role in providing both physical and emotional support to their loved ones during heart transplant. Qualitative accounts suggest that partners are extremely interwoven into the transplant journey and describe themselves as co-participants (McCurry & Thomas, 2002). However, it may be challenging for partners to negotiate how much and what type of support will be the most beneficial for the transplant recipient (Conway, 2013). Given the responsibility partners have in the transplant journey, it is important to better understand their specific experiences and challenges they go through, for example, to ensure that they are adequately supported where needed.

Although the recipient's partner often provides support without question, they may as a result experiences physical, mental and social demands (Ivarsson, Bodil, Björn Ekmeahag & Trygve Sjöberg, 2014). Studies show that a lot of partners/ relatives feel unprepared to fulfil their supportive role adequately and often experience high levels of burn-out,

IRAS Form

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stress and depression (Miyazaki et al., 2010; Ullrich, Jansch, Schmidt, Struber & Niedermeyer, 2004). From the time the patient is diagnosed with end stage heart/ lung failure, there may be significant disruptions and experiences of distress in the partner relationships while adjusting to the illness, including communication difficulties, intimacy concerns and difficulties with changing domestic roles (Dalteg, Benzein, Fridlund & Malm, 2011). During the waiting period, spouses for example, face significant levels of stress particularly related to the uncertainty and fear that their partner has a life-threatening diagnosis and may die whilst waiting for a donor organ (Collins, White-Williams & Jalowiec, 1996). The strain on partners has been shown to continue post-transplant and can lead to a deterioration in the relationship (Bunzel, Laederach-Hofmann & Schubert, 1999) and an increased risk for developing depression and anxiety related disorders in the long-term (Dew et al., 2004).

Although receiving a transplant has been associated with increased stress and strain in both transplant recipients and their families, there is also evidence to suggest alternative experiences to this. Posttraumatic growth (PTG) refers to a positive psychological change following a major life crisis or traumatic event (Tedesco & Calhoun, 1996; Tedeschi & Calhoun, 2004) to a point where the person may be "better than before" (Wu, Tang & Leung, 2011, pp. 91). These positive changes are typically observed in the way the person views themselves, their relationships and their philosophy of life (Tedesco & Calhoun, 1996). A growing body of literature has indicated PTG experiences in patients who have experienced potentially life-threatening illness, including cancer, heart disease, stroke, and HIV (Hefferon, Grealy & Mutrie, 1999) and more recently, transplant recipients (Tallman, Shaw, Schultx & Altmaier, 2010; Fox et al., 2014). Although it is difficult to determine whether or not a person will experience PTG following a traumatic event, some factors have been significantly associated with the phenomenon. These have included subjective beliefs; such as having purpose and meaning, demographic factors; such as social support, having paid work, stable relationships, spirituality and psychological health (Powell, Gilson & Collin, 2012; Grace, Kinsella, Muldoon & Fortune, 2015; Prait & Pietrantonii, 2009). Although being a partner to someone in these situations may be an equally stressful experience, there is evidence to suggest that those supporting a person through a life-threatening illness can too show PTG (Cadell, 2007).

The relatively small number of studies in relation to the experiences of supporting someone through heart transplant gives rise to the need for further exploratory research in this area. As the experiences of different family members may vary depending on their relationship to the transplant recipient, this study will focus specifically on the experiences of partners who have supported someone through heart transplant. The positive impact this care has on the health and well-being of the transplant recipient has drawn attention to the need to better understand the experiences and needs of these support persons. To ensure partners are able to offer the best support they can, it is important to understand how the transplant journey specifically impacts on them. In addition to this, exploring the potential for PTG in this population would be a valued initial investigation into this area of study. As this is a subject area where there is relatively little research, the opportunity to conduct a qualitative study presents itself, results of which will be useful to increase understanding of how partner of transplant recipients specifically experience supporting someone through the transplant journey. Findings from this could also potentially be helpful in highlighting the importance of working systemically with transplant recipients and their family and provide guidance on how partners could be best supported through this process to promote long-term adjustment.

Therefore the primary research question of this study is to explore the experiences of spouses who have supported their partner through heart transplant. The aim of this will be to provide insight into then potential costs and benefits associated with this experience from a qualitative point of view. This insight would potentially also have important implications for psychological services protocol and service delivery within transplant units and in wider health and social care domains.

**A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.**

As the research study is aimed at understanding participants' experiences of supporting their partner through heart transplant, a qualitative design and methodology will be used. A qualitative method of enquiry allows for the use of semi-structured interviews to elicit detailed personal accounts of the individual's lived experiences (Clarke & Jake, 1998). The data gathered from interviews will be analysed using a qualitative design to enable a detailed look into the lived experiences of partner who have supported someone through heart transplant. The responses they give will be looked at in detail and any information that appears to represent a certain theme within participant's accounts will be identified. Similar themes that come up in other parents responses will also be identified and collated.

The chosen method of analysis will be Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This approach offers a flexible and accessible method for analysing qualitative data for themes and "takes an idiographic approach whereby insights produced as a result of intensive and detailed engagement with individual cases are integrated only at a later stage" (Willig, 2001, p.54).

This approach appreciates that it is impossible to infer from the findings that the participant's lived experiences have been directly accessed and presented. Therefore, the approach recognises that the researcher's own interpretation of what the participant is sharing is an active component to the conclusions gathered. This acknowledges that the researcher's interpretations will largely be governed by their own world view along with the interaction between

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researcher and participant.

Due to the qualitative nature of the study, it is important to recruit a sample size that allows for an in-depth, rich analysis of individual interview. Smith and Osborn (2007) argue that a relatively small sample size allows for the in-depth analysis required within IPA. Based on this, the following research will aim to recruit up to a maximum of 8 participants. If participants are eligible to take part, they will be interviewed on a first come basis until reaching the target recruitment. However, if the researcher is inundated with eligible participants in one go, they will select the most homogenous sample (in consistency with the chosen method of analysis) in terms of time since transplant was received.

The field supervisor will identify potential participants that meet the inclusion criteria. To maximise the number of potential participants reached, a poster will be placed in the clinic areas and on the ward about the study including the researchers contact details. Once potential participants are identified they will be given information about the research by the field supervisor. In addition to this, nursing staff will be asked to hand out information about the research to parents who attend the nurse-led appointments. Advertising material will be produced and disseminated in print and electronic format. Online advertisements will be posted on various platforms including a Lancaster University hosted webpage. Participants who have contacted the researcher directly after seeing an advertisement will be telephoned to decipher whether or not they meet inclusion criteria.

The method of recruitment was decided upon through consultation with the field supervisor as to be the most appropriate and efficient way of reaching potential eligible participants. It was also considered the most appropriate method of maintaining confidentiality of potential participants before they agree to their details being shared with the researcher.

To begin with, participants will be recruited from the site hospital Transplant Unit. However, if at the target recruitment number of participants has not been reached by the end of the first recruitment phase (4 weeks) the following recruitment strategy will be implemented:

- Recruitment Phase 2 (4 weeks) Recruitment will be expanded to second site. This will follow an identical recruitment strategy to the first site, whereby the field supervisor will give out participant information packs to potential participants.

In addition to this, a secondary recruitment avenue will use online platforms including social media. The chief investigator will upload the recruitment poster onto their personal (exclusively professional) twitter and facebook page requesting others who see the post to share (e.g. other trainee clinical psychologists). Charities and networks will be contacted by the researcher using email (University email account) and provided with a copy of the participant information sheet, along with any other information they may wish to review before making a decisions about advertising the study. If the organisation agrees to assist with recruitment, they will be provided with electronic copies of recruitment poster and participant information sheets. They will be asked to advertise the study through available channels including: webpages; online forums; associated social media (including Facebook pages and Twitter accounts); newsletters; and noticeboards in waiting rooms (if applicable). The chief investigator will "tweet/re-tweet" adverts from charities and networks using their personal (professional use only) twitter and facebook account in order to further share the advert. Posters and information sheets will contain the contact information for the researcher. Participants will then contact the researcher by email or telephone if they are interested in

- Recruitment Phase 3 (4 weeks) Widen inclusion criteria to include other family members not exclusive to partner.

An outline of interview questions has been developed in respect of the research aims and the related research literature. A service user has also provided feedback on the study materials. A brief demographic information questionnaire designed by the researcher will be administered at the start of the interview to gain a basic overview of factual information.

The interview schedule consists of a series of questions that are aimed at covering the main topic areas and help participants talk openly about their experiences. The aim of the interview schedule is to introduce discussion within specified topic areas whilst allowing for the participant to go onto other topics or issues that are important to them. Each interview recording will be given a participant pseudonym to maintain anonymity.

Participants who are identified to meet the inclusion criteria will be given an information pack about the study containing a covering letter, a participant information sheet, a consent to contact sheet and a freepost envelope addressed to the researcher. The pack will be distributed by the field supervisor. Nursing staff will also give out information packs to potential participants attending nurse-led appointments.

The covering letter will request those interested in taking part to contact the chief investigator by returning the consent to contact sheet in the freepost envelope or by contacting them on the telephone number (specifically provided for the research study by Lancaster University Doctorate in Clinical Psychology Department) or university email provided.



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The option will also be made available for the potential participant to contact the field supervisor directly if they would prefer to talk to them in the first instance about taking part in the research project.

If the potential participant wishes to continue with recruitment, a convenient time for interview will be arranged. The participant will have the option of completing the research interview in a room at the Transplant Unit, at home, over the phone, or via Skype. Skype interviews are not wholly secure due to the nature of the platform. However, Skype have an encryption process in place and further information around Skype's security can be found at: <https://www.skype.com/en/security/#encryption>. Participant's will be informed of this in the participant information sheet and consent form.

If the participant wishes to complete the interview at the Transplant unit, the researcher will discuss the arrangements for receiving reimbursement for travel expenses. For interviews that take place in the participant's home the researcher will adhere to the Lone Worker Policy of Lancashire Care NHS Foundation trust.

This will involve the researcher using a 'buddy' system. To operate the 'buddy' system a Lone Worker must nominate a 'buddy'. This is a person who is their nominated contact for the period in which they will be working alone. The nominated 'buddy' will: Be fully aware of the movements of the Lone Worker; have all necessary contact details for the Lone Worker, including personal contact details, such as next of kin; attempt to contact the Lone Worker, if they do not contact the 'Buddy' as agreed; and; Follow the agreed local escalation procedures for alerting their Senior manager or the police, if the Lone Worker cannot be contacted or if they fail to contact their 'buddy' within agreed and reasonable time scales.

Contingency arrangements should be in place for someone else to take over the role of the 'buddy' in case the nominated person is called away to a meeting

The researcher will carry an ID badge and be prepared to identify themselves. They will carry out a "10 second" risk assessment when they first arrive at the house and the front door is opened. If they feel there is a risk of harm to themselves, they will have an excuse ready not to enter the house and to arrange for an alternative appointment. They will also be aware of animals in the house and ask for them to be removed, prior to entry. The researcher will ensure that when they enter the house, they shut the front door behind them and make themselves familiar with the door lock, in case they need to make an emergency exit. The researcher will not walk in front of a participant. They will not position themselves in a corner or in a situation where it may be difficult to escape. The researcher will remain calm and focused at all times and keep their possessions close to them. The researcher will be aware of their own body language (as well as the body language of the participant).

**Risk Assessment – Vehicles:** Before setting out, the researcher will ensure that they have adequate fuel for their journey. They will give themselves enough time for the journey to avoid rushing or taking risks, owing to time pressure. Items such as bags, cases, CDs, or other equipment will never be left visible in the car. These will be placed out of sight, preferably stored in the boot of the vehicle. The researcher will always hold the vehicle keys in their hand when leaving premises, in order to avoid looking for them outside, which could compromise their personal safety. Once inside the vehicle the researcher will lock all doors, especially when travelling at slow speed, when stopped at traffic lights and when travelling in inner-city areas. The researcher will always try to park close to the location that they are visiting, in a well-lit area, facing the direction in which they will leave. The researcher will not park on the participants' drive-way. If the researcher is followed, or suspect they are being followed, they will drive to the nearest police station or manned and lit building, such as a petrol station, to request assistance.

In case of vehicle breakdown, Lone Workers will contact their 'buddy' immediately.

The participant will be required to complete a consent form before they are interviewed. The participant will be invited to ask any questions they would like answering before they continue. Following this, the participant will be asked to complete a demographic information sheet. The digital recorder will then be switched on and the researcher will open the recording with the participant pseudonym, date and time of interview, and researcher name. The researcher will then start the interview using the interview schedule which is planned to last approximately 1 hour.

After the interview, participants will be given a debrief sheet and be informed about the process of receiving a summary of the research findings if they have expressed an interest to receive such. If they have agreed to the latter, the researcher will post out a 2 to 4 page summary of this to the participant after the research project has been submitted along with a cover letter.

All interview data will be transcribed verbatim into anonymised transcripts within 3 months of the interview date.

At the first opportunity, the consent forms will be scanned in and stored electronically on Lancaster University's secure (encrypted and password protected) network using a Virtual Private Networking (VPN) system. This information will only be accessed by the Chief Investigator. Paper copies of consent forms will be then destroyed. Any additional forms collected containing identifiable information of the participant will be destroyed/ deleted once the research has

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been completed and participants who requested a summary of the findings have been contacted. Similarly this information will be destroyed immediately if participants decide to withdraw from the study.

All interviews will be recorded on an audio recorder and will be uploaded the same day of the interview onto the secure university network which may be accessed via the researcher on their home computer. Once the recording is uploaded it will be deleted from the recording device. The audio file will then be typed up into an anonymised transcript within 3 months of the interview date and then deleted from the secure network. The anonymised transcript will then be uploaded and stored on to secure network and accessed by the researcher on their home computer during the analysis stage. The academic supervisor will also have access to the recordings/ transcripts where it is deemed necessary to assist in the research project.

Following the submission of the report, in line with the Lancaster University Doctorate in Clinical Psychology guidelines, electronic copies of the transcripts will be stored, along with scanned copies of the consent forms and any coded data produced in the analysis, on the secure network for up to 10 years. After this time the all this data will be deleted.

Dec 2016- Submit to ethics process

Once ethical approval has been gained time scale will be as follows (adjust appropriately according to when approval received):

Jan 2017 – Begin recruitment (phase 1: 4 weeks; phase 2: 4 weeks, phase 3: 4 weeks)

Jan – April/ May 2017 – Data collection and begin transcription

June 2017 – end recruitment

July 2017– Complete transcription and analyse data

Aug 2017 – Nov 2017 – Write up and draft reads

Dec 2017 – Submit report

Jan 2018 – Feedback summary of findings to participants

March 2018 – Submit paper for publication

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

A Lancaster University service user panel member has also been involved in giving feedback on the materials used within the study.

#### 4. RISKS AND ETHICAL ISSUES

##### RESEARCH PARTICIPANTS

**A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

- Blood
- Cancer
- Cardiovascular
- Congenital Disorders

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- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Gender: Male and female participants

Lower age limit: Years

Upper age limit: Years

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Inclusion criteria:

- Participant identifies as supporting the transplant recipient through their transplant
- Participant identifies as being in a relationship (married and/or cohabiting) with the transplant recipient for at least a year and during the transplant process.
- The transplant recipient received a heart transplant within the last 6 months to 10 years
- Transplant recipient is still currently alive

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

Exclusion criteria:

- Those who require an interpreter to engage in an interview.

**RESEARCH PROCEDURES, RISKS AND BENEFITS****A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)

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## 4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
They read and confirm their agreement to 11 questions by writing their initials and signature	1		15 minutes	Jessica Morley Chief Investigator Location: Participant choice (room at the [REDACTED] participant's home)
Demographics questionnaire. Participant will be asked to answer 7 factual questions	1		5 minutes	Jessica Morley Chief Investigator Location: Participant choice (room at the [REDACTED] participant's home)
Semi-structured interview: Participants will be asked a series of semi-structured interview questions about their experiences supporting their partner or spouse through cardiothoracic transplant	1		1 hour	Jessica Morley Chief Investigator Location: Participant choice
Reimbursement for travel expenses: Participant will be asked to produce receipts for public travel cost where applicable, complete receipt of payment received and receive payment from the researcher.	1		5 minutes	Jessica Morley Chief Investigator Location: Participant choice
Recruitment: Receiving and reading the participant information sheet.	1		15 minutes	[REDACTED] Field Supervisor. Or nursing staff on site.
Recruitment: Receiving, completing and responding to the consent to contact sheet	1		5 minutes	[REDACTED] Field Supervisor. Or nursing staff on site.
Arranging interview: Discussing with the researcher over the phone or via email, where and when they would like to be interviewed and discuss any additional information e.g. process of reimbursement	1		10 minutes	Jessica Morley Chief Investigator Location: Participant choice (Over the phone or via email)
Receiving a summary of the research findings: If participants have expressed a wish to receive this, they will be posted a 2-4 page summary	1		15 minutes	Jessica Morley Chief Investigator Posted out to participant to read in their own time

**A21. How long do you expect each participant to be in the study in total?**

9 months (from being informed about the study to receiving a summary of the findings)

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

To protect the confidentiality of the potential participant before they are recruited, the Chief Investigator will not have sight of their information until they have explicitly expressed an interest in taking part in the study by completing and returning a consent to contact form or contacting the Chief Investigator themselves. All potential participants will be given participant packs by the field supervisor or other staff on site. Once they have been recruited, only the Chief Investigator will know the information of those who are taking part. There are a few exceptions to this. One will be if the participant wishes to complete the interview at the Transplant Unit, those staff working there may infer that they are taking part. Participants will be made aware of this in the participant information sheet. Another will be where the

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participant discloses information that leads the researcher to believe that their, or another person's, health and safety are at risk. In these cases, the researcher may need to contact their supervisors for further advice and may potentially need to contact an outside authority, for example safeguarding services. Participants will be made aware of this in the participant information sheet and will agree to this in the consent form. Finally, the participants details may be accessed by a nominated professional 'buddy' if they are concerned about the researcher's safety during a home visit. A 'buddy' system will be used for lone working whereby the researcher will give their buddy a sealed envelope containing details of the participant name, contact details and location of the interview and a time in which they will be calling them to confirm they are safe following the interview. If the researcher does not get in touch at this time the buddy will attempt to make contact with the researcher. If this is not successful the buddy will open the envelope and attempt to make contact again and may contact the emergency authorities to pass on their concern. If the researcher does contact their buddy at or before the agreed time, the buddy will keep the envelope sealed and give it back to the researcher at the soonest available time. The researcher will then destroy the envelope.

If the researcher has already recruited 8 participants they will not recruit any more. This will be explained in the participant information sheet. If the participant does get in touch at this point the researcher will respond to them, thanking them for their response and telling them that unfortunately the study is no longer recruiting new participants because of the reasons stated above. The participant will be made aware in the participant information sheet, that if they do not wish to take part in the study, that this decision will not affect their relationship with the any other services.

The participant may wish to take part in the research interview in their own home. This option will be made available. If the participant would prefer to be interviewed in a room at the Transplant Unit, they will be able to claim back up to £20 for any travel costs incurred.

Participants may find talking about their experiences difficult and distressing. The researcher will only ask questions that are aimed at covering the research aims. For example the researcher will not ask for details about why a transplant was needed. If the participant volunteers information that is not covered in the interview schedule, the researcher will be guided by the participant at these points and continue with the interview schedule when appropriate. The participant will be told in the information sheet that they do not have to answer any questions they do not wish to and that they are free to pause or discontinue the interview at any point if they feel they need a break or do not want to carry on with the interview. This will be reiterated by the researcher before the interview starts. If the participant does appear to become distressed or upset during the interview, the researcher will use their clinical skills and knowledge gained through their training to date to manage this. The researcher will offer breaks and ask how the participant is where appropriate. If the researcher feels that continuing the interview further would be detrimental to the health and well-being of the participant, the researcher will stop the interview. At this point, or alternatively at the end of a completed interview, the researcher will give the participant a debrief sheet containing contact information for further support.

Participants may be reluctant to answer demographic information and be uncomfortable in doing so. They will be reminded in the participant information sheet and at the beginning of the interview that they do not have to answer anything they do not wish to. The demographic information that is gathered has been chosen in conjunction with the project supervisors to represent the most essential information needed in respect of the research project aims.

**Data storage:** Paper consent forms will be scanned at the first available opportunity to produce electronic copies. The electronic copies will be uploaded onto the Lancaster University's secure network using a Virtual Private Networking (VPN) system accessed by the researcher's home computer. Paper copies of consent forms will then be destroyed. This information will only be accessed by the Chief Investigator. Any additional forms collected containing identifiable information of the participant will be destroyed/ deleted once the research has been completed and participants who requested a summary of the findings have been contacted. Similarly this information will be destroyed immediately if participants decide to withdraw from the study. All interviews will be recorded on a digital audio recording device and will be uploaded the same day of the interview onto the secure (encrypted and password protected) university network which may be accessed via the researcher on their home computer using the VPN. Once the recording is uploaded it will be deleted from the recording device. The audio file will then be transcribed into an anonymised transcript within 3 months of the interview date and then deleted from the secure network. The anonymised transcript will then be uploaded and stored on to secure network and accessed by the Chief Investigator on their home computer during the analysis stage. The academic supervisor will also have access to the recordings/ transcripts where it is deemed necessary in the supervision of the research project. Following the submission of the report, in line with the Lancaster University Doctorate in Clinical Psychology guidelines, electronic copies of the transcripts will be made and stored, along with scanned copies of the consent forms and any coded data produced in the analysis, on the secure network for up to 10 years. After this time the all this data will be deleted.

**Withdrawal:** The participants will be made aware that they are free to withdraw from the study at any point up to 2 weeks after their interview date. At this point it is likely that the data will have been anonymised, transcribed and incorporated into the analysis. If they wish to withdraw before this date, all their data and information will be deleted/ destroyed. They will also be reminded in the consent form that choosing to withdraw from the research will not have

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any impact on their future involvement in NHS services.

To protect the anonymity of the participants during the data analysis and write up stages, the participant name will be replaced with a pseudonym. Participants will be given the option of choosing this name themselves. Any additional names used will also be removed and replaced with pseudonyms or professional title names. Therefore the transcripts will not contain any identifying information.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

Yes  No

*If Yes, please give details of procedures in place to deal with these issues:*

The researcher will be guided by the participant at these points and continue with the interview schedule where appropriate. The participant will be told in the information sheet that they do not have to answer any questions they do not wish to and that they are free to pause or discontinue the interview at any point if they feel they need a break or do not want to carry on with the interview. This will be reiterated by the researcher before the interview starts. If the participant does appear to become distressed or upset during the interview, the researcher will use their clinical skills and knowledge gained through their training to date to manage this. The researcher will offer breaks and ask the participant how they are where appropriate. If the researcher feels that continuing the interview further would be detrimental to the health and well-being of the participant, the researcher will stop the interview. At this point, or alternatively at the end of a completed interview, the researcher will give the participant a debrief sheet containing contact information for further support.

In order to manage any risk or safeguarding issues that arise during the interview it may be necessary for the researcher to act immediately on information received. Discussion of this will be made with the field supervisor and information shared with appropriate agencies where necessary. The details of this are included in the participant information sheet and will be discussed during the consent process.

**A24. What is the potential for benefit to research participants?**

There are no direct benefits to the participant in taking part in the research. Although some people sometimes like the opportunity to talk about their experiences. This information will be contained within the participant information sheet.

**A26. What are the potential risks for the researchers themselves? (if any)**

The researcher may be at risk during lone working home visits. The researcher has completed relevant mandatory training, including conflict resolution and breakaway training. The researcher will adhere to the Lancashire Care NHS Foundation Trust lone working policy to help protect their safety during home visits.

Risks to the researcher privacy will be minimised by the researcher using a research mobile phone and not giving out any personal details to the participant. It is a possibility that the researcher may find the content of the research data distressing, both during collecting and analysing interview data. The researcher will remain aware of these issues throughout the study and use their skills to remain resilient. However if the researcher does feel effected by the research data, they will discuss this with their supervisor.

**RECRUITMENT AND INFORMED CONSENT**

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).**

The field supervisor will identify eligible potential participants through the outpatient clinic that take place at the Transplant Unit. In this instance, the field supervisor will give out the participant information pack to the potential participant. In addition to this, other staff will be asked to hand out information about the research to people who meet the inclusion criteria. Where the researcher is available to attend relevant clinics, they too will hand out packs to

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potential participants.

To maximise the number of potential participants reached, Advertising material will be produced and disseminated in print and electronic format, including a Lancaster University hosted webpage.

To begin with, participants will be recruited from the site hospital Transplant Unit. However, if at the target recruitment number of participants has not been reached by the end of the first recruitment phase (4 weeks) the following recruitment strategy will be implemented:

- Recruitment Phase 2 (4 weeks) Recruitment will be expanded to second site hospital Transplant Unit. In addition to this, advertisements will be posted on online social media platforms (e.g. twitter and facebook). Advertisements on Twitter will use the DClinPsy (@LancsDClinPsy) and Division of Health Research (@LancsDHR) Twitter feeds. The researcher will also make use of their personal (exclusively professional use) social media accounts, and will ask relevant organisations to share information about their study. Relevant organisations will be contacted via the lead researcher's professional university email address where the researcher will seek permission of forum moderators to advertise the study.
- Recruitment Phase 3 (4 weeks) Widen inclusion criteria to include other family members not exclusive to partner.

Contained within participant information packs will be a consent to contact form. Participants will be asked to complete this and send it in a freepost envelope to the researcher. Alternatively, if they would prefer to contact the researcher themselves, they will also be given the option to do so by calling the researcher on their research mobile or emailing them at their university email address.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

Yes  No

Please give details below:

To assess whether the potential participant is eligible for the research study, members of the clinical care may have access to identifiable information.

**A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected. Please consult the guidance notes on this topic.**

To protect the confidentiality of the potential participant before they are recruited, the Chief Investigator will not have sight of their information until they have explicitly expressed an interest in taking part in the study by completing and returning a consent to contact form or contacting the researcher themselves. Once they have been recruited, only the Chief Investigator will know the information of those who are taking part. There are a few exceptions to this. One will be if the participant wishes to complete the interview at the Transplant Unit, those staff working there may infer that they are taking part. Participants will be made aware of this in the participant information sheet. Another will be where the participant discloses information that leads the researcher to believe that their, or another person's, health and safety are at risk. In these cases, the researcher may need to contact their supervisors for further advice and may potentially need to contact an outside authority. Participants will be made aware of this in the participant information sheet and will agree to this in the consent form. Finally, the participants details may be accessed by a nominated professional peer if they are concerned about the researcher's safety during a home visit. A 'buddy' system will be used for lone working whereby the researcher will give their buddy a sealed envelope containing the location of the interview and a time in which they will be calling them to confirm they are safe following the interview. If the researcher does not get in touch at this time and the buddy can not make contact with them, the buddy will open the envelope and make contact with the may contact the emergency authorities to pass on their concern. If the researcher does contact their buddy at or before the agreed time, the buddy will keep the envelope sealed and give it back to the researcher at the soonest available time. The researcher will then destroy the envelope.

**A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?**

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 Yes  No**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?** Yes  No

*If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).*

Advertising material will be produced and disseminated in print and electronic format. Posters will be put up at the Transplant Unit. Online advertisements will be posted on various platforms including social media (facebook and twitter) and a Lancaster University hosted webpage.

Advertisements on Twitter will use the DClinPsy (@LancsDClinPsy) and Division of Health Research (@LancsDHR) Twitter feeds. The researcher will also make use of their personal (exclusively professional) Twitter account, and will ask relevant organisations to tweet about their study. Relevant organisations will be contacted via the lead researcher's professional university email address.

**A29. How and by whom will potential participants first be approached?**

Potential participants will first be approached either by the field supervisor, or by a member of the Transplant staff team. The field supervisor will give out an information pack to the potential participants. The nursing staff will hand out an information pack to the potential participant during nurse-led appointments.

**A30-1. Will you obtain informed consent from or on behalf of research participants?** Yes  No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

Participants will be required to read a participant information sheet before they give informed consent. They will be encouraged to ask any questions they have before they give consent about the study. Once these questions have been answered satisfactorily, the researcher will continue to obtain informed consent. The researcher will give the participant the consent form to read and complete. This will contain 13 points with a box to sign their initials to agree to each point. They will then sign, print their name and write the date at the bottom of this consent form. The researcher will also sign, print their name and date at the bottom of this consent form.

*If you are not obtaining consent, please explain why not.*

*Please enclose a copy of the information sheet(s) and consent form(s).*

**A30-2. Will you record informed consent (or advice from consultees) in writing?** Yes  No**A31. How long will you allow potential participants to decide whether or not to take part?**

Up to the last day in June 2017

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**



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Only participants who fully understand the study information and the implications of their participation will be recruited into this study. Due to funds not being available for this project, those participants who require an interpreter to take part, or any study documents to be translated will not be deemed eligible.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

Where it becomes apparent during the research process that the participant no longer has capacity to consent the participant will be withdrawn from the study. Subject to ethical approval, data that has been already collected and anonymised may be used for the purposes for which consent has already been given.

#### CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

#### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)**

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
- Manual files (includes paper or film)
  - NHS computers
  - Social Care Service computers
  - Home or other personal computers
  - University computers
  - Private company computers

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 Laptop computers*Further details:*

Participants will be asked to provide their name, address, contact number and email address on a consent to contact form. If participants choose to phone or email the Chief Investigator, this information will be asked for and written on to a consent to contact form at this point. The form will then be scanned into an electronic copy. The paper copy will be destroyed and the electronic copy will be uploaded on to the Lancaster University's secure network via a Virtual Private Network accessed by the Chief Investigator using their personal laptop. The Chief Investigator will contact participants using a research mobile phone provided by the Lancaster University Doctorate in Clinical Psychology programme. The call history of this phone will be deleted on any days that the principle investigator has used the phone to contact participants.

The participant's name, contact details and address will also be placed within a sealed envelope and given to the a 'buddy' identified by the researcher who will only open this envelope if they are concerned for the safety of the principle investigator during a home visit to the participant's address. Otherwise, the 'buddy' will return the sealed envelope at the soonest opportunity to the principle investigator who will destroy it.

Participant consent forms will be scanned at the first available opportunity to produce electronic versions which will be uploaded on to the university's secure network. Paper copies will be destroyed.

Direct quotations may be used in the write-up of this research project. Participants will provide consent for this when completing their informed consent. Interviews will be recorded using a digital audio recording device and uploaded on the same day onto the University's secure network. All files will be password protected. Participants will consent to having their interviews recorded in this way. The researcher will then delete the file from the electronic device. The audio files will then be accessed by the principle investigator and will be typed up into anonymised transcripts within 3 months of the interview date. Once this has been done, the principle investigator will delete the audio file from the secure network and upload the anonymised transcript on to the secure network. The Chief Investigator and the academic supervisor will have access to the audio files and anonymised transcripts during the analysis phase of the research project.

Once the research project has been submitted, the Chief Investigator will send encrypted password protected electronic copies of consent forms, transcripts and any coded data, to the research coordinator at Lancaster University. This will be sent using ZendTo file transfer software. The research coordinator will then transfer these files onto an space on the secure network accessible to them. In a separate email, the principle investigator will send the password for the encrypted data and the year which the files should be destroyed to the Research Coordinator. This date will be 10 years after the research project has been submitted, in line with the procedures outlined by Lancaster University Doctorate in Clinical Psychology programme.

**A37. Please describe the physical security arrangements for storage of personal data during the study?**

All personal data will be scanned to produce electronic copies which will stored on the Lancaster University secure network, which will be accessed by the Chief Investigator using their personal computer. This information will only be accessed by the Chief Investigator up to the point of the research project's submission. At the end of the study, and once those participant who wished to receive a summary of the findings have been contacted, the consent to contact forms will be deleted. The principle investigator will produce encrypted password protected electronic files of consent forms which will be sent to the research coordinator at Lancaster University using a ZendTo file transfer software. In a separate email, the principle investigator will send the password for the encrypted data and the year which the files should be destroyed to the Research Coordinator. This date will be 10 years after the research project has been submitted, in line with the procedures outlined by Lancaster University Doctorate in Clinical Psychology programme.

Interviews will be audio recorded. Since it is not possible to encrypt the portable audio recording device, the audio files will be uploaded to the Lancaster University secure network immediately for secure storage and sharing with supervisors where necessary. The audio files will then be deleted from the audio recorder. Where immediate transfer is not possible, the audio recorder will be locked away until the researcher can access a computer to transfer the file. All files will be saved to Lancaster University server as soon as possible. Audio files will be kept on the university server until the project has been marked and will then be deleted.

**A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.**

Each participant will be allocated a unique pseudonym at study entry and will be identified by this on all study related

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documentation throughout the course of the research. Any identifiable information given in the interview of the participant or other people or services will be anonymised. The participant and their partner will be given a pseudonym which will be used to refer to the participant in the analysis phase and in the write-up, including with any direct quotations that are used.

**A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.**

The principle investigator will have access to the participant's personal data during the study. This will only be accessed once a potential participant has consented to be contacted.

The academic supervisor will have access to audio recordings and anonymised transcripts to assist with the analysis of data. Participants will consent to this.

A nominated professional peer 'buddy' will have access to the participant's contact details if they are concerned about the safety of the Chief Investigator during a home visit. Participants will consent to this.

The field supervisor will have access to the participant's personal details where the principle investigator has contacted them in regards to receiving information related to risk or safeguarding concerns. Participants will consent to this.

#### Storage and use of data after the end of the study

**A41. Where will the data generated by the study be analysed and by whom?**

Data in the form of anonymised transcripts will be generated by the Chief Investigator. Anonymised interview transcripts and questionnaire data will be stored electronically on the university's secure network and will be only accessible to the principle investigator and the academic supervisor during the study up to the point the study is submitted. The Chief Investigator will analyse this data at their home address.

**A42. Who will have control of and act as the custodian for the data generated by the study?**

	Title	Forename/Initials	Surname
	Professor	Bill	Selwood
Post	Programme Director, Doctorate in Clinical Psychology, Lancaster University		
Qualifications	PhD		
Work Address	Division of Health Research Furness College, Lancaster University Lancaster		
Post Code	LA1 4YG		
Work Email	b.sellwood@lancaster.ac.uk		
Work Telephone	01524592858		
Fax	01524592401		

**A43. How long will personal data be stored or accessed after the study has ended?**

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

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**A44. For how long will you store research data generated by the study?**

Years: 10

Months:

**A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.**

Once the research project has been submitted, the Chief Investigator will send encrypted password protected electronic copies of consent forms, transcripts and any coded data, to the research coordinator at Lancaster University. This will be sent using ZendTo file transfer software. The research coordinator will then transfer these files onto a space on the secure network accessible to them. In a separate email, the principle investigator will send the password for the encrypted data and the year which the files should be destroyed to the Research Coordinator. This date will be 10 years after the research project has been submitted, in line with the procedures outlined by Lancaster University Doctorate in Clinical Psychology programme.

**INCENTIVES AND PAYMENTS****A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?** Yes  No

*If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.*  
If the participant wishes to complete the interview at the Transplant Unit they will be able to claim up to £20 for their travel expenses, following the guidelines outlined for reimbursing participant travel expenses developed by the Lancaster University Doctorate in Clinical Psychology programme.

At the point of arranging the interview, the researcher will ask for an estimate of the expense they will incur. At this point, if the participant intends to travel by public transport, the researcher will check whether they are able to provide the researcher with the receipts/tickets for their travel at the interview or whether they may need their ticket for the return journey. If they are unable to provide receipts/tickets at the interview, the researcher will explain that they would not be able to reimburse their expenses on the day of the interview. If this is the case, the participant will be asked to complete a business expense claim form and return it to the researcher in a free post envelope. When this is received, payment will be authorised and processed for payment. If the participant plans to travel by car, or are able to provide the receipt of travel on the day, they will be informed that they will be reimbursed on the day of the interview.

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?** Yes  No**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?** Yes  No**NOTIFICATION OF OTHER PROFESSIONALS****A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?** Yes  No

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If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

#### PUBLICATION AND DISSEMINATION

**A50. Will the research be registered on a public database?**

Yes  No

Please give details, or justify if not registering the research.  
Lancaster University hosted webpage

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- Peer reviewed scientific journals  
 Internal report  
 Conference presentation  
 Publication on website  
 Other publication  
 Submission to regulatory authorities  
 Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators  
 No plans to report or disseminate the results  
 Other (please specify)

**A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?**

Real names of participants and their partner will be replaced with pseudonyms. Wherever the participant refers to a professional or service within their interviews by name, this data will be removed in the transcripts. Any other identifiable personal data will be anonymised.

**A53. Will you inform participants of the results?**

Yes  No

Please give details of how you will inform participants or justify if not doing so.  
Participants will be asked whether they would like to receive a summary of the research findings after the research project has been submitted as part of the Chief Investigators course submission. At this point, the principle investigator will post/ email (depending on participant's preference) a 2-4 page summary of the findings to the participant along with a cover letter.

#### 5. Scientific and Statistical Review

**A54. How has the scientific quality of the research been assessed? Tick as appropriate:**

Independent external review

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- Review within a company  
 Review within a multi-centre research group  
 Review within the Chief Investigator's institution or host organisation  
 Review within the research team  
 Review by educational supervisor  
 Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

Peer review process: The project has been reviewed using a peer-review process set up on the Doctorate in Clinical Psychology programme at Lancaster University. Here a research proposal was discussed with a panel of peers, a course tutor and a member of the Service User panel.

The research proposal was then reviewed by the principle investigators research supervisor. The research proposal was then reviewed and approved by the Examinations Board.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.**

Total UK sample size: 8

Total international sample size (including UK):

Total in European Economic Area:

*Further details:*

**A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.**

Due to the qualitative nature of the study, it is important to recruit a sample size that allows for an in-depth, rich analysis of individual interview. Smith and Osborn (2007) argue that a relatively small sample size allows for the in-depth analysis required within an interpretative phenomenological analysis (IPA). Based on this, the following research will aim to recruit up to a maximum of 8 participants.

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

As the research study is aimed at understanding participants' experiences of supporting their partner through heart transplant, a qualitative methodology will be used. A qualitative method of enquiry allows for the use of semi-structured interviews to elicit detailed personal accounts of the individual's lived experiences (Clarke & Jake, 1998). The data gathered from interviews will be analysed using a qualitative design to enable a detailed look into the lived experiences of partner who have supported someone through heart transplant.

The chosen method of analysis will be Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This approach offers a flexible and accessible method for analysing qualitative data for themes and "takes an idiographic approach whereby insights produced as a result of intensive and detailed engagement with individual cases are integrated only at a later stage" (Willig, 2001, p.54). IPA was considered to be consistent with the epistemological position of the research question: to gain knowledge of how partners made sense of and ascribed meaning to their personal experiences by obtaining subjective accounts in context of the phenomenon under investigation (Smith & Osborn, 2007).

This approach appreciates that it is impossible to infer from the findings that the participant's lived experiences have been directly accessed and presented. Therefore, the approach recognises that the researcher's own interpretation of what the participant is sharing is an active component to the conclusions gathered. This acknowledges that the researcher's interpretations will largely be governed by their own world view along with the interaction between researcher and participant.

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## 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title	Forename/Initials	Surname
Dr			
Post	[REDACTED]		
Qualifications			
Employer			
Work Address			
Post Code			
Telephone	[REDACTED]		
Fax			
Mobile			
Work Email	[REDACTED]		

## A64. Details of research sponsor(s)

## A64-1. Sponsor

Lead Sponsor	
Status:	Commercial status:
<input type="radio"/> NHS or HSC care organisation <input checked="" type="radio"/> Academic <input type="radio"/> Pharmaceutical industry <input type="radio"/> Medical device industry <input type="radio"/> Local Authority <input type="radio"/> Other social care provider (including voluntary sector or private organisation) <input type="radio"/> Other	
<i>If Other, please specify:</i>	
<b>Contact person</b>	
Name of organisation	Lancaster University
Given name	Diane
Family name	Hopkins
Address	Research Services, B14 Furness College, Lancaster University,
Town/city	Lancaster
Post code	LA1 4YW
Country	UNITED KINGDOM

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Telephone 01524592838  
 Fax  
 E-mail ethics@lancaster.ac.uk

**Is the sponsor based outside the UK?**

Yes  No

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

**A65. Has external funding for the research been secured?**

- Funding secured from one or more funders  
 External funding application to one or more funders in progress  
 No application for external funding will be made

What type of research project is this?

- Standalone project  
 Project that is part of a programme grant  
 Project that is part of a Centre grant  
 Project that is part of a fellowship/ personal award/ research training award  
 Other

Other – please state:

**A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1)? Please give details of subcontractors if applicable.**

Yes  No

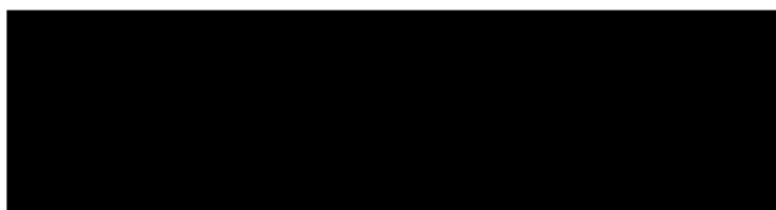
**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

Yes  No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

Organisation  
 Address





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Post Code  
Work Email  
Telephone  
Fax  
Mobile



Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 01/12/2016  
Planned end date: 01/02/2018  
Total duration:  
Years: 1 Months: 1 Days: 1

**A71-1. Is this study?**

- Single centre  
 Multicentre

**A71-2. Where will the research take place? (Tick as appropriate)**

- England  
 Scotland  
 Wales  
 Northern Ireland  
 Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

- Yes  No

**A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:**

- NHS organisations in England 2  
 NHS organisations in Wales  
 NHS organisations in Scotland  
 HSC organisations in Northern Ireland  
 GP practices in England  
 GP practices in Wales  
 GP practices in Scotland  
 GP practices in Northern Ireland  
 Joint health and social care agencies (eg community mental health teams)  
 Local authorities  
 Phase 1 trial units

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<input type="checkbox"/> Prison establishments <input type="checkbox"/> Probation areas <input type="checkbox"/> Independent (private or voluntary sector) organisations <input type="checkbox"/> Educational establishments <input type="checkbox"/> Independent research units <input type="checkbox"/> Other (give details)	
Total UK sites in study:	2

**A73-1. Will potential participants be identified through any organisations other than the research sites listed above?**

Yes  No

**A74. What arrangements are in place for monitoring and auditing the conduct of the research?**

Academic supervisor: Email updates on a fortnightly basis. Arrange face to face meetings on a monthly basis and increase frequency when needed. Feedback to field supervisor.

Field supervisor: Email updates on a fortnightly basis. Arrange face to face meetings every 6 weeks if agreed necessary. Feedback to academic supervisor.

**A76. Insurance/ indemnity to meet potential legal liabilities**

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (NHS sponsors only)  
 Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.*

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.**

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
 Other insurance or indemnity arrangements will apply (give details below)

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Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.***A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
 Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.***A78. Could the research lead to the development of a new product/process or the generation of intellectual property?**

- Yes  No  Not sure

**PART C: Overview of research sites**

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For further information please refer to guidance.

Investigator identifier	Research site	Investigator Name
IN1	<input checked="" type="radio"/> NHS site <input type="radio"/> Non-NHS site  Country: England  Organisation name Address  Post Code	Forename Middle name Family name Email Qualification (MD...) Country
IN2	<input checked="" type="radio"/> NHS site <input type="radio"/> Non-NHS site  Country: England  Organisation name Address  Post Code	Forename Middle name Family name Email Qualification (MD...) Country

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**PART D: Declarations****D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - ◊ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - ◊ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
  - ◊ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
  - ◊ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
  - ◊ May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

**Contact point for publication(Not applicable for R&D Forms)**

*NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.*

☛ Chief Investigator

IRAS Form

Reference:  
17/LO/0343

IRAS Version 5.4.0

- Sponsor
- Study co-ordinator
- Student
- Other – please give details
- None

**Access to application for training purposes (Not applicable for R&D Forms)***Optional – please tick as appropriate:*

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Jessica Morley on 26/01/2017 09:39.

Job Title/Post:        trainee Clinical Psychologist  
Organisation:        Lancaster University  
Email:                 j.morley2@lancaster.ac.uk

IRAS Form

Reference:  
17/LO/0343

IRAS Version 5.4.0

**D2. Declaration by the sponsor's representative**

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

*Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publicly accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 06/02/2017 12:01.

Job Title/Post:            Research Support and Systems Manager  
Organisation:            Lancaster University  
Email:                      b.gordon@lancaster.ac.uk

IRAS Form

Reference:  
17/LO/0343

IRAS Version 5.4.0

**D3. Declaration for student projects by academic supervisor(s)**

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

This section was signed electronically by Dr Craig Murray on 06/02/2017 12:33.

Job Title/Post: Senior Lecturer  
Organisation: Lancaster University  
Email: c.murray@lancaster.ac.uk



**Research Protocol (Version 2: 22.12.16)**

Study title: Experiences of Supporting a Partner through Heart Transplant

Researcher: Jessica Morley, Trainee Clinical Psychologist, Lancaster University

Supervisors: Research Supervisor: Craig Murray, Deputy Research Director, Senior Lecturer,  
Doctorate in Clinical Psychology, Lancaster University



Heart transplant involves the transplantation of a heart organ due to end of stage heart failure in the recipient. Internationally, an estimated 4,055 heart transplants take place per year (ISHLT International Registry for Heart and Lung Transplantation, 2015). The 2015/ 2016 annual report for cardiothoracic transplantation within the United Kingdom (UK) revealed that in March 2016, 248 patients were on the active heart transplant list. The report also found that over a ten-year period between 2006 and 2016, 3218 cardiothoracic transplants were made (NHS blood and transplant, 2016).

A transplant recipient can experience a vast array of emotions and challenges when undergoing the critical, acute and rehabilitation stages of the transplant journey. Coming to terms with their illness, waiting for a potential match and the acceptance of carrying someone else's organs can be a time of significant stress and difficulty (Sadala & Stolf, 2008). Heart transplant recipients have reported several negative feelings after transplant including fear, low-mood, guilt and grief (Sadala & Stolf, 2008; Kaba, Thompson, Burnard, Edwards & Theodosopoulou, 2005). The experience and diagnosis of psychological distress in the recipient post-heart transplant is therefore not uncommon (Dew & Di Martini, 2006).

For most recipients, this journey is not experienced in isolation from the partners and family members who are there to support and assist them on the way. In fact, the care from others, including

family and friends, has been considered by heart transplant recipients as an essential supportive resource in the face of psychological distress (Conway, 2013) and social support is often an eligibility criterion for receiving a transplant. The capacity to thrive through adverse life events has been linked with the presence and quality of social support (Feeney & Collins, 2014). Indeed, the social support given by partners/ family members has been associated with superior post-transplant outcomes in recipients, including rates of survival (Coglianese, Samsi, Leibo & Herox, 2015).

Partners play a major role in providing both physical and emotional support to their loved ones during heart transplant. Qualitative accounts suggest that partners are extremely interwoven into the transplant journey and describe themselves as co-participants (McCurry & Thomas, 2002). However, it may be challenging for partners to negotiate how much and what type of support will be the most beneficial for the transplant recipient (Conway, 2013). Given the responsibility partners have in the transplant journey, it is important to better understand their specific experiences and challenges they go through, for example, to ensure that they are adequately supported where needed.

Although the recipient's partner often provides support without question, they may as a result find the experiences physically, mentally and socially demanding (Ivarsson, Bodil, Björn Ekmehag & Trygve Sjöberg, 2014). Studies show that a lot of partners/ relatives feel unprepared to fulfil their supportive role adequately and often experience high levels of burn-out, stress and depression (Miyazaki et al., 2010; Ullrich, Jansch, Schmidt, Struber & Niedermeyer, 2004). From the time the patient is diagnosed with end stage heart failure, there may be significant disruptions and experiences of distress in the partner relationships while adjusting to the illness, including communication difficulties, intimacy concerns and difficulties with changing domestic roles (Dalteg, Benzein, Fridlund & Malm, 2011). During the waiting period, spouses for example, face significant levels of stress particularly related to the uncertainty and fear that their partner has a life-threatening diagnosis and may die whilst waiting for a donor organ (Collins, White-Willaims & Jalowiec, 1996). The strain on partners has been shown to continue post-transplant and can lead to a deterioration in the relationship (Bunzel, Laederach-Hofmann & Schubert, 1999) and an increased risk for developing depression and anxiety related disorders in the long-term (Dew et al., 2004).

Although receiving a transplant has been associated with increased stress and strain in both transplant recipients and their families, there is also evidence to suggest more positive experiences post-transplant. Posttraumatic growth (PTG) refers to a positive psychological change following a major life crisis or traumatic event (Tedesco & Calhoun, 1996; Tedeschi & Calhoun, 2004) to a point where the person may be “better than before” (Wu, Tang & Leung, 2011, pp. 91). These positive changes are typically observed in the way the person views themselves, their relationships and their philosophy of life (Tedesco & Calhoun, 1996). A growing body of literature has indicated PTG experiences in patients who have experienced potentially life-threatening illness, including cancer, heart disease, stroke, and HIV (Hefferon, Grealy & Mutrie, 1999) and more recently, transplant recipients (Tallman, Shaw, Schultx & Altmaier, 2010; Fox et al., 2014). Although it is difficult to determine whether or not a person will experience PTG following a traumatic event, some factors have been significantly associated with the phenomenon. These have included subjective beliefs; such as having purpose and meaning, demographic factors; such as social support, having paid work, stable relationships, spirituality and psychological health (Powell, Gilson & Collin, 2012; Grace, Kinsella, Muldoon & Fortune, 2015; Prait & Pietrantonio, 2009). Although being a partner to someone in these situations may be an equally stressful experience, there is evidence to suggest that those supporting a person through a life-threatening illness can too show PTG (Cadell, 2007).

The relatively small number of studies in relation to the experiences of supporting someone through heart transplant gives rise to the need for further exploratory research in this area. As the experiences of different family members may vary depending on their relationship to the transplant recipient, this study will focus specifically on the experiences of partners who have supported their loved one through heart transplant. The positive impact this care has on the health and well-being of the transplant recipient has drawn attention to the need to better understand the experiences and needs of these people. To ensure partners can offer the best support they can, it is important to understand how the transplant journey specifically impacts on them. In addition to this, exploring the potential for PTG in this population would be a valued initial investigation into this area of study. As this is a subject area where there is relatively little research, the opportunity to conduct a qualitative study presents itself, results of which will be useful to increase understanding of how partner of transplant

recipients specifically experience supporting someone through the transplant journey. Findings from this could also potentially be helpful in highlighting the importance of working systemically with transplant recipients and their family and provide guidance on how partners could be best supported through this process to promote long-term adjustment.

Therefore, the primary research question of this study is to explore the experiences of partners who have supported someone through heart transplant. The aim of this will be to provide insight into then potential costs and benefits associated with this experience from a qualitative point of view. This insight would potentially also have important implications for psychological services protocol and service delivery within cardiothoracic transplant units and in wider health and social care domains.

## **Method**

### **Design**

As the research study is aimed at understanding participants' experiences of supporting their partner through heart transplant, a qualitative methodology will be used. A qualitative method of enquiry allows for the use of semi-structured interviews to elicit detailed personal accounts of the individual's lived experiences (Clarke & Jake, 1998). The data gathered from interviews will be analysed using a qualitative design to enable a detailed look into the lived experiences of a partner who have supported someone through heart transplant.

The chosen method of analysis will be Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This approach offers a flexible and accessible method for analysing qualitative data for themes and "takes an idiographic approach whereby insights produced as a result of intensive and detailed engagement with individual cases are integrated only at a later stage" (Willig, 2001, p.54). IPA was consistent with the epistemological position of the research question: to gain knowledge of how partners made sense of and ascribed meaning to their personal experiences by obtaining subjective accounts in context of the phenomenon under investigation (Smith & Osborn, 2007).

This approach appreciates that it is impossible to infer from the findings that the participants' experiences have been directly accessed and presented. Therefore, the approach recognises that the researcher's own interpretation of what the participant is sharing is an active component to the

conclusions gathered. This acknowledges that the researcher's interpretations will largely be governed by their own world view along with the interaction between researcher and participant.

Due to the qualitative nature of the study, it is important to recruit a sample size that allows for an in-depth, rich analysis of individual interview. Smith and Osborn (2007) argue that a relatively small sample size allows for the in-depth analysis required within an interpretative phenomenological analysis (IPA). Based on this, the following research will aim to recruit up to a maximum of 8 participants.

### **Participants**

The study will aim to recruit up to 8 partners of people who have had a heart a transplant. Participants will be appropriate for inclusion in the study if they meet all of the following criteria;

Inclusion criteria:

- Participant identifies as supporting the transplant recipient through their transplant
- Participant identifies as being in a relationship (married and/or cohabiting) with the transplant recipient for at least a year and during the transplant process.
- The transplant recipient received a heart transplant within the last 6 months to 10 years
- Transplant recipient is still currently alive

Exclusion criteria:

- Those who require an interpreter to engage in an interview.

Potential participants who meet these inclusion criteria will be identified in collaboration with the field supervisor through the services routine outpatient clinics. In addition to this, nursing staff will be asked to hand out information about the research to people who meet the inclusion criteria when patients are attending nurse-led appointments. In order to maintain awareness amongst staff of the research project, where possible, the researcher will be present in the department before the outpatient clinic starts in order to introduce themselves and offer a summary of participant inclusion

criteria to the nurses involved with outpatient clinics. To maintain the confidentiality of the patients and partners who are identified at this stage, the researcher will not have sight of the potential participant's information until an expressed interest of the potential participant has been received.

Advertising material will be produced and disseminated in print and electronic format and posted on various platforms including a Lancaster University hosted webpage and the Hospital Newsletter (see Appendix 4-C).

If participants are eligible to take part, they will be interviewed on a first come basis until reaching the target recruitment. However, if the researcher is inundated with eligible participants in one go, they will select the most homogenous sample (in consistency with the chosen method of analysis) in terms of time since transplant was received.

### **Materials**

A brief demographic information questionnaire designed by the researcher (see Appendix 4-F) will be administered at the start of the interview to gain a basic overview of demographic information.

A semi-structured interview schedule has been devised (see Appendix 4 - D). The interview has been developed in respect of the research aims, the related research literature and in conjunction with the feedback from a service user. The interview schedule consists of a series of open-ended questions that are aimed at covering the main topic areas pertinent to eliciting participants' descriptions of their experiences of supporting their partner through heart transplant. The aim of the interview schedule is to introduce discussion within specified topic areas whilst allowing for the researcher to be guided by the participant's responses and issues raised by them as the interview proceeds. It is intended that the interview will last approximately 1 hour and will be recorded on a digital recorder. Each interview recording will be given a participant pseudonym to maintain anonymity.

### **Procedure**

Those participants who are identified to meet the inclusion criteria will be given an information pack by a member of the Transplant team. This will include a covering letter, a participant information sheet (see Appendix 4 - A ), a consent to contact sheet (see Appendix 4 - B) and a freepost envelope

addressed to the researcher. The covering letter will request those interested in taking part to contact the researcher by returning the consent to contact sheet or by contacting the researcher on the telephone number (specifically provided for the research study by Lancaster University Doctorate in Clinical Psychology Department) or university email provided. The option will also be made available for the potential participant to contact the field supervisor directly if they would prefer to talk to them in the first instance about taking part in the research project.

Once the researcher has been contacted by the potential participant, they will discuss over the phone any questions the potential participant has about the study. Once these have been satisfactorily answered, and if the potential participant wishes to continue with recruitment, a mutually convenient time for interview will be arranged. The participant will have the option of completing the research interview in a room at the Transplant Unit, at home (provided that they can offer a space in which the interview can proceed uninterrupted for the duration and provided they live in the North West of England, UK), over the phone, or over Skype. Skype interviews are not wholly secure due to the nature of the platform. However, Skype have an encryption process in place and further information around Skype's security can be found at: <https://www.skype.com/en/security/#encryption>. Participants will be informed of this in the participant information sheet and consent form.

If the participant wishes to complete the interview at the Transplant Unit, the researcher will ask for an estimate of the expense they will incur to travel to and from the interview. At this point, if the participant intends to travel by public transport, the researcher will check whether they are able to provide the researcher with the receipts/tickets for their travel at the interview or whether they may need their ticket for the return journey. If they are unable to provide receipts/tickets at the interview, the researcher will explain that they would not be able to reimburse their expenses on the day of the interview. If this is the case, the participant will be asked to complete a business expense claim form and return it to the researcher in a freepost envelope. When this is received, payment will be authorised and processed for payment. If the participant plans to travel by car or are able to provide the receipt of travel on the day, they will be informed that they will be reimbursed on the day of the interview.

For interviews that take place in the participant's home the researcher will adhere to the Lone Worker Policy of Lancashire Care NHS Foundation trust (See Appendix I; HS 007). In practice this will include:

1. Completing the relevant mandatory training
2. Using a 'Buddy' system to check in and out of home visits and to raise an alarm if concern arises
3. Following the policies guidelines on taking reasonable care for own health and safety before, during and following home visits.

At the start of the research interview appointment the researcher will begin by presenting and discussing with the participant a participation consent form (see Appendix 4 - E) which the participant will be required to agree to and sign before the interview commences.

Before the interview commences the participant will be reimbursed up to £20 travel expenses incurred. They will be asked to provide the ticket of travel and will be asked to complete 2 copies of the payment receipt. If they require the receipt/ ticket for an onward journey, they will be given a business expense claim form and a free post envelope to complete and send back when their journey is complete. Following this, the participant will be asked to complete the demographic information form (Appendix 4 - F). The digital recorder will then be switched on and the researcher will open the recording with the participant pseudonym, date and time of interview, and researcher name. The researcher will then commence with the interview using the interview schedule (Appendix 4 - D) which is planned to last approximately 1 hour.

After the interview, participants will be given a debrief sheet (see Appendix 4 - G) and be informed about the process of receiving a summary of the research findings if they have expressed an interest. If they have agreed to the latter, the researcher will post out a 2 to 4-page summary of this to the participant after the research project has been submitted along with a cover letter.

All interview data will be transcribed verbatim into anonymised transcripts within 3 months of the interview date.

### **Data storage**



At the first opportunity, the consent forms will be scanned in and stored electronically on Lancaster University's secure network using a Virtual Private Networking (VPN) system. This information will only be accessed by the researcher. Paper copies of consent forms will be then destroyed. Any additional forms collected containing identifiable information of the participant will be destroyed/ deleted once the research has been completed and participants who requested a summary of the findings have been contacted. Similarly, this information will be destroyed immediately if participants decide to withdraw from the study up to 2 weeks after their interview date. All interviews will be recorded on a digital recording device and will be uploaded the same day of the interview onto the secure encrypted password protected university network which may be accessed via the researcher on their home computer using the VPN. Once the recording is uploaded it will be deleted from the recording device. The audio file will then be transcribed into an anonymised transcript within 3 months of the interview date and then deleted from the VPN. The anonymised transcript will then be uploaded and stored on to VPN and accessed by the researcher on their home computer during the analysis stage. The academic supervisor will also have access to the recordings/ transcripts where it is deemed necessary in the supervision of the research project.

Following the submission of the report, in line with the Lancaster University DCLinPsy guidelines, electronic copies of the transcripts, consent forms, and coded data will be encrypted and sent to the Research Coordinator using ZendTo file transfer software. The Research Coordinator will then save these files in password-protected file space on the university server. The researcher will also send an email to the Research Coordinator with the password for any encrypted files, the end date of the study and the year that the data should be deleted/ destroyed. This is normally 10 years after submission.

### **Proposed analysis**

#### **Procedure**

Interview transcripts will be analysed using IPA (Smith, Flowers & Larkin, 2009). As such, a series of steps will be taken to analyse the data in this way: This will involve the researcher engaging with each transcript in an open and then systematic way to identify thematic labels. These themes will

then be clustered into categories of shared meanings. After which the findings from each transcript will be integrated to obtain a more generalised understanding of these experiences.

### **Credibility in Analysis**

Several steps will be put in place in order to uphold the trustworthiness and credibility of the findings. This will include constructing an audit trail where the emergent qualitative findings can be shown to be representative of the original raw data and be inclusive of all participant data sets (as described by Wolf, 2003). This will involve the researcher reading through and comparing the original transcripts to the initial analysis. In collaboration with the academic supervisor, considerations will then be made, where necessary, to incorporate alternative interpretations before the final interpretations are agreed upon. A 'paper trail' will be kept, whereby the process of producing interpretative findings can be traced back to the original transcripts.

IPA recognises the impact of the researcher on the construction of this knowledge and considers the influence their standpoint will have on shaping the research and interpreting the data (Smith, Larkin & Flowers, 2009). This relates to the process of 'double hermeneutics' whereby the participant interprets their experiences which are in turn interpreted by the researcher (Giddens, 1996). The researcher must therefore adopt a position of reflexivity within the research: they must strive to be aware of their own feelings and expectations in relation to the interpretation of the results and identify and 'bracket' these assumptions in order to privilege the viewpoints of the participants during the analysis (Alvesson & Sköldberg, 2009). Therefore, in addition to this the researcher will keep a detailed reflective log throughout the study to capture ideas on patterns, codes and themes and consider the researcher's own position in regard to the data and emerging findings.

### **Contingency plan**

To begin with, participants will be recruited from the first site hospital Transplant Unit. However, if at the target recruitment number of participants has not been reached by the end of the first recruitment phase (4 weeks) the following recruitment strategy will be implemented:

- **Recruitment Phase 2 (4 weeks)**

Recruitment will be expanded to second site. This will follow an identical recruitment strategy to the first site, whereby the field supervisor will give out participant information packs to potential participants.

In addition to this, a secondary recruitment avenue will use online platforms including social media. The chief investigator will upload the recruitment poster onto their personal (exclusively professional) twitter and Facebook page requesting others who see the post to share (e.g. other trainee clinical psychologists). Charities and networks will be contacted by the researcher using email (University email account) and provided with a copy of the participant information sheet, along with any other information they may wish to review before making a decision about advertising the study. If the organisation agrees to assist with recruitment, they will be provided with electronic copies of recruitment poster and participant information sheets. They will be asked to advertise the study through available channels including webpages; online forums; associated social media (including Facebook pages and Twitter accounts); newsletters; and noticeboards in waiting rooms (if applicable). The chief investigator will “tweet/re-tweet” adverts from charities and networks using their personal (professional use only) twitter and Facebook account in order to further share the advert. Posters and information sheets will contain the contact information for the researcher. Participants will then contact the researcher by email or telephone if they are interested in taking part.

- **Recruitment Phase 3 (4 weeks)** Widen inclusion criteria to include other family members not exclusive to partner.

#### **Practical issues**

Where the participant chooses to be interviewed at the Transplant Unit, a room will be booked which will be arranged in collaboration with the field supervisor. As discussed above, where the participant chooses to be interviewed at home, the researcher will adhere to the LCFT lone working policy. For example, this will involve using a ‘Buddy’ system. A colleague will be nominated who will be aware of the timing of the researcher’s home visit. They will be given a sealed envelope containing the address at which the interview is taking place, the name of the participant and their contact details. The researcher will ‘check-out’ with their nominated buddy by ringing them at an agreed time. Once the researcher has contacted their buddy after the interview to confirm their

safety, the buddy will return the envelope unopened to the researcher and the researcher will destroy it. If the researcher does not contact the buddy at the agreed time, the buddy will open the envelope and contact the authorities indicating their concern for the researcher. Participants will be asked to consent to contact details being shared in this way to ensure researcher safety. Where a participant is interviewed over the phone, they will be asked to complete the consent forms and send back in advance of the interview.

All photocopying and postage will be paid for by Lancaster DClinPsy course. All electronic equipment, including a research mobile phone, will also be supplied and paid for by the course. Participants will be reimbursed for their travel expenses when attending a research appointment at the Transplant Unit, the costs of which will again be covered by the course.

### **Ethical issues**

As the participant may potentially comment on individual professionals and service delivery it will be important to consider how this will be managed. The participant will be asked within the interview schedule to refer to any professionals by their professional title and avoid using names. Where names have been referred to, these will be anonymised within the transcripts. Any additional information that is contained within the transcripts that could potentially identify the participant, the service and professionals within the service will also be removed/ anonymised. Raw research data will not be accessible to professionals within the transplant team.

Participants may be resistant to providing demographic data at the start of the interview. Participants will be reminded that they do not have to answer any questions they do not feel comfortable in doing so and will be given the option to refrain from providing this information.

Due to the nature of the study, interviews will be targeted around exploring participants' experiences of potentially upsetting events. This could potentially lead to participants showing signs of stress during the interview process. Prior to interviewing, participants will be reminded that they are free to withdraw at any time up to 2 weeks after their interview date. They are also informed that they are free to discontinue or have a break from the interview if they feel they need to. Where the participant appears to become distressed or upset during the interview the researcher will employ the skills and knowledge they have developed through their clinical psychology training to date to contain

and reduce the distress occurring. The researcher will offer breaks to the participant and will ask the participant how they are. Where participants become distressed to the point where it seems that participating further will be detrimental to their psychological well-being, the researcher will terminate the interview. Participants will be given a debrief sheet (Appendix 4 - G) after the interview which will contain a list of contacts for sources of further support.

In order to manage any risk or safeguarding issues that arise during the interview it may be necessary for the researcher to act immediately on information received. Discussion of this will be made with the field supervisor and information shared with appropriate agencies where necessary in line with the relevant hospital policies and procedures. This information is included in the participant information sheet and will be discussed during the consent process.

Risks to the researcher will be minimised by the means discussed above. This includes using a research mobile phone and not giving out any personal details to the participant. Where home visits are conducted, adherence to the relevant lone working policies will be conducted. It is a possibility that the researcher may find the content of the research data distressing, both during collecting and analysing interview data. The researcher will remain aware of these issues throughout the study and use their skills to remain resilient. However, if the researcher does feel effected by the research data, they will discuss this with their supervisors. The field supervisor will offer clinical supervision where requested.

### **Timescale**

Dec 2016- Submit to ethics process

Once ethical approval has been gained time scale will be as follows (adjust appropriately according to when approval received):

Jan 2017 – Begin recruitment (phase 1: 4 weeks; phase 2: 4 weeks, phase 3: 4 weeks)

Jan – April/ May 2017 – Data collection and begin transcription

June 2017 – end recruitment

July 2017– Complete transcription and analyse data

Aug 2017 – Nov 2017 – Write up and draft reads

Dec 2017 – Submit report

Jan 2018 – Feedback summary of findings to participants

March 2018 – Submit paper for publication

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**Appendix 4 – A: Participant Information Sheet (Version 3)**

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**Research Study: Experiences of supporting a partner through heart transplant.****Participant Information Sheet**

You are being invited to take place in a research study. Before you continue it is important that you understand why the study is taking place and what will be involved in you taking part. Please read through the following Information Sheet and let the researcher know if you have any questions or if you would like some more information about anything which you are not sure about.

**Who is carrying out the study?**

The study will be carried out by Jessica Morley, Trainee Clinical Psychologist, as part of a Doctorate in Clinical Psychology at Lancaster University.

**What is the study about?**

The purpose of the study is to talk to partners of people who have had a heart transplant in the last 6 months to 10 years. The study is interested in how partners experience supporting their loved one through this process. We hope that this will help inform how we can better support partners of recipients through the transplant journey for their own well-being and for the well-being of their partner.

**Do I have to take part?**

No. Taking part in this research is entirely up to you. Deciding not to take part will not affect your relationship with the Transplant Unit team. The researcher is aiming to speak to up to 8 people. If you do take part you are free to withdraw up to 2 weeks after your interview, the data you provided will be destroyed and not be used for the study. However, after this point your data will remain in the study. You will not have to provide a reason for why you wish to withdraw.

**What is involved if I decide to take part?**

If you agree to take part you will be asked to attend in a research interview. The interviews will be arranged with you and can be completed in person at the Transplant Unit, or at your home (if based in the North-West of England) or via Skype or telephone. Please note that Skype interviews are not wholly secure due to the nature of the platform. However, Skype have an encryption process in place and further information around Skype's security can be found at: <https://www.skype.com/en/security/#encryption>

Firstly, we will ask you to sign a consent form to take part. You will then be asked to complete a short questionnaire which will include asking you for factual information about your partner's transplant. You will then be asked to take part in an interview, lasting approximately 1 hour that will be audio-recorded. The interview will focus on your experiences of supporting your partner throughout the transplant journey. If you choose to take part you do not have to answer any question that you feel uncomfortable answering. You are free to stop the interview without giving a reason at any point if you need a break or would like to finish.

**Where can I access further support?**

If you feel that you or your partner need further support during this study the researcher will also be able to direct you to the most appropriate support service.

**Are there any benefits or risks?**

We do not anticipate any risks in taking part in the research study. However, it is possible that talking about your experiences may be upsetting. Should this be the case, you do not need to continue with the interview and the researcher will provide you with information about how to access any further support. There are no direct benefits in taking part in the research although some people like the opportunity to talk about their experiences. It is hoped that the information gathered for the study will help improve services in the future.

**How will you protect my privacy?**

If you choose to take part in the study your personal details will be treated as confidential and will be destroyed after you have taken part in the research. If you do choose to complete your interview in a room at the Transplant Unit those people who work for the service may realise that you are taking part in the research.

If you choose to take part, all of your names and any other personal information, including that of your partner, will be removed and replaced with different names. Your data will be stored securely at all times.

If the researcher becomes concerned that you or anyone else is at risk of harm I may have to share my concerns with someone else who may be able to help. In most instances this is likely to be my supervisors. I will discuss this with you beforehand.

### **What will happen to my data?**

Any information that contains your personal information will be treated confidentially and will be stored securely at Lancaster University. Following the interview, the researcher will type up your responses as anonymous scripts. All the anonymised scripts and consent forms will be scanned and stored electronically on a secure network at Lancaster University network for up to 10 years. The final write-up will be submitted to Lancaster University as part of the Doctorate in Clinical Psychology. Anonymised direct quotes may be used in the write-up of this study.

### **Who is organising the study?**

The study is being organised jointly by Lancaster University and University Hospital of South Manchester NHS Foundation Trust. This study has been reviewed and been considered for approval by an NHS Ethics Committee. The research project is supervised by [REDACTED]

[REDACTED] *Dr Craig Murray (Division of Health Research, Lancaster University; 01524 592 730; c.murray@lancaster.ac.uk)*

### **Will I have my travel expenses covered?**

You will be paid for your travel expenses for up to £20. Please bring your receipts. In addition to this, reasonable mileage expenses will also be paid.

### **What do I do if I want to participate?**

If, after reading this information, you are interested in taking part in the research or would like to ask any questions please **complete and return the enclosed contact information form**

Alternatively, please leave your name and contact information in a message on my research mobile phone below and I will return your call:

***Jessica Morley (Trainee Clinical Psychologist)***

██████████

Or email: [j.morley2@lancaster.ac.uk](mailto:j.morley2@lancaster.ac.uk)

Due to the nature of the study, the researcher has a set number of participants they are aiming to recruit. If the researcher has already recruited this amount of people, they may contact you to explain that you will not be able to take part. If the researcher has a large amount of interest at once they will recruit participants whose partners have had a transplant most recently.

**Who do I contact if I have any concerns or complaints about the study?**

***Professor Bill Selwood (Programme Director)***

Phone: 01524 593 998

Email: [b.sellwood@lancaster.ac.uk](mailto:b.sellwood@lancaster.ac.uk)

Address: Division of Health Research, Furness College, Lancaster University, Lancaster, LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate programme, you may also contact

***Professor Roger Pickup (Associate Dean for Research)***

Phone: 01524 593746

Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)

[Address: Faculty of Health and Medicine, Division of Biomedical Life Sciences, Lancaster University, Lancaster, LA1 4YG](#)

***Professor Bruce Hollingsworth (Head of Department)***

Phone: 01524 594154

Email: [b.hollingsworth@lancaster.ac.uk](mailto:b.hollingsworth@lancaster.ac.uk)

[Address: Division of Health Research, Furness College, Lancaster University, Lancaster, LA1 4YG](#)

***Patient Advice and Liaison Service (PALS)***

PALS offers confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers. You can find your nearest PALS office on the NHS choices website. You can also ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS.

***Thank you for taking the time to read this Information Sheet***

**Appendix 4 – B: Consent to Contact Sheet (Version 3)**



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**Consent to Contact Form**

Thank you for taking the time to read the information about this study.

If you would like more information about the study and/ or you are interested in taking part please complete and return the contact information below

I would like to take part in the study:

Name:

.....

Address:.....

.....

Contact telephone number:.....

Best time to contact:.....


Is it appropriate to leave a message? Y/ N

Email address:.....

Many thanks,  
 Jessica Morley  
 Trainee Clinical Psychologist



## Appendix 4 – C: Study Advertisement (Version 2)



**We would like to invite you to take part in our research study**

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**The experience of supporting a partner through heart transplant**

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- Have you supported your partner through heart transplant?
- Was that transplant within the last 6 months to 10 years?
- Would you like to **share your experiences** of this and help with a **research study**?

We are looking for **people** who have **supported their partner through heart transplant** to help us with a project.

We are interested to learn more about **what this experience was like from your point of view**

If you would like more information or would like to take **part** please get in contact with the researcher:

**Jessica Morley**  
j.morley2@lancaster.ac.uk  
[REDACTED]

**Appendix 4 – D: Interview Schedule (Version 2)****Interview Schedule**

**Research Title:** Experiences of Supporting a Partner through Heart Transplant

Before the interview begins the interviewer will spend 10-15 minutes going over the participant information sheet with the participant and answering any questions they have at this stage. Once this is complete the researcher will continue with the consent process, going over the participant consent form and asking the participant to sign where necessary. At this point they will also be asked to change the names of anybody they may refer to in the interview and refer to professionals by their professional title. Participants will be asked at this point if they would like to provide a pseudonym or would prefer the researcher to allocate them one after the interview. Participants will be reminded that the interview will cover topics that may be upsetting to talk about. Participants will be reminded that they are free to stop the interview at any point if they feel they are becoming distressed and that they are under no obligation to answer any questions they do not feel comfortable in doing so.

The participant will then be asked to complete a brief demographics questionnaire.

Following this the interview will begin. The researcher will switch the audio recorder on and open the recording with the participant ID, date and time, and name of researcher. The researcher will explain what aim of the research interview, emphasising that they are interested in the participants own experiences and that there are no right or wrong answers.

*The interview schedule overleaf gives an example of the types of questions that will be asked in regards to the broader topic areas. This is intended to be used flexibly and allow for the researcher to ask additional questions in relation to any different topics raised by the participant:*

End of interview.

Following the interview, the participant will be given the debrief sheet and thanked for their time. They will be given their copy of the consent form. If the participant is displaying any distress at the end of the interview the researcher will use their skills developed through training to contain and manage this. The researcher will ensure the participant is aware of how to seek support if they feel this is necessary.

Finally, the researcher will confirm whether the participant would like to receive a summary of the findings after the study is completed. This will be noted on the participants contact details sheet.

**Prompts:**

- *Thoughts? Feelings? Way you behaved.*
- *What was that like for you?*
- *What words/ images comes to mind?*

**Interview Schedule****Experiences of supporting partner through transplant: Life prior to transplant**

- Tell me about your experiences when you first learned that your partner needed a transplant
- How would you describe the way in which you supported your partner during this time?
- What did the experience of supporting your partner during this time mean to you?

**Experiences of supporting partner through transplant: Life during the wait**

- Tell me about your experiences waiting for the transplant
- What were your experiences of supporting them during this time?
- What did the experience of supporting your partner during this time mean to you?
- Tell me about your experience when you found out a transplant organ was available?
- What were your experiences of supporting them during this time?
- What did the experience of supporting your partner during this time mean to you?

**Experiences of supporting partner through transplant: Life during transplant surgery**

- Tell me about your experience of your partner undergoing transplant surgery?
- What were your experiences of supporting them during this time?
- What did the experience of supporting your partner during this time mean to you?

**Experiences of supporting partner through transplant: Life during recovery**

- Tell me about your experience shortly following the transplant surgery?
- What were your experiences of supporting your partner during this time?
- What did the experience of supporting your partner during this time mean to you?

**Experiences of supporting partner through transplant: Life in the long term**

- Tell me about your experiences since your partner returned from hospital What were your experiences of supporting your partner during this time?
- What did the experience of supporting your partner during this time mean to you?

**Experiences of supporting partner through transplant: Overall**

- How would you describe your overall experiences of supporting your partner through their transplant journey?
- What did the experience of supporting your partner during this time mean to you?
- How would you summarise your whole experience?

**Closing questions:** I think I have covered everything I wanted to ask. Is there anything else you would like to add?

**Appendix 4 – E: Participant Consent Form (Version 3)**



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**Participant ID:**  
\_\_\_\_\_  
(Researcher to complete)

**CONSENT FORM**

**Research Study: Experiences of Supporting a Partner through Heart Transplant**

**Name of researcher: Jessica Morley**

Please initial each box

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understood the participant information <a href="#">sheet</a> (Version 3 01.03.17) about the above study and I understand what participation in the study will involve.  | <input type="checkbox"/> |
| 2. I have had the opportunity to consider the participation information, ask questions to researcher and have had these questions answered satisfactorily.  | <input type="checkbox"/> |
| 3. I understand that my participation is voluntary and that I am free to change my mind and withdraw up to 2 weeks after my interview. I understand that I do not have to provide a reason for withdrawing and that this will not affect my future involvement with NHS services. | <input type="checkbox"/> |
| 4. I agree to my interviews being digitally recorded and typed up into anonymised transcripts within 3 months of the interview date. I understand that the digital recording will be deleted after the anonymous transcripts have been made.                                      | <input type="checkbox"/> |
| 5. I agree to Lancaster University storing anonymised transcripts of the interviews and scanned copies of consent forms for up to 10 years after the study has finished.  | <input type="checkbox"/> |
| 6. I understand that relevant sections of the anonymised data collected during the study may be looked at by the researcher’s supervisor to assist in the project. I give permission for these individuals to have access to this data.   | <input type="checkbox"/> |
| 7. I agree for anonymised quotes from my interview to be used in the final report.  | <input type="checkbox"/> |
| 8. I understand that the interview is confidential. However, if the researcher is concerned that I or someone else is at risk, this information may be shared with other professionals.   | <input type="checkbox"/> |

10. I understand that the lead researcher is unable to guarantee anonymity or confidentiality for interviews using Skype due to the nature of the platform.
11. I understand that my contact information may be accessed if there is concern about the researcher's safety during a home visit.
12. I understand that I do not have to answer a question if I do not wish to.
13. I understand all of the above and fully consent to taking part in this study.

Name of participant (please print)

Signature of participant \_\_\_\_\_ Date \_\_\_\_\_

Researcher signature \_\_\_\_\_ Date \_\_\_\_\_

(2 copies to be signed: 1 copy to be kept by the participant and 1 copy to kept by the researcher)

I would like to receive a summary of the research findings once the research is complete via post/ email  
(please delete)

Address/ email address: \_\_\_\_\_

*(researcher to tear off and keep)*

### Appendix 4 – F: Demographics Questionnaire (Version 3)



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**Participant ID:**

#### Demographic Information Questionnaire

If you feel happy to do so, please could you respond to the following questions. Your answers will help the researcher learn more about the people taking part in the research study.

#### Information about yourself:

**Gender:** \_\_\_\_\_

**Age:** \_\_\_\_\_

#### What is your ethnic group? (please tick)

- White
- Mixed/ Multiple ethnic groups
- Asian/ Asian British
- Black/ Africa/ Caribbean/ Black British
- Other ethnic group

#### Relationship to transplant recipient:

**What is your relationship to transplant recipient?** \_\_\_\_\_

**How long have you been in this relationship?** \_\_\_\_\_

#### Information about your partner's transplant:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**When was the transplant?** \_\_\_\_\_

*Thank you for completing this questionnaire*

## Appendix 4 – G: Participant Debrief Sheet (Version 2)



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### Participant Debrief Sheet

I would like to thank you again for taking part in this research study. As discussed, if you have expressed an interest to be contacted in the future to receive a summary of the findings once the research study has been submitted I will contact you.

If for any reason you wish to withdraw from the study you are free to do so within 2 weeks of your interview date. If you wish to do this please contact Jessica Morley on [REDACTED]. You do not have to give any reason for withdrawing and this will not affect your rights to access services in the future.

If you feel upset or distressed by anything that we have discussed today and would like to receive further support for any of these issues raised please contact your GP. For further advice you can contact the Clinical Psychologist, attached to the Transplant Unit at

[REDACTED]

### Suggested contacts for further support

The following organisations may also be contacted for advice and support:

**Samaritans**  
Phone: 08457 909090  
Website: [www.samaritans.org](http://www.samaritans.org)

**Mind**  
Phone: 0300 123 3393  
Website: [www.mind.org.uk](http://www.mind.org.uk)

**British Heart Foundation**  
Phone: 0300 330 3322  
Website: [www.bhf.org.uk](http://www.bhf.org.uk)

**British Lung Foundation**  
Phone: 03000 030 555  
Website: [www.blf.org.uk](http://www.blf.org.uk)

**Heart Transplant Families UK Community Group**  
Website: [www.facebook.com/HeartTransplantFamiliesUk/](https://www.facebook.com/HeartTransplantFamiliesUk/)

[REDACTED]

## Appendix 4 – H: Final Approval from Research Ethics Committee



Health Research Authority

Miss Jessica Morley  
Trainee Clinical Psychologist

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)



26 April 2017

Dear Miss Morley

**Letter of HRA Approval**

**Study title:** Experiences of Supporting a Partner through Heart Transplant  
**IRAS project ID:** 217227  
**REC reference:** 17/NW/0134  
**Sponsor** Lancaster University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.



IRAS project ID	217227
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It is critical that you involve both the research management function (e.g. R&D office) 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](http://www.hra.nhs.uk/hra-approval).

#### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

#### After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

In addition to the guidance in the above, 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](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto: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](http://www.hra.nhs.uk).

#### 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

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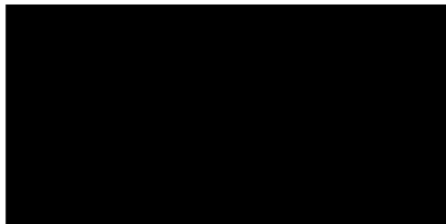
procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

**HRA Training**

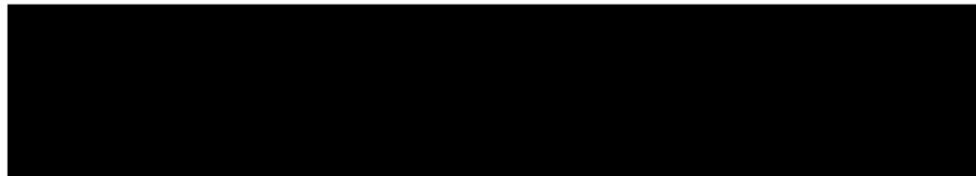
We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 217227. Please quote this on all correspondence.

Yours sincerely



Copy to:



IRAS project ID	217227
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#### Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants	2	01 March 2017
Covering letter on headed paper	3	01 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL & PN]		20 July 2016
Interview schedules or topic guides for participants	2	22 December 2016
IRAS Application Form [IRAS_Form_06022017]		06 February 2017
IRAS Application Form XML file [IRAS_Form_06022017]		06 February 2017
IRAS Checklist XML [Checklist_03032017]		03 March 2017
Letter from sponsor [IRAS Sponsorship Letter ]		23 January 2017
Non-validated questionnaire	3	01 March 2017
Other [Statement of Activities]	1	24 April 2017
Other [Schedule of Events]	1	24 April 2017
Other [Consent to Contact Sheet ]	3	01 March 2017
Other [Covering letter for participants summary of findings ]	3	01 March 2017
Other [Facebook/ twitter advert]	3	01 March 2017
Other [Facebook/ twitter advert (with changes highlighted)]	2	01 March 2017
Other [LCFT Lone worker Policy]		01 June 2013
Other [Covering letter for participants summary of findings ]	2	22 December 2016
Other [Field Supervisor GCP Certificate ]		11 October 2016
Other [Additional Evidence of Sponsor insurance or indemnity]		01 August 2016
Other [Chief Investigator GCP evidence]		09 January 2017
Other [Facebook/ twitter advert]	1	22 December 2016
Other [Field Supervisor CV page 1]		21 November 2016
Other [Field Supervisor CV page 2]		21 November 2016
Other [Participant Receipt for travel expenses ]	2	22 December 2016
Other [Participant Debrief Sheet]	2	22 December 2016
Participant consent form [consent to participate ]	3	01 March 2017
Participant information sheet (PIS)	3	01 March 2017
Research protocol or project proposal	2	22 December 2016
Response to Request for Further Information		
Summary CV for Chief Investigator (CI)	1	09 October 2016
Summary CV for supervisor (student research)		04 November 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flow Diagram ]	1	22 December 2016
17.NW.0134 favourable opinion		07 March 2017

IRAS project ID	217227
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#### Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

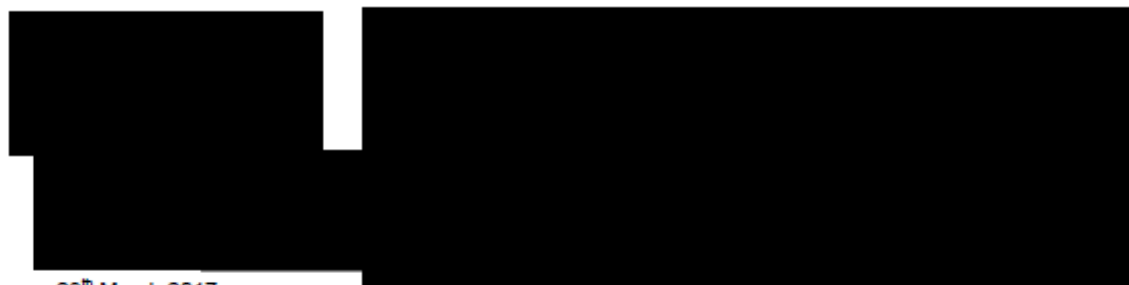
Name: Dr Diane Hopkins  
 Tel: 01524 592 838  
 Email: ethics@lancaster.ac.uk

#### HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites.  The sponsor is not requesting, and does not require any additional contracts with study sites.
4.2	Insurance/indemnity	Yes	Where applicable, independent contractors (e.g. General Practitioners)

IRAS project ID	217227
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Section	HRA Assessment Criteria	Compliant with Standards	Comments
	arrangements assessed		should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made. No study funding will be provided to sites, as detailed at Schedule 1 of the Statement of Activities.  Postage costs and patient travel expenses will be paid for by Lancaster University. This will be administered directly by the Researcher.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

**Appendix 4 – I: Approval from Primary Research Site Research and Development Department**

28<sup>th</sup> March 2017

Jessica Morley  
Trainee Clinical Psychologist  
Faculty of Health and Medicine  
Doctorate in Clinical Psychology  
Division of Health Research  
Furness College  
Lancaster University (Employed by Lancashire Care NHS Foundation Trust)  
Lancaster  
LA1 4YG

Dear Jessica Morley

### NHS TO NHS Letter of access for research

Thank you for providing us with the following documentation:

- *Curriculum Vitae*
- *GCP Training Certificate*
- *NHS to NHS "Confirmation of Pre-engagement Checks" Form*

This letter confirms your right of access to conduct research at the [REDACTED] [REDACTED] for the purpose and on the terms and conditions set out below, and for the following research studies:

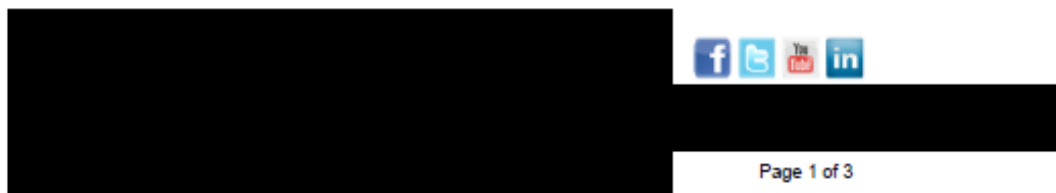
- Experiences of Supporting a Partner Through Heart Transplant

This right of access commences on 28<sup>th</sup> March 2017 and ends on 28<sup>th</sup> May 2018 unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with [REDACTED] [REDACTED] satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation(s). Evidence of checks should be available on request to [REDACTED]

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by this



[REDACTED]

organisation to employees and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through [REDACTED] you will remain accountable to your employer Lancashire Care NHS Foundation Trust but you are required to follow the reasonable instructions of your nominated manager [REDACTED] in each organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by [Insert organisation] or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED]. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating [Insert organisation] prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.


[REDACTED] not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation(s) terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately

[REDACTED]

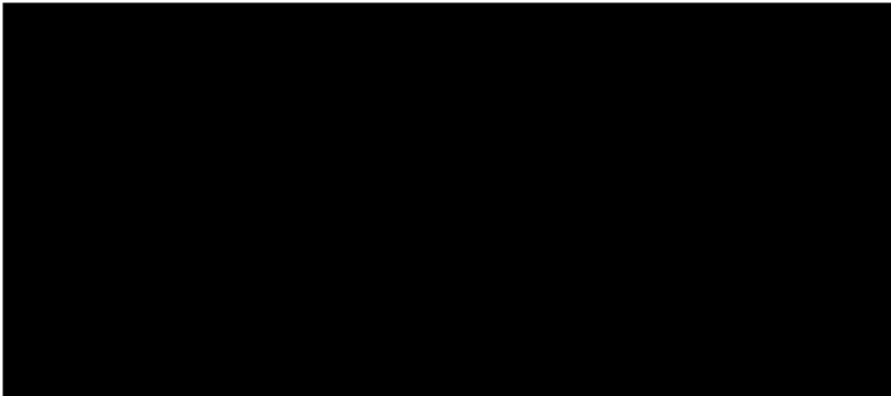
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terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation..





**Appendix 4 – J: Approval from Secondary Site Research and Development Department**

02 June 2017

Jessica Morley  
Trainee Clinical Psychologist  
Faculty of Health and Medicine  
Division of Health Research  
Furness College  
Lancaster University  
Lancaster, UK  
LA1 4YG

Dear Jessica Morley

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through [REDACTED] for the purpose and on the terms and conditions set out below. This right of access commences on 01/06/2017 and ends on 01/02/2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that the Principal Investigator for the research project has received a letter from us giving the organisation permission to conduct the project.

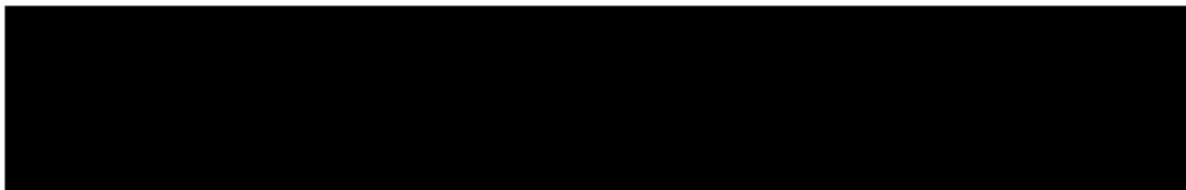
You are considered to be a legal visitor to [REDACTED] premises. You are not entitled to any form of payment or access to other benefits provided by [REDACTED] or this organisation.

While undertaking research through [REDACTED], you will remain accountable to your employer [REDACTED] but you are required to follow the reasonable instructions of your nominated manager [REDACTED] in this organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by [REDACTED] or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [REDACTED] policies and procedures, which are available to you upon request, and the Research Governance Framework.





are required to co-operate with in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating prior to commencing your research role at each site.

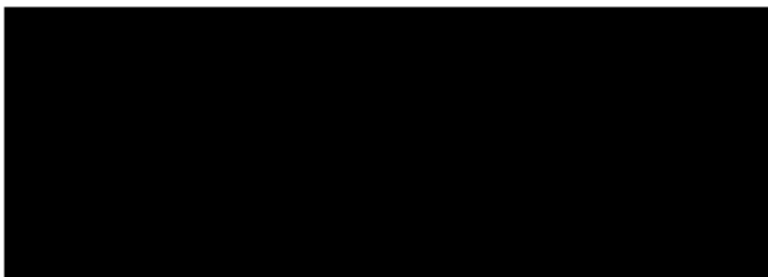
You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation(s) terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation.



**Appendix 4 – L: Response from Ethics Committee Chair Regarding Widening Inclusion Criteria**

[Redacted]

Thu 21/09/2017, 15:06

Please see advice from Chair as below:

“If the data helps with the **research** question, I would suggest that the **researcher** explains this to the participant she interviewed if possible and if the participant agrees she can use the data, she may want to get the participant to sign that she agrees. If she cannot contact the participant, then I would suggest she does not use the data.

In future to stop this happening again she should ask **all** potential participants prior to recruiting them into the study how long ago the transplant took place.

I would also suggest that she checks with her supervisor(s) if they are ok with her using this data as it falls outside what she set out to do.”

BW

[Redacted]

**REC Assistant**  
**Health Research Authority**

[Redacted]

[Redacted]

E: [Redacted]